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think+

opinion and editorial

Bringing co-infection communities together

by Ken Thomson

How do HIV and hepatitis C fit together in the world of service providers? Well, despite the wishes of some bureaucrats, we are not dealing with McViruses. One size does not fit all.

Areas of overlap, however, do exist. Co-infection may be one of them. We need to ask, “What do co-infected people need and how should it be delivered? Does consolidation of expertise make more sense than having many options?” More importantly, we need to ensure that co-infected people are provided with opportunities to answer those questions.

Some have suggested that the complexity of co-infection requires that it be regarded as a separate entity. What are the ramifications of that approach? Would it lead to greater clinical expertise but cause further social isolation? Would it eventually lead to even fewer resources for co-infected people?

We need two strong communities working together. Through hard-won experience, the HIV/AIDS community has learned the importance of making sure that HIV-positive people play a central role in all aspects of the planning, delivery, and evaluation of services. Otherwise, things can go off the rails and stay that way for a long time. Capacity building, infrastructure development, systemic advocacy, and expertise in the areas of human and legal rights are some of the key strengths that have been developed in the AIDS community. The AIDS community needs to support the same principles in the hepatitis C community.

Some service providers might look at their client loads and see that the number of co-infected and HCV mono-infected

people looking for services is expanding. They face some tough choices: turn people away or use their connections, expertise, and infrastructure to vacuum up the little funding that does exist.

Do they really want to provide services to over six times as many people for one-twentieth of the funding? Do they really want to buy into the old “divide and conquer” strategy, or risk that the mistaken but growing public perception that “AIDS isn’t all that serious anymore” will spill over to funders and policy makers in the next funding cycle?

Or, do they see the value of two strong communities working together and supporting each other? Do they see that striving for adequate funding and self-sufficiency is the only acceptable course of action? Do they see the value of collaboration and innovation?

AIDS service organizations are great resources for coping with the complexities of HIV, but for them hepatitis C is something of a recent sideline. Hepatitis C organizations are woefully underfunded. Because only five percent of people with HCV are co-infected, these organizations know about extrahepatic manifestations like porphyria cutanea tarda (PCT), a skin disorder, but many of them are not yet well-versed in the world of opportunistic infections.

If we want HIV specialists and hepatologists to work together, we need to lead the way.

There is much to do. ⊕

Ken Thomson is the chairperson of the Hub Team (working group) of the BC Hepatitis C Collaborative Circle.

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REALITY BITES



Vancouver loses elder statesman

Terry Wallace, a key member of Vancouver's gay and lesbian community in its formative years, passed away on February 1. He had suffered from multiple health problems, including cancer, for many years.

In the 1970s and 1980s, Wallace managed The Castle, and then managed the Royal Hotel. However, it was his contribution to local non-profits where he truly made his mark. Affectionately known as "Papa", he was one of the founders of the Pride Society and the Gay and Lesbian Business Association as well as a tireless fundraiser for Pride Week and various other local charities, including such AIDS organizations as Meals on Wheels.

Novel approach to detect and eliminate HIV

US scientists report that infection of lymph nodes in early and asymptomatic HIV infection is far more limited than previously believed. They identified lymphoid tissue packed with activated lymphocytes using a technique, usually used to identify cancerous tumors, called Positron Emission Tomography (PET) scanning. Research revealed that in recent seroconverters and non-progressors (CD4s above 400) there was little HIV activity in lymph nodes (main reservoirs of HIV) below the chest.

Researchers found a distinct and predictable anatomical sequence as the disease progressed. Activated lymphoid tissue was confined to the head and neck in early stage of disease, moved to a generalized pattern of peripheral lymph node activation at mid stages and involved abdominal lymph nodes during

late stages. Outside the lymph nodes, PET scanning could not detect substantive levels of lymphocyte activation.

This method of tracking HIV progression and identifying "hot spots" of viral activity may lead to new types of interventions such as surgery or radiotherapy. Targetting drug delivery to reservoirs, coupled with strategies to activate latently infected cells rather than saturating the entire body, may be possible. Lymph node removal could extend treatment interruption with a smaller viral rebound.

The researchers also discovered a substantial amount of undiagnosed cancer associated with HIV, mostly lymphoma.

Tom Mountford

T-1249 development suspended

Early in 2004, Roche and Trimeris announced their decision to halt further development of T-1249, their second-generation fusion inhibitor. There were high hopes for T-1249 because it would only require one injection per day, compared to two for T-20, and because it showed activity against T-20-resistant strains of HIV.

The company cited problems with the formulation of T-1249, saying that too high doses are required for adequate viral suppression. However, many activists believe that another reason is the company's preference to maximize their market share with T-20 before launching a new fusion inhibitor. T-20 is faring less well on the market than they had anticipated.

Why alcohol worsens hepatitis C

Researchers from the Children's Hospital of Philadelphia have found that alcohol

increases the activity of nuclear factor kappa B, a protein that makes the hepatitis C virus replicate. Nuclear factor kappa B is important in regulating the gene productions that are involved in inflammation.

Alcohol interferes with the activity of interferon-alpha, a key antiviral therapy used for patients with hepatitis C. Naltrexone, a drug used by alcoholics that helps avoid relapse, may block the harmful effects of alcohol in promoting the hepatitis C infection.

Naltrexone prevents opiates from binding to their receptor sites, thus reducing the effects of alcohol. Naltrexone might also provide further benefits in reducing the hepatitis C virus, though further study is needed.

Source: www.internationalmedicalnews.com

Study reports high rate of superinfection

At this year's annual Conference on Retroviruses and Opportunistic Infections in San Francisco, researchers suggested that the annual rate of HIV "superinfection"—a second infection with another drug-resistant strain of HIV—might be 5 percent or more.

During the late 1990s, many scientists were convinced that an HIV-infected person could not be infected again. However, in 2002 two independent cases demonstrated that superinfection had indeed happened through unprotected sex, and both patients were progressing more rapidly toward AIDS.

A new study of 78 HIV-positive people (mostly gay men) from 1997 to 2003 has identified patients becoming reinfected with a second strain at a rate of 5 percent per year. While the sample size is

REALITY BITES



News from home & around the world

admittedly small, the genetic analysis technique used to differentiate between strains is a conservative one, so the actual rate may be even higher.

Source: NATAP

Comfrey products can cause liver damage

In December 2003, Health Canada warned consumers not to use the herb comfrey or any health products made with or containing comfrey, including creams or lotions that are applied to broken skin.

These products may contain echimidine, a compound that could cause liver damage. While not all comfrey products contain echimidine, some products do not specify the type of comfrey they contain. Comfrey is an ingredient in herbal and homeopathic preparations and is marketed to treat digestive problems, lung problems, arthritis, ulcers, bruises, wounds, sprains, and fractures. It is also found in lip balms, burn salves, diaper rash ointments, and other therapeutic skin care products.

Manufacturers, importers, and distributors of unapproved products were instructed to remove these products from the Canadian market immediately.

Source: www.hepcbc.ca

Girls twice as likely to get HIV in womb

Girls are twice as likely as boys to be infected with HIV in their mothers' wombs, according to a European study published in the journal *AIDS*. Investigators believe that this may be due to genetic differences between the sexes, as well as different immunological responses, and could explain why infant

girls have consistently lower viral loads than boys do.

The European Collaborative study is a prospective cohort involving infants infected with HIV by mother-to-child transmission. A total of 3231 mother and child pairs enrolled in the study between 1986 and 2003.

In total, 350 infants were infected with HIV—170 boys and 180 girls. In univariate analysis, the association between sex and mother-to-child transmission was of only borderline significance, but when the investigators adjusted for antenatal HIV therapy, maternal CD4 cell count, and elective caesarean, they found that girls had a 1.5 times higher risk of infection than boys.

Source: www.aidsmap.com

Passing of Schedule C champion

AIDS activist Philip Haines passed away suddenly in early February. At the time of his death, he was the executive director of the North Island AIDS Coalition in Campbell River and Courtenay. For several years, he also served as a member of the Working Group of the Pacific AIDS Network.

As an advocate at the BCPWA Society from 1996 to 1999, he assisted many members in the early battles for Schedule F and Schedule C benefits, among many other advocacy matters. It was at Haines's insistence that the very first meeting was held in 1998 with the provincial government to find a solution to the Schedule C problem. The eventual outcome was the introduction of the \$225 Monthly Nutritional Supplement Benefit in 2002.

PWAs over 50 at increased risk of cognitive impairment

Preliminary data from an ongoing study into the impact of aging on cognitive function in older highly active anti-retroviral therapy (HAART)-treated HIV-positive individuals suggests that patients over 50 are more likely to have abnormal cognitive function than those under 40. The study is published in *AIDS*, in a special supplement devoted to HIV and aging.

Two distinct forms of cognitive impairment can be associated with HIV infection: minor cognitive motor disorder, and HIV-associated dementia.

Although the incidence of both these disorders declined with the advent of HAART, there have been reports that, as HIV-positive individuals live longer, the overall prevalence of the disorders has increased. During post-mortem examinations, HIV encephalopathy has been found in a quarter of all HIV-positive patients dying and undergoing autopsy.

Data from the US Centers for Disease Control suggest that the incidence of HIV-associated dementia increases with age and is present in a little under 20 percent of all HIV-positive patients aged over 75. ⊕

Source: www.aidsmap.com

A good death

Euthanasia continues to be a controversial topic in Canada

by Raymond Campeau



Euthanasia is unquestionably the most controversial end-of-life topic. The word “euthanasia” derives from the Greek word *euthanos*, which means “a good death.” But is there such a thing as a good death?

In 1994, the Canadian Senate struck a committee to report on the legal, social, and ethical issues relating to euthanasia and assisted suicide. The committee heard testimony for fourteen months, but they were unable to reach an agreement. Ultimately, they voted against a legalization proposal, which shows no consensus existed to define a good death. Even members of the Canadian Medical Association express divergent opinions, although they uphold the position that members should not participate in any type of euthanasia.

For many people, a good death means having the right to choose the time and means of their own death. However, in many cases, people who wish to die require the help of another person. In Canada, the debate came to the forefront in 1993 when Sue Rodriguez, a 42-year-old BC woman who suffered terribly from ALS (amyotrophic lateral sclerosis) and had fourteen months to live, petitioned the court to invalidate section 241(b) of the Criminal Code. This section prohibits anyone from giving assistance to commit suicide. The Supreme Court of Canada ruled against her in a 5-4 decision.

The case of Robert Latimer also focussed attention on euthanasia. To end his severely disabled daughter’s suffering, he killed her in 1993 by means of carbon monoxide poisoning. In 2001, the Supreme Court of Canada upheld Latimer’s conviction, arguing that regardless of the motive, mercy killing is considered murder. Latimer received life imprisonment with no chance of parole for ten years.

The Latimer case crystallized the moral issue of who has the right to decide who lives and who dies. Sue

Rodriguez spoke for herself until she was no longer able to do so. Both cases are examples of active euthanasia in which a third party has to do something for the person to die. The ongoing argument in these situations seems to be a fear of errors and abuse.

Belgium and the Netherlands have legalized active euthanasia and created a whole bureaucracy around dying.

In 1994, the BCPWA Society drafted a position paper on euthanasia entitled “Choices.” The Society argues that each individual has the right to choose how to die and the right to safe and easily accessible medically assisted euthanasia.

Belgium and the Netherlands have legalized active euthanasia and created a whole bureaucracy around dying. Death must be specifically requested by the person suffering, and it must be carried out in a controlled situation. After the death, the doctor must submit a report to a federal investigative commission that is charged with verifying whether the euthanasia has taken place under the proper rules set out by the law.

For those of us who have witnessed a loved one’s end-of-life struggle between the two realms of here and there, we know the importance of a good death.

The BCPWA Society position paper can be found on the BCPWA Society Web site <www.bcpwa.org> under the heading “About BCPWA”. ⊕

Raymond Campeau was an assistant to the Treatment Information Program and Advocacy Department at the BCPWA Society.



Patently prohibitive

Laws must be relaxed to get drugs to developing countries

by Lisa Gallo

Ugandan-born Nakyeeyune Sanyu weeps uncontrollably for days. She is one of five children orphaned by her mother's death from AIDS. The future is uncertain for six-year-old Nakyeeyune and her two brothers and two sisters, ranging in age from six months to twelve years old.

Sub-Saharan Africa accounts for 95 percent of the world's 13.2 million AIDS orphans. In Uganda alone, such orphans represent 10 percent of the population, and a quarter of all families are caring for a child orphaned by AIDS. It's a frightening challenge for the country's mostly poor residents.

According to the United Nations, about six million people in developing countries require antiretroviral (ARV) treatment, but fewer than 300,000 receive it. In sub-Saharan Africa, where the majority of HIV-positive people live, only 50,000 people are receiving it. The failure to deliver ARV treatment to millions of people worldwide is a global health emergency.

"To deliver antiretroviral treatment to the millions who need it, we must change the way we think and change the way we act," said Dr. Lee Jong-Wook, director-general of the World Health Organization (WHO) in a WHO news release. "Business as usual will not work. Business as usual means watching thousands of people die every single day."

Patent laws at root of the problem

Canada produces the medicines to treat persons living with HIV/AIDS, but because of strict patent laws and high prices, these drugs are not reaching the men, women, and children in sub-Saharan Africa and around the world who are dying of AIDS.

"The scale of the global HIV treatment emergency should not be underestimated: about 99% of HIV-positive people who need HIV treatment today in sub-Saharan Africa do not have access to it," said Dr. Peter Piot, UNAIDS executive director in a United Nations news release. "However, AIDS therapy is a long-term commitment, not a one shot. We therefore need dramatic and sustained increases in resources and political commitment—including from hard-hit countries themselves. Above all, we must incorporate treatment into wider emergency plans for HIV prevention and care, without which we stand no chance of reversing the tide of the AIDS epidemic."

A unanimous World Trade Organization (WTO) decision at the end of August 2003 relaxed stiff international rules on patents. The decision means WTO member countries can allow generic pharmaceutical companies to make and export less expensive, generic versions of patented drugs to developing countries. This change would allow those developing

countries with their limited healthcare budgets to afford desperately needed medicines for their sick and dying people. Also, because the majority of people in developing countries must pay for medicines out of their own pocket, but most are too poor to afford them, major reductions in prices will bring treatment within reach of more people.

Canada's flawed legislation initiative

Canada has been the first country to take action to amend its patent law. On November 6, 2003, the federal government introduced Bill C-56, legislation aimed at getting more affordable medicines to people in poor countries. The idea behind Bill C-56 is to allow generic manufacturers to obtain a license permitting them to make cheaper, generic versions of patented drugs. The bill only got as far as committee study before the

Drug pricing advocacy groups are concerned that Bill C-56's current restrictions may defeat the goal of responding to global health needs.

ending of the Parliamentary session in November erased it from the agenda. At the time of writing, it was expected that Bill C-56 would be re-introduced at the committee level when Parliament convened in February 2004.

While there is tremendous support for Canada's initiative, both within Canada and around the world, fair drug pricing advocacy groups are concerned the bill's current restrictions may defeat the goal of responding to global health needs. The groups ask that the Canadian government carefully consider how it amends the act and consider four critical issues.

First, Bill C-56 currently permits companies holding drug patents to block generic pharmaceutical manufacturers from obtaining licenses. The bill states that the holder of a Canadian drug patent has the right, once a generic manufacturer has negotiated an agreement with a developing country's government, to take over the contract, thus preventing generic manufacturers from acquiring a license. Since that can happen every time a generic company negotiates a contract, activists are concerned that generic manufacturers would soon lose any incentive to negotiate contracts to supply medicines at prices below what the brand-name company is charging. By eliminating this competition, brand-name pharmaceutical companies will make the bill ineffective in achieving the objective of lower-priced medicines for poor people in developing countries.

Second, Bill C-56 limits the pharmaceutical products for which a compulsory license may be sought, applying it only to patented drugs that are on a "model" list of the WHO. It doesn't protect the right (as has been unanimously recognized by all

countries belonging to the WTO) of developing countries to decide for themselves which drugs they need to address their respective public health problems. While Bill C-56 allows the Canadian government to add or remove other patented pharmaceutical products deemed to address public health problems including AIDS, there is no guarantee that Canada will respect the decisions of other sovereign countries in deciding which medicines they need. Many people with HIV/AIDS do not respond to particular drugs and need a variety of options. However, if only a limited range of drugs is available, they will soon exhaust their options and die more quickly

Non-WTO developing countries excluded

Bill C-56 also excludes generic exports to some developing countries that are not WTO members. If a country is designated "least developed" according to a United Nations list, they can benefit under Bill C-56. However, the legislation does not recognize "developing" countries that are not WTO members, and, therefore, those countries will be unable to import generic pharmaceuticals from Canadian manufacturers. Vietnam, a developing country stricken with more than 50,000 reported cases of HIV, desperately needs cheaper antiretroviral drugs, but it will not be eligible because it is not a WTO member country.

Another issue is that Bill C-56 permits only a developing country's government or government organizations to enter into a contract with a Canadian generic pharmaceutical company. Bill C-56 excludes private or non-governmental organizations, including humanitarian or charitable organizations, from being able to contract directly with a generic drug maker to purchase medicines it uses in hospitals or health clinics that it runs in a developing country. Fair drug pricing advocacy groups are concerned that patients' access to affordable medicines should not depend on whether their government has negotiated a contract with a generic drug maker, if some other qualified healthcare provider can supply it.

Canada is taking an historic step in the realm of global human health and its legislation will set an example for other countries to follow. Fair drug pricing advocacy groups believe that it is essential that the legislation does not unethically limit developing countries' access to more affordable medicines.

If Canada passes Bill C-56 with these flaws, it is clear that Canada will have folded under the pressure of corporate giants more concerned about bottom lines and shareholder interests. Paul Martin and the federal government can easily fix the problems in Bill C-56. They should do so as soon as possible and then pass the legislation. The global need is urgent. ☉



Lisa Gallo is the director of communications and education for the BCPWA Society.

Help yourself

Easy steps to patient empowerment

by Glen Bradford

People with HIV/AIDS must become empowered as active participants in their own healthcare decisions. The more knowledgeable we become about treatment options, the better we will feel about our decisions. Taking control of our own health can be intimidating, but it's our right to be involved in the decisions that will affect our lives.

Your healthcare providers must know from the beginning that you are planning to be an active participant and partner in your healthcare. Call your doctors by their first names. This approach may help to create a level playing field.

Prepare a list ahead of time so you will remember your priority questions about your HIV symptoms and treatments when you have an appointment with your physician. There isn't always enough time to get answers to all questions during your brief office exam.

Don't start a discussion with your clothes around your ankles. Discuss your condition and treatment while you are fully dressed and both of you are sitting down. This may take place before or after your exam. Either way, insist on it. You'll feel much more comfortable, confident, and assertive. If necessary, you can have someone accompany you to medical procedures, appointments, or hospitalizations.

Create an open dialogue. It can be difficult, but if you aren't happy with your doctor/patient relationship, tell your doctor. It doesn't have to be an attack, just feedback. Doctors may appreciate the honesty and your part-

nership will be stronger for it. Let your physician know it is safe for her or him to be honest with you as well. We should encourage our doctors to be up front with us if they don't know the answer to our situation. Don't judge them for it. Value them more when they say, "I don't know," rather than when they play Blind Man's Bluff with your health. You can work together with your healthcare providers to find the answers.

Be prepared to communicate to your healthcare providers the sort of treatments or therapies you would like to con-

The more knowledgeable we become about treatment options, the more we will feel good about our decisions.

sider. For example, do you want to integrate your HIV management with healthcare providers that are knowledgeable about alternative medicines, exercise, or supplements?

You are responsible for being your own healthcare advocate. Medical appointments can be intimidating, so don't be afraid to ask questions or disagree. Don't lower your expectations for your own health and your quality of life because you can't find relief. Keep pushing for answers.

To help you remember details, create your own treatment journal where you record important information such as your date of diagnosis, medicines, CD4 count, and viral load. This treat-

ment journal may be handy when confronted with unexpected healthcare situations such as emergency room visits. It also helps you inform your healthcare providers of your daily living experiences with medications. If you require hospitalization, write in your journal the name of any healthcare professional that comes to speak with you and why. You may need to refer back to your journal as the days progress and as the steady stream of unfamiliar professionals grows. Record the names of the people on your healthcare team, emergency numbers, contact information for clinics, and all other relevant information to help you get in touch more easily with anyone you need.

Seek out reliable agencies, either in person or online, dedicated to providing people with trustworthy HIV treatment information (including alternative treatments) and resources to help you keep current on your treatment plans.

Logging all of this information in a treatment journal is not something to begin when you're at your weakest. Actively participating in your treatment plan is an evolution and requires determination and patience. Start when you are feeling healthy. ☺



Glen Bradford is the chair of the BCPWA Society.



The golden years

Many PWAs are unprepared for aging with HIV

by Lawrence C.

Does aging start when you see fifty candles on your birthday cake? Of course not. Aging begins when we are born, and it continues, we hope, well after we blow out our first candles. Some people become old and frail at forty, while others stay young and vigorous until they die at ninety. Many factors contribute to the aging process, including illness. People living with HIV/AIDS are certainly not strangers to illness.

According to Health Canada, the number of older people with HIV/AIDS is on the rise. About 10 percent of all people living with HIV/AIDS in Canada are aged fifty and older. The majority of cases, however, are between the ages of 30 and 39. Because of advances in combination antiretroviral therapy and early diagnosis, people are living longer with HIV/AIDS.

In the next decade or so, HIV/AIDS will significantly affect a greater proportion of older people than ever before. Additionally, the overall population is growing older, which means there will be increased numbers of older people at risk for HIV infection.

Since the beginning of the HIV/AIDS epidemic, little research has been conducted regarding the concerns of older HIV-positive people. However, for older people who are diagnosed later, survival is shorter and existing prevention programs don't work. Lack of public awareness of infection rates, transmission routes, and risk factors probably accounts for this higher mortality rate among older people who contract HIV. In some cases, older people do not understand they can become infected with HIV.

continued on next page

Seroconverting in middle age

Generational attitudes may be partly responsible for the reluctance of older adults to receive sex education. They may feel it does not apply to them. Many associate the disease with having sex and injecting drugs, and, therefore, they are embarrassed and fearful of being tested for HIV. Older people and some healthcare professionals even sometimes mistake HIV/AIDS symptoms such as fatigue, weight loss, dementia, skin rashes, and swollen lymph nodes for the normal aches and pains of aging. Consequently, older people are less likely than younger people to be tested for HIV/AIDS. In fact, they may have HIV for years before being tested, and by the time they are diagnosed, the disease may be in its advanced stages.

Allen, for example, is a happily married middle-aged professional who usually maintains a healthy lifestyle, but on occasion he uses the services of prostitutes. Although he thinks about safety while having sex, he sometimes forgoes using condoms when he thinks it is safe to do so. Recently, he complained about aches, pains, weight loss, and frequently feeling sick and fatigued. His doctor ordered standard tests, which revealed nothing significant except slightly elevated cholesterol levels, a condition attributed to Allen's indulgence in sweets. The doctor told him that his complaints might be related to aging.

“To be honest, I thought I’d be long gone before I reached 50,” says Jane, a single mother, “but I’m still here.”

The symptoms continued for weeks, so Allen broached the issue of HIV with his doctor, but he did not reveal that he had had unprotected sex. The doctor told him that, based on his lifestyle, he was not at risk for HIV. Allen persisted, and he was tested for HIV. The results were positive. Allen is now living and aging with advanced HIV disease.

Complications among long-time survivors

Not only are older people at risk of HIV infection, some older persons have been living with HIV/AIDS for well over a decade. Medical problems and their treatment consume a lot of time and energy for aging PWAs. Complications may arise between antiretroviral drugs and drugs that are likely to be used frequently by the elderly. This combination of drug treatments can significantly complicate a PWA's drug regimen. Interactions have been known to occur with cardiovascular drugs, lipid-lowering drugs, antihistamine drugs, neuropsychotropic drugs, and some antibacterials. Careful planning is required to build a successful drug regimen.

Emotional, social, and mental health issues are equally demanding. “To be honest, I thought I’d be long gone before I reached 50,” says Jane, a single mother, “but I’m still here.” She

feels some guilt about surviving so long while most of her friends have died, but she is grateful for her friends and family who have given her emotional support over the last few years.

Bill, on the other hand, who is 55 and has been HIV-positive for 15 years, expresses frustration with his longevity. Like most people with a life-threatening illness, he planned for dying long ago. Now, having survived longer than anticipated, he says, “I’ve paid for my funeral, but now it’s difficult to manage my monthly expenses.”

Pages from a diary

Clearly, aging with HIV poses its own unique challenges. These excerpts from the diary of Ryan, who lives in Vancouver with his partner, illustrate these challenges.

November 1992 (age 41) — Last week I got my results from my HIV test. It came back positive. I’m totally devastated, and I don’t know what to do. I have a follow-up appointment next week. I guess I need to make a will and get prepared for the worst. I’m scared. I think I have to start taking AIDS drugs.

February 1993 (age 42) — I’ve started AZT, and now I feel more sick than I ever have before. Vomiting and nausea are unbelievable, and I feel tired all the time. Made my will and need to let Mom and Dad know about me. I’m sure they will freak out. They don’t even know I’m gay!

March 1993 — I’m not tolerating AZT now, so they’re switching me to ddI....

June 1993 — I’m not tolerating ddI now, so they’re switching me to d4T on a study. We’ll see how it goes.

December 1993 — So far so good with d4T, but now they want to add something called a protease inhibitor. Yuk! D4T is only twice a day, but with these new ones, it is three times a day on an empty stomach. I’m taking eight pills a day now and I feel awful.

April 1995 (age 45) — They told me I just about died. I was rushed to hospital with pneumonia. Apparently, this pneumonia is called PCP and is common with people with AIDS. Some people do die. Now I’m really scared. I really need some support, and I don’t know where to go....

November 1995 — Found a support group and I’m feeling better. Started triple combination therapy. It’s very complicated, and I’m now up to 20 pills a day. Jason died last week. His memorial service is tomorrow.

June 1996 (age 46) — Ended up in hospital again. I feel so weak, and it looks like I’m withering away to nothing.

September 1998 (age 48) — The company I work for closed. Now I’m unemployed, I can’t find a job, I’m really tired a lot and need assistance. Had another change of meds. I’ve stopped counting the pills. I’ve lost 20 lbs and my face looks deformed. On a good note, my blood work is great! I’m undetectable.

August 2000 (age 50) — I’m so relieved. Finally, I got some assistance. I’m eating well. If I can just keep it down.

March 2001 (age 51) — Looks like I’ve aged 20 years. I hate the way I look. Blood work is still good and I feel fine.

January 2003 (age 52) — Still feeling pretty good, but I'm bored.

November 2003 (age 53) — Been stable for quite some time now...thinking about going back to work. I've been having some aches and pains, which I thought were drug related.... Doctor said I'm just getting older and that goes with the territory. Great! Now I'm old. What's next!

Indeed, what is next? A generation and a half of people live with HIV, and for many, the usual pattern of aging is something they never anticipated. They once thought growing old gracefully was a luxury that wouldn't come their way. Now, despite all the rigours of medications and other regimens, many people are taking charge of their own aging in ways they never dreamt of before.

Social support plays an important role in the well-being

of older people. Understanding how age affects PWAs will require an increased knowledge of social support networks and socio-demographic factors associated with growing older. Healthcare providers on all levels still need education on HIV risk behaviours and symptoms of HIV infection. Programs aimed at reaching healthcare providers should cover misdiagnosis, testing, treatments, and support groups. More information on HIV and aging can be found at <www.hivoverfifty.org>.

More research is needed to study aging and HIV. In the meantime, get your birthday candles ready. Your next birthday celebration is coming soon. ⊕

Lawrence C. is a volunteer for the BCPWA Society.

Hot flashes versus cold sweats

by *Françoise Gröthe*

A key question has puzzled women in my family for three generations: Are we strong and funny or are we downright dumb? All I know is that laughter has always been a part of my life and is, I think, as important as any medication.

A few months ago, I nervously went to an emergency room because I believed I was laying an egg. My HIV mind told me I was so full of disease that this giant thing was coming out of me. My menopausal self realized that I had bladder problems.

"Perfectly normal at your age," said the doctor. I wanted to kick him.

All joking aside, aging is usually accompanied by some discomfort or illness, and every woman must, at an early age, start to know her mind's mood swings and her body's metabolic changes. We need to be on top of the situation and, if possible, find an understanding physician we trust.

For those of us who are HIV-positive and menopausal, it's the only way we can distinguish between changes that are just part of the aging process and indications of drug side effects or opportunistic ailments. Often we must deal with both.

That's when laughter, rather than looking for the nearest bridge, helps.

How can you tell if you are experiencing hot flashes or cold sweats? If you are sweating only at night, chances are it's from the virus, since hot flashes can occur at any time. To deal with hot flashes, take long breaths, use scented handkerchiefs, open windows, and use fans. Stick your left foot out of your blankets. (It must be your left foot.) I learned that trick from a very hot, old lady.

To fight the effects of lipodystrophy, you must exercise. Walking will do the trick. A daily half-hour walk will keep your legs firm and keep you from looking like you're nine months pregnant. Watch television standing up. Walk up and down stairs instead of using elevators. If I stop walking because I'm not feeling well, my stomach blows up like a hot air balloon in a few days, and it takes longer than that to get it back to normal again.

If your bones start to break suddenly or for no reason (I broke a rib doing yoga) and you have no family history of osteoporosis, you must look at your pill regimen. Osteoporosis doesn't happen overnight if it's part of the aging process. Get a bone density test every year so that you and your doctor understand what's happening. And be careful. I had to stop biking because I fell and broke my hip. So then I started trekking and not only am I exercising, I'm constantly outdoors

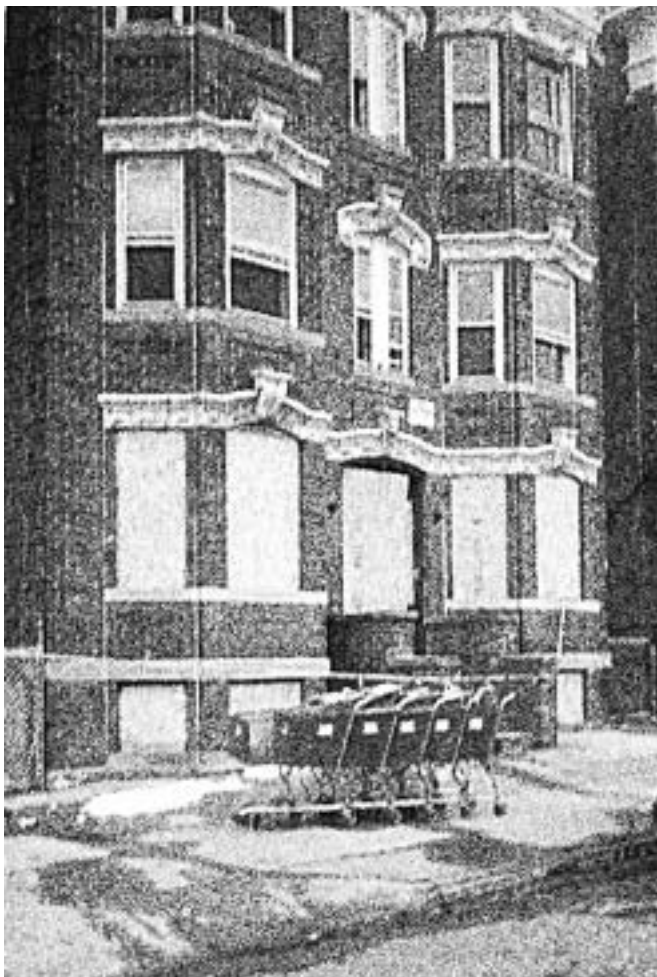
and meeting interesting people. Sometimes simple is best.

Wrinkles, big stomach, skinny legs, lipodystrophy, osteoporosis, cold sweats, and hot flashes—when you reach your fifties, almost every HIV-positive woman experiences these symptoms. No doubt, people will scream when I say this, but living with HIV/AIDS and its side effects is more traumatic physically when you are young, when the visual impact of the disease is more apparent. Those of us who are HIV-positive and over fifty don't look any different from many of our HIV-negative friends.

What is different, though, is what ails us. Some of our HIV-negative friends may have cancer or diabetes, but we may have these illnesses over and above our condition. We have The Virus. Even if things are improving, the taboos are still there.

Many HIV-positive women claim their libido is shot to hell because of the medications. Most 50-year-olds have lost it anyway. That's when knowing yourself comes into play. I have many good friends. I get as big a kick from a beautiful walk, a good meal at a restaurant, and an intelligent conversation as I do from an hour in the sack with a prostrate, inefficient Adonis.

We have been dealt a bum rap, but we have two choices: live with it or bitch about it. The first choice leaves me feeling freer and happier. It is no bed of roses, but it is life—and it's ours! ⊕



Nobody's home

Studies link proper housing to good health

by JoAnne Fahr and Ken MacDonald

The invention of the wheel is generally considered the greatest human advancement. However, compared to the variety of housing options created in the past million years, perhaps the wheel is the second most important development! Consider the difference between a drafty, infested cave and a free-standing house with electricity and heat and you can see how far housing has come since the invention of the wheel.

When humans stopped living in the open or in earth-based dwellings, our ability to fight off diseases and other harmful physical problems dramatically increased. Our skin is meant to protect us from all sorts of alien invasions, allowing us to continue to function in a healthy way. But the skin barrier is not enough to protect us in many situations, so we have had to produce supplemental protection.

The need to have a protective and supportive barrier is undeniable. Proper housing provides this kind of protection and more. Numerous health, medical, and sociological studies have proven that a direct relationship exists between proper housing and good health.

Many PWAs lack access to affordable housing

Housing is one of the greatest unmet needs among people liv-

ing with HIV/AIDS. Because many individuals living with HIV are impoverished or become so during the course of their illness, lack of access to affordable housing has become a crisis for HIV-positive people.

In BC's Lower Mainland, over 800 individuals and families living with HIV/AIDS are currently on wait lists for housing assistance. These persons are registered at several different agencies that provide housing. The number of HIV-positive people needing affordable housing in that region may be even higher when you consider that estimates suggest that 17,000 persons in Canada are currently unaware they are HIV-positive.

Some of the Lower Mainland's HIV-positive poor live in single rooms in Vancouver's Downtown Eastside hotels, where conditions are dire compared to what they need to cope adequately with their disease. The often debilitating side effects of HIV/AIDS treatment are exacerbated by not having consistent access to clean housing. Sharing bathroom and kitchen facilities in a communal atmosphere can expose a PWA to deadly infections. PWAs require a standard of housing higher than that required by an uninfected person. In many situations, relying on friends or family, who themselves may be unable to support the unique needs of HIV/AIDS, is not the answer because the potential for life-threatening situations will still exist.

In a January 1999 survey of people living with HIV/AIDS, the City and County of Los Angeles found that 65 percent of respondents had been homeless at some point in their lives and had experienced homelessness an average of 2.3 times in the previous three years. Although studies have demonstrated that the homeless and marginally housed can be highly adherent to the complex HIV treatment regimens, the stress related to homelessness and poverty can often exacerbate symptoms, accelerate disease progression, and decrease drug regimen adherence.

Housing providers need more support

The majority of funds for HIV-related housing in BC are derived from provincial sources, such as the BC Housing Management Commission. Unfortunately, this source has not been able to provide all PWAs with adequate housing, so some housing providers have had to raise funds privately in an effort to compensate for this shortfall. Corporate, private, and government bodies should step forward and play a larger role in supporting programs that would increase the availability of affordable housing for low-income individuals, especially those with fatal, chronic, and disabling conditions. Although they are not alone in their need for adequate housing, PWAs meet these criteria and must share top priority status with all others who have similar requirements.

Adequate housing also allows individuals to participate more effectively within their society, which translates into participation in the market system and workforce. Few oppose the concept that all members of society should contribute to the community in a significant way, including through employment and volunteer opportunities.

At the New Partnerships for Ending Homelessness Conference in July 2003, Donald Chamberlain of AIDS Housing Washington and Christine Campbell from Bailey House in New York stated in a presentation that PWAs have to choose too often between healthcare and housing. They estimate that in the US between one-third and one-half of all PWAs are either homeless or in imminent danger of losing their homes. In the Lower Mainland, a person receiving disability income from the Ministry of Human Resources cannot afford

to live in adequate housing even if he or she chose to spend all of their funds on housing and nothing on their medical needs.

Chamberlain and Campbell added that a very high correlation exists between homelessness and infection rates. In fact, rates of infection are three times higher among the homeless population than among the adequately housed population. Easily accessed harm reduction programs could go a long way toward curbing this rate of infection.

A correlation between good housing and good health


Staying in a hospital costs almost \$1,000 a day compared to \$15 per day to remain independent and able to live and care for one's own health in appropriate affordable and safe housing. Large numbers of studies in both Canada and the US have documented the cost-effectiveness of low-income housing, and more studies are currently being conducted to examine the correlation between adequate housing and good health.

These studies appear to have had no effect on setting priorities for a federal healthcare plan for all Canadians. Why has the federal government not used the information gathered in these studies to strive to provide adequate housing for everyone in Canada? Adequate housing would put less stress on the healthcare system and create a healthier population.

Healthy people live in healthy housing, and people that are inadequately housed invariably end up unhealthy. Lack of affordable housing is a burden on our healthcare system. PWAs in particular need more housing supports because the well-documented negative effects of personal environment on health can be fatal.

The effect of safe, affordable housing would be improved health and more productive human beings. We are no longer cave dwellers. ☺

JoAnne Fahr is the executive director of McLaren Housing Society of British Columbia. Ken MacDonald is the executive director of Wings Housing Society. Both societies are based in Vancouver and have a mandate to provide housing to all persons with HIV/AIDS in BC.



**BCPWA
Advocacy
gets
results!**

The BCPWA Society's Advocacy Program continues to work hard to secure funds and benefits for HIV+ individuals. The income secured for October and November 2003 is:

- ▼ **\$62,499.41** in debt forgiveness.
- ▼ **\$58,173.29** in housing, health benefits, dental and long-term disability benefits.
- ▼ **\$24,845.00** in Monthly Nutritional Supplement Benefits.
- ▼ **\$376,162.78** into members' hands for healthcare needs, from grandfathered Schedule C benefits.



Corporate greed threatens Canada's health care system

BCPWA calls a boycott on Abbott products

by Glen Bradford

On Friday, February 27, 2004, the BCPWA Society and the Canadian Treatment Action Council (CTAC) held a news conference to sound the alarm about questionable practices by multinational pharmaceutical giants. Not only have the drug companies hiked the price of some drugs, they are now limiting the supply of treatments in Canada, they are trying to influence Canada's drug price regulations, and they are creating potential health and safety risks for cross-border Internet drug recipients in the United States.

BCPWA and CTAC are part of a group of health care organizations, consumers, and professionals that condemned the astronomical 400 percent price hike in the US of the AIDS drug Ritonavir, manufactured by Abbott Laboratories, arguing that the increase is punitive, unethical, and greedy.

The BCPWA Society is calling on all Canadians to refrain from purchasing any Abbott products that are not medically essential until Abbott rescinds these exorbitant price increases. This humanitarian issue needs the support of all PWAs. American AIDS activists have already launched a US boycott, and British AIDS activists have followed suit.

Despite Abbott's history of substantial support for BCPWA programs and services, we will not accept any further grants or donations from them until they roll back their prices for Ritonavir in the US. This decision will cost BCPWA \$30,000 in 2004 alone.

The price hike renders Ritonavir unaffordable for many Americans. This may force some people to try purchasing

it through Canadian cross-border Internet pharmacies. The free market pricing system for drugs in the US, which is causing Americans to go north of the border for more affordable drugs, is already taking its toll in Canada. Four pharmaceutical companies, including GlaxoSmithKline,

Eli Lilly, AstroZenica, and Pfizer, have limited their drug allocation to Canada to deter the sale of the drugs to Americans at Canadian prices. This will lead to reduced availability of some drugs for Canadians.

At the news conference, BCPWA and CTAC also demanded that the Canadian government ban cross-border Internet pharmacy sales, as well as support and

strengthen Canada's price regulation system.

Cross-border importation is leading multinational pharmaceutical companies to put increased pressure on Canada to dismantle our drug pricing regulation system; as well, they are beginning to impose a quota system on the bulk purchasing of pharmaceuticals. Partly in consequence, pharmacies across Canada are experiencing shortages of lifesaving and life-enhancing medications.

Paul Martin and the federal government need to address this issue. Cross-border internet sales are threatening Canada's public approach to health care. We must be vigilant against an American-style drug pricing system influenced by multinational pharmaceutical corporations, and we must do everything in our power to compel Abbott to abandon its destructive grab for super profits and roll back the Ritonavir price hike. ☪

Glen Bradford is the chair of the BCPWA Society.



TRUE CONFESSIONS

HIV-positive women struggle with the decision when to disclose

by Peter Hall

Deciding when and how to disclose your HIV status is a personal and complicated decision. There is no single best way to tell someone, nor is there a way to predict any one person's reaction to the news. Some HIV-positive women have found it helpful to ask themselves a few questions prior to making the decision to disclose: Who do I want to tell and why do I want them to know? Do I need to share this information with this particular person? Is the person ready to hear? What risks are involved in disclosing my status to this person? What reactions do I fear? How will I benefit from disclosure? In practical terms, you might need to disclose for legal, medical, or employment reasons.

Consider when to tell. Although there is generally no one right time, most women tell when they feel ready or when they are legally required to do so (for example, if they are going to be involved in unprotected vaginal or anal sex, which is considered to be a high risk activity). In Canada, the law requires that

HIV-positive mothers must also decide when to tell their children and whether to ask them to keep the information within the family.

individuals who have unprotected sex must disclose their HIV status before knowingly exposing someone else to HIV. Currently, penalties could include a charge of aggravated assault or attempted aggravated assault.

Deciding who to tell

To ensure appropriate care, tell doctors and other healthcare providers. Your doctor will also need to know how the infection

occurred to determine risk for other diseases, such as hepatitis C for injection drug users and other sexually transmitted diseases for women infected through sex.

You are not required to tell your employer that you are HIV-positive. However, if you decide to tell your employer, the Canadian Human Rights Act may not provide protection from discrimination.

Disclosure creates a responsibility for all parties involved and can be a source of significant stress for women. Some women gain strength from finding a doctor, counsellor, community AIDS organization, or community elder who can support them through this difficult process.

People will respond differently to the news. Some people may respond with love and support while others may not be as accepting. Family and friends may immediately comprehend the situation. Others might react negatively, or they might need time to process the information and overcome fears they have about HIV.

Women often choose to disclose their status to close friends and family. For many, telling those closest to them provides them with both emotional and practical support. Whether to tell family and close friends that you are HIV-positive may depend on the type of relationship you had with them before you discovered your HIV status. Who, if anyone, is told and when and why are usually decisions for the HIV-positive woman.

If there is any risk that you have exposed someone to HIV, those people need to be informed so that they can be tested and seek medical attention if necessary. These people could be sexual contacts or people with whom you have shared needles. For women who are uncomfortable delivering this information, someone at your doctor's office or health clinic can inform these people without identifying you.

In the public eye

To prevent HIV/AIDS from becoming their primary defining characteristic, some women decide to go public and use their stories to advocate for PWAs. Others may disclose for educational purposes to neighbours, community and religious groups, schools, other HIV-positive people, or healthcare providers. Many women find a sense of purpose and increased self-esteem by telling their story. However, in this process, many women have had to consider how much of their story they want to tell. People will ask about the method of transmission. Women who have decided not to share that information have replies prepared such as, "Does it really matter?" or "I am not ready to talk about that."

People who receive the news may need support as well. A good idea might be to provide them with written information about HIV, including phone numbers of local support groups. Also, let them know who else is aware of your status, so that they can go to each other for support.

HIV-positive mothers must also decide when to talk to their children about HIV and whether to ask them to keep the information within the family. It may help build confidence by listening to other women with HIV speak about their experiences of talking with their children. Disclosure may be stressful for parents because of fears that their children will face discrimination and social rejection. Many parents may not tell anyone and keep their children isolated from social supports.

HIV-positive mothers may worry that their children are HIV-positive and may want to talk to an HIV specialist about having their children tested. Mothers of HIV-positive children face further decisions regarding whether and when to tell them.

The dating dilemma

Women with HIV who are dating may find it difficult to know when to disclose. Do you tell someone on the first date or when the relationship gets serious? There is no correct answer, but the longer the wait, the more difficult it may become. It can be difficult to speak with partners, husbands, or girlfriends about sex after having received an HIV-positive diagnosis. Women may be blamed for bringing HIV into the relationship, regardless of whether it is true or not, or women may feel too scared to reveal their HIV-positive status to their partner.

Can a woman with HIV feel sexy and be sexual? Feeling sexy for women with HIV may mean more than having a healthy sex life. It can be about feeling good about being a woman and channeling sexual energy into something—or someone—favourable.

Some women, especially pregnant women, may be at risk for violence when disclosing their HIV status. If you have any concerns that your partner may become violent, you may want to consider having the discussion in the presence of a neutral third party such as a doctor, counsellor, or HIV advocate.

Studies have shown that living with a secret such as HIV can be more emotionally harmful than the rejection that could result from disclosure. Women who have kept a secret for a long time may feel a sense of relief after telling. Community-based organizations and AIDS clinics may offer resources to guide women through the disclosure process. ⊕



Peter Hall is the director of prevention for the BCPWA Society.

We need people like you. BCPWA has volunteer opportunities in the following areas:

Website maintenance > Communications

Administration > Internet research, filing, database management, reception, etc.

Special events > AccoAIDS Awards Banquet and AIDS Walk

Writers > living ⊕ magazine, Communications and Positive Prevention

Workshop development and delivery > Positive Prevention, Communications and living ⊕ magazine

Benefits of becoming a volunteer:

- ◆ *Make a difference in the Society and someone's life*
- ◆ *Gain work experience and upgrade job skills*
- ◆ *Find out more about HIV disease*

If you are interested in becoming a volunteer and/or to obtain a volunteer application form, please email volunteer@bcpwa.org, call 604.893.2298 or visit www.bcpwa.org.

volunteer @ BCPWA

TREATMENT INFORMATION
PROGRAM MANDATE &
DISCLAIMER

In accordance with our mandate to provide support activities and facilities for members for the purpose of self-help and self-care, the BCPWA Society operates a Treatment Information Program to make available to members up-to-date research and information on treatments, therapies, tests, clinical trials, and medical models associated with AIDS and HIV-related conditions. The intent of this project is to make available to members information they can access as they choose to become knowledgeable partners with their physicians and medical care team in making decisions to promote their health.

The Treatment Information Program endeavors to provide all research and information to members without judgement or prejudice. The program does not recommend, advocate, or endorse the use of any particular treatment or therapy provided as information. The Board, staff, and volunteers of the BCPWA Society do not accept the risk of, nor the responsibility for, damages, costs, or consequences of any kind which may arise or result from the use of information disseminated through this program. Persons using the information provided do so by their own decisions and hold the Society's Board, staff, and volunteers harmless. Accepting information from this program is deemed to be accepting the terms of this disclaimer.

The cost of hunger



Food security is essential to promote and maintain health

by Sue Moen

Food security is the physiological and psychological absence of hunger. It is a feeling of security from the well-founded expectation of continued nutritional support. As Satya Brink states in *Lack of Food Security: Focussed Literature Review and Research Framework*, it is “the certainty or confidence that there will be sufficient food in the foreseeable future.” C. C. Campbell defines food security in *The Journal of Nutrition* as “the assured ability to acquire personally acceptable foods in a socially acceptable way,” which emphasizes the value placed on personal choice and dignity.

Dietitians and their community partners in British Columbia are increasingly concerned about the ability of people with low incomes, especially families receiving income assistance, to access safe and healthy food in a digni-

fied manner. A study entitled *The Cost of Eating in BC* reported that individuals and families receiving income assistance must spend between 31 percent and 44 percent of their income to meet standard nutritional guidelines.

The likelihood of reporting food insufficiency increases dramatically as income adequacy deteriorates. Individuals from food-insufficient households had significantly higher odds of reporting poor or fair health; of having poor functional health, restricted activity, and multiple chronic conditions; of suffering from major depression and distress; and of having poor social support. Individuals in food-insufficient households were also more likely to report heart disease, diabetes, high blood pressure, and food allergies. These findings suggest that food insufficiency is one dimension of a more

continued on next page



There appear to be direct relationships between food insecurity and increased health care costs, decreased healthy child development, and decreased productivity.

pervasive vulnerability to a range of physical, mental, and social health problems among households struggling with economic constraints.

How does this situation affect social and health costs? What are the implications for persons living with HIV/AIDS who have additional and specific nutritional requirements? Direct relationships exist between food insecurity and

increased healthcare costs, decreased healthy child development, and decreased productivity.

To begin to address the needs of PWAs in a broader context, A Loving Spoonful has been working with a small target group of HIV-positive individuals in Vancouver's Downtown Eastside for three years to determine the impact of increased food security. A Loving Spoonful has offered three nutritious meals per day to this target group. As a result, the average number of meals accessed per person per day has increased from less than 1 to 2.4. Participants report increased levels of energy, increased activity, increased medication adherence, improved physical and mental health, and decreased visits to emergency health services.

They also report decreased reliance on other emergency food services, such as food banks and line-ups. As individuals and small groups become more food secure, communities become more food secure and are able to move resources to skills-building programs and efforts that promote participant-driven food security initiatives, such as community kitchens.

Food security is essential for the promotion and maintenance of health. The causes and effects of food insecurity include poverty or lack of health. All levels of government and the NGO sector need to respond to this problem. Dietitians in BC have been leaders in responding to food security issues, and we thank them for their efforts. We also applaud and encourage the Vancouver Agreement Food Task Group and the Vancouver Food Policy Working Groups in their efforts to improve food security in Vancouver for all of us. ⊕

Sue Moen is the executive director of A Loving Spoonful.

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The key to success



One person's story of managing high lipids without more drugs

by David Hillman

One of the side effects of long-term HIV and its treatment is a phenomenon called lipodystrophy. This syndrome includes abnormal levels of cholesterol and triglycerides (blood lipids) that increase the risk of both heart disease and insulin resistance, a risk factor for type II diabetes. Another disturbing aspect is the change in one's physical appearance, with body fat disappearing or accumulating in all the wrong places.

Recently published guidelines for the evaluation and management of lipodystrophy recommend “vigorous” lifestyle changes before pharmaceutical interventions. A successful outcome is not guaranteed, but it did work for me. Two of the key recommendations are to stop smoking and to minimize alcohol consumption, something I did ten years ago. Another strong recommendation in the guidelines is to consult with a qualified dietitian to follow a “healthy heart” diet.

With indinavir (Crixivan) as part of my first combination therapy, my cholesterol and triglyceride levels were acceptable, although not within the ideal range. My main concern was my increasing girth, despite working out at the gym for over a year. My healthcare provider suggested metformin (Glucophage), a common diabetic drug that also helps weight loss by preventing a high rise in blood sugar after eating. It worked. After six months, I lost 15 pounds, mostly from around my waist, and shrank to a pant size I hadn't seen since the 1980s.

In 2001, I switched to a different HIV combination therapy that included lopinavir/ritonavir (Kaletra), a potent drug with a great track record for suppressing HIV, but with the potential side effect of moving blood lipids into the danger zone. Within the first four weeks, my triglyceride level more than quintupled from 1.8 (which is acceptable) to 9.2 (definitely not okay). My total LDL (bad) and HDL (good) cholesterol levels were far from acceptable.

My doctor recommended a statin drug, but I wanted to explore other options first. We decided to try high dose niacin.

I was aware of the infamous skin flushing effect, so I opted for the non-flushing version available at health food stores. What a disappointment.

After a three-month trial, my lipid levels all moved in the wrong direction. Then I switched to the real stuff. The side effects

My CD4 count reached an all-time high —and continues to climb — after regular exercising.

were as bad as I expected, but their intensity diminished slowly as my body adjusted. Today, 16 months later, I seldom experience any unpleasant effects. After three months of niacin, my lipid levels moved significantly in the right direction. However, the numbers were still not within the desirable range.

After a 14-month absence from the gym for medical reasons, I began a vigorous exercise program, alternating resistance weight training with intensive aerobics for 60 to 75 minutes, six days a week. At the next set of lab tests, all my lipid levels shifted well into the desirable range and continue to stay there. At the same time, my CD4 count reached an all-time high—and continues to climb—after regular exercising. Today my HDL and LDL cholesterol are at their best levels in seven years, without statin drugs. My triglyceride level has dropped to an acceptable range without fibrate drugs. My blood pressure is perfect without antihypertensive drugs, and my fasting glucose levels are well below the pre-diabetic level.

This program takes a lot of commitment—and maybe a bit of luck—but I've found the benefits to be worth the trouble. Ask your physician whether a similar program might be helpful for you. ⊕

David Hillman volunteers as a treatment information provider with the Victoria PWA Society.

A recipe for longevity

Healthy diet and lifestyle choices can help you live to a ripe old age

by Michele Blanchet



With the advancement of highly active anti-retroviral therapy (HAART), individuals with HIV are living longer and leading successful, satisfying, and productive lives. Adapting to the many changes brought on by HIV and aging can be challenging. As with HIV in general, nutrition and exercise are key components of a healthy aging process.

A healthy diet and lifestyle cannot prevent problems that are part of normal aging. However, scientific research confirms that good nutrition, exercise, and healthy lifestyles promote longevity and prevent or delay such chronic conditions as osteoporosis, diabetes, and heart disease. Health professionals not only need to focus strongly on managing HIV, but should also concentrate on the prevention of these age-related conditions.

The downside of fad diets

Whether you are over- or underweight, successful aging begins with achieving and maintaining a healthy body weight. Nutritionist Pamela Fergusson noted in the November/December 2003 issue of *Living +*, “As the picture of HIV changes and new therapies and their side effects impact health, keeping that extra layer of fat is becoming more unnecessary and unhealthy.”

Avoid following fad diets. High protein/low carbohydrate diets are extremely popular right now as a way to lose weight. Although these diets seem to offer immediate results, we are just beginning to understand the long-term effects and health consequences, and the weight loss is often temporary. After experiencing kidney failure, one individual expressed his regret that he traded his health for a 34-inch waist. Dieting that causes rapid weight loss not only reduces fat stores but diminishes muscle mass as well.

Research has shown that if you are severely overweight, even a 10- to 15-pound decrease can have significant health benefits. Start with small goals of losing 1 to 2 pounds per week. Behavioural changes that lead to a smart diet and that include exercise are the best ways to achieve long-term results.

Getting off the couch

In general, two-thirds of all Canadians are not sufficiently active to sustain good health and a healthy body weight. Make exercise a part of your lifestyle and daily routine.

It is important to maintain your muscle mass as you age. Very low muscle mass is associated with poor survival for HIV. Loss of muscle mass leads to a spiralling effect that decreases your metabolism, leads to the need for fewer calories, reduces your energy requirements, and can lead to loss of strength and to increased weight.

Exercise offers many benefits. Aerobic exercise increases good cholesterol, lowers blood pressure, and can be effective in preventing depression. Resistance exercises help to maintain muscle mass. Most exercises also decrease general anxiety and tension.

When you start exercising, consider your current fitness level, health, and HIV treatment. Choose the type of exercise that is appropriate and enjoyable to you. If you begin with an exercise regimen that is too strenuous, you will not enjoy it and you will be more likely to quit.

Exercise can be a challenge for people living with complications from HIV. Start by making small changes, such as going for a refreshing walk. You can do many exercises without leaving your home, including stretching, using hand

weights or resistance bands, and performing yoga and certain aerobic exercises.

Eating a healthy diet

Oxygen-free radicals are behind many of the conditions associated with aging, such as cardiovascular disease and cancer. Free radicals may also be the cause of deteriorating brain function associated with aging disorders, such as dementia and Alzheimer's disease. Strong evidence shows that a high intake of fruits and vegetables combats these diseases and may help defend against hypertension and memory loss.

Eat at least five fruits and vegetables per day. (See Table 1) These foods are a rich source of powerful disease-fighting

The aging body becomes less efficient at digesting, absorbing, and utilizing nutrients, increasing the need for certain vitamins.

antioxidants, such as ascorbate (vitamin C), and carotenoids, such as beta-carotene, lutein, and lycopenes.



Although no consensus exists regarding the use of antioxidant supplements to treat HIV, vitamins C and E are widely recommended in clinical practice. They are generally inexpensive and non-toxic. Suggested doses are 500-1000mg of vitamin C and 400-800IU of vitamin E per day. (Vitamin E is not easily found in low-fat food sources.)

Studies show that consuming lots of fibre can prevent and treat a variety of diseases, such as diabetes, heart disease, hypertension, and cancer. Fibre also helps to maintain healthy bowels by preventing constipation. It is important to eat a lot of fibre from a variety of sources rather than concentrating on the sources and nature (soluble or insoluble) of the fibre. That said, individuals with chronic diarrhea should use caution when increasing their fibre intake. Soluble fibre in oatmeal, rice, applesauce, and the supplement Metamucil are beneficial because they slow intestinal transit.

Fibre is found in whole grain breads and cereals, beans, fruits, and vegetables. Add dried fruit, ground flax seed, sliced banana, or a handful of fresh or frozen berries to your cereal. Make a hearty soup with split peas, beans, lentils, or barley. Add ground flax seed or bran along with extra vegetables to your tomato or meat sauce.

continued on next page

Table 1. Top antioxidant fruits and vegetables (in no particular order)

FRUITS	VEGETABLES
	
plums and prunes red grapes and raisins blueberries blackberries strawberries raspberries oranges cherries	kale spinach Brussels sprouts broccoli onions beets eggplant corn

Calcium helps prevent bone loss

HIV-positive individuals and older adults are more prone to low bone density than the general population. The disease process of HIV is a major contributor. The aging body also becomes less efficient at digesting, absorbing, and utilizing nutrients, which increases the need for certain vitamins, such as vitamin D, and certain minerals, such as calcium.

You don't need special supplements to ensure a healthy aging process.

You need calcium to prevent bone loss that leads to osteoporosis. Individuals living with HIV, as well as older adults, should be taking at least 1200mg of calcium daily. Theoretically, requirements would be higher for an older individual with HIV; although no set recommendations are available, most HIV clinics recommend between 1200 - 1500mg daily. Kidney stones are one potential side effect of too much calcium.

Calcium is available in small quantities in plant sources; however, low-fat dairy products provide excellent sources of calcium. Try adding some coffee to heated milk or fortified soy beverage to make a latte. Whip up your own version of a yogurt fruit shake. Make a pot of rice pudding; add some almonds and a dollop of yogurt. Cook up some old-fashioned macaroni and cheese. For those who have trouble digesting milk, try heating it to break down the lactose without destroying the calcium.

No quick fixes

Advertisements for quick-fix health products that claim to help

you stay young and healthy are common. Sales of these products have become big business. Remember that nutritional and herbal remedies can be expensive and harmful. Use caution. Unlike prescription and over-the-counter drugs, these products are not strictly regulated and have no standardization or quality control. The risk also varies depending on your age, genetic makeup, nutritional status, health status, dose, and duration of use. Supplements can also interact with medications such as HAART.

You don't need special supplements to ensure a healthy aging process. You can age more slowly by remaining active. Physical, mental, and social activity all appear to be important to health and well-being in later life.

Get started now. It's never too late to improve your nutrition, endurance, and strength.

You can take control. Taking care of yourself is an important part of healthy aging and managing HIV. Poor health often results from controllable factors: over- and undereating, stress, inactivity, excess alcohol, and smoking. You have the power! Start by making small lifestyle changes that optimize your health as you manage your HIV and lead a long healthy life. *For more information on HIV and bone loss, see the July/August 2002 issue of Living +. For more information on high protein diets and fibre, see the November/December 2002 issue of Living +.* ⊕



Michele Blanchet is the registered dietitian at Gilwest Clinic, a Richmond clinic that specializes in HIV and hepatitis treatment and methadone maintenance.

D is for downside

The adverse effects of the “d” drugs

by Sam Friedman

Stavudine (d4T), didanosine (ddI), and zalcitabine (ddC) are nucleoside analog reverse transcriptase inhibitors (NRTIs) used in many combination therapies. The biochemical process that makes this class of drugs so effective is also at the heart of growing concerns regarding severe side effects associated with long-term NRTI use.

NRTIs mimic the natural nucleoside particles that our bodies produce and use for cell division (mitosis). Nucleoside particles are microscopic chemical building blocks of DNA and ribonucleic

Lipodystrophy, hyperlactatemia, peripheral neuropathy, pancreatitis, and fat developing in the liver have all been linked to long-term use of d4T.

acid (RNA). HIV uses these same natural nucleoside particles in its own replication processes, which provides drug researchers with a point of attack. When artificial nucleoside particles, like those found in stavudine (d4T), are used by the RNA of HIV or human DNA during replication or mitosis and are added to an elongating DNA or RNA chain, the next nucleotide sequence is blocked, stopping DNA or RNA replication at that point. This process produces copies of HIV that are incomplete and therefore ineffective. However, this result also raises concerns.

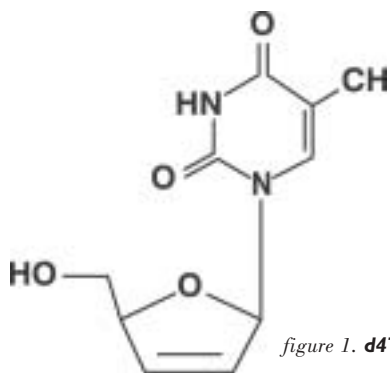


figure 1. d4T

Mitochondria are specialized parts of cells that provide all the energy required for all cell functions. They have their own nucleus containing mitochondrial DNA, giving them the ability to reproduce themselves independently within a cell through the process of mitosis.

However, unlike the DNA in the nucleus of a cell, the DNA in the nucleus of mitochondria cannot distinguish between natural nucleoside particles and the nucleoside analogs present in NRTIs. So when the mitochondria use these nucleoside analogs during mitosis, incomplete (mutant) copies of mitochondria are produced.

These mutants are at the heart of the controversy. The process in which mitochondrial DNA synthesis is terminated before completion is exactly the same way NRTI drugs terminate HIV replication before its completion. HIV replication is stopped, but mutant copies of mitochondria, which lack the normal bioenergetic abilities needed to power the cell, are produced and eventually outnumber normal mitochondria. This production of mutant mitochondria negatively affects all cell

functions. When the cells that make up our tissues and organs do not function properly because of mitochondrial damage, tissues break down and organs are damaged, which can lead to organ failure.

Other severe side effects, such as lipodystrophy, hyperlactatemia (too much lactic acid), peripheral neuropathy, pancreatitis, and fat developing in the liver, have all been strongly linked to long-term use of stavudine (d4T), as well as didanosine (ddI), zalcitabine (ddC), and protease inhibitors. Many PWAs also attribute depression, agitation, and anxiety to stavudine (d4T) use, though these side effects have never been proven.

Studies have proven, however, that using any of these three NRTIs—stavudine (d4T), didanosine (ddI), or zalcitabine (ddC)—especially any two or more of these drugs in any combination therapy, can dramatically increase the risk of developing mitochondrial damage. Therefore, researchers recommend switching from these three NRTIs to other NRTIs with less toxic profiles or to drugs from other classes, whenever possible, to reduce mitochondrial damage and its consequences.

For the basics on dosing, drug interactions, common side effects, and contraindications for stavudine (d4T) and other NRTIs, call the BCPWA Society Treatment Information Program at 604.893.2243. ☎

Sam Friedman is a treatment information counsellor with the BCPWA Society's Treatment Information Program and has been HIV-positive for 18 years.



Pay now, save later

The costs of not fully addressing the hepatitis C epidemic

by *Ken Thomson*

Hepatitis C is called the “silent epidemic,” an apt but somewhat baffling title. On an individual basis, it is understandable. The initial infection can be asymptomatic or dismissed as the flu. The liver is a resilient organ that seldom sends out distress signals until extensive damage has occurred. Many people are not diagnosed with hepatitis C until they have been infected for many years.

More puzzling is the limited response from governments and health policy makers. Hepatitis C is the most reported viral infection in Canada, with 16,000 cases reported in each of the last two years. Approximately 250,000 Canadians are infected, yet up to 70 percent remain unaware, uninformed, and unable to take steps to protect their health and the health of others.

The costs are substantial. An episode of liver failure can cost \$50,000. For those lucky enough to receive one, a liver transplant can cost from \$125,000 to \$250,000. In Canada, liver transplants necessitated by hepatitis C infection cost up to \$30 million annually. These figures do not include the lifetime costs of expensive anti-rejection drugs.

The Canadian Institutes of Health Research estimates that hepatitis C costs Canadians \$500 million annually, and within five years, that figure will double to \$1 billion. A US study shows a similar pattern of escalating cost. By 2021, the cost of hepatitis C in Canada is estimated to reach \$3.2 billion annually.

Inadequate funding in Canada

What is being done? In 1999, following the tainted blood scandal, the federal government agreed to transfer to the provinces an average of \$15 million annually for 20 years to cover the treatment, immunization, and nursing care costs related to hepatitis C for those not covered under the 1986-90 compensation agreement. However, a weak accountability clause may allow the provinces to simply deposit the money into their general revenue accounts.

What about surveillance, prevention, education, support, care management, and research activities? During the past five years, the federal government has committed an average of \$10 million annually to the Hepatitis C Prevention, Support, and

Research Program. That amounts to \$40 per infected person. Unfortunately, this program is ending, and it is unclear what will happen in 2004.

Community-based organizations are calling for an immediate increase to \$50 million annually, including increased funding for training.

We know that effective approaches are available. Australia has achieved a substantial return on investment from needle exchange/harm reduction programs. From 1988 to 2000, \$7.75 billion in treatment costs for HIV and HCV were avoided by preventing an estimated 46,000 infections.

Although preventing new infections is a priority, testing, increasing public awareness, and preventing disease progression among those already infected present greater challenges.

With only forty hepatologists in Canada and approximately 50,000 Canadians who either now have or will soon develop the most serious consequences of hepatitis C, such as cirrhosis, liver failure, and cancer, the need for new models of treatment provision is great. Multidisciplinary team approaches that include community services and peer supports need to be developed.

The expense of treatment

Treatment is expensive (\$20,000 for 48 weeks), difficult, and often complicated. As with HIV treatment, adherence is very important. Under current formulary criteria, if the treatment fails, it is unlikely to be repeated.

Overall, sustained viral response occurs in approximately 55 percent of those treated with the new pegylated interferon plus ribavirin combination. Up to 20 percent of patients discontinue treatment because of side effects. Some side effects require medical interventions, but community resources can effectively deal with others at a much lower cost.

Recently, physicians, researchers, and some policy makers began to consider making treatment available to every infected person, even those with early or mild disease progression. With increased treatment efficacy, the need to incur the expense and risks of liver biopsy would be lessened, disease progression would be minimized, quality of life would be improved, and the reservoir of infected and potentially infectious individuals would be reduced.

Paradoxically, people who are now considered to be the least in need of immediate treatment, particularly individuals who are young, recently infected, and female (estrogen may be a protective factor), are more likely to have successful treatment outcomes. Yet, Harvard School of Public Health researcher Dr. Joshua Salomon cautions, “For patients at low risk of progressing, the overall health gain from treatment may be minimal given the potential for toxic side effects.”

Spend on treatment for other cost savings

In a study commissioned by the risk management consulting firm Milliman USA, Sherrie Dulworth, Sunit Patel, and Bruce Pyenson examined the impact of treating all eligible HCV-infected people. They found that treatment would pay for itself within ten years and that does not even factor in avoided disability and lost productivity costs. This calculation included both patients who respond to treatment and those who do not. Their cost-benefit analysis states that every dollar spent on combination therapy resulted in about four dollars in medical cost savings.

The federal government has committed an average of \$10 million annually to the hepatitis C program—only \$40 per infected person.

However, those gains are largely theoretical because treatment access is restricted and uneven across the country. ALT levels are used as a key criterion for approving treatment despite their imprecision as an indicator of liver damage. Reports of people being so desperate to access treatment that they have used dangerous methods, such as drinking large quantities of alcohol to raise their ALT levels, illustrate the point.

The cost of treatment can be considerable for people not fully covered by private or government drug plans. Even with PharmaCare, many people find they have to spend \$2,000 to \$4,000, depending on which month in the year their treatment starts. The new Fair PharmaCare may reduce the cost for people who have a net family income under \$40,000. These costs can be a significant barrier, particularly when added to those of

lost work, home care, travel to appointments, and over-the-counter medications.

One area that is not well researched is treatment-induced medical conditions and post-approval surveillance. A significant number of patients report the onset of medical conditions or the worsening of existing conditions following treatment. The full extent and cost of these conditions is not known.

Co-infection with HIV is also becoming an increasingly important issue. In Canada, one of every four people with HIV is also infected with HCV. End-stage liver disease is now a leading cause of death for co-infected people.

The escalating costs of the disease

It is difficult to find accurate figures on the cost of each HCV infection. Australia has pegged it at about \$50,000 per person. The C. Everett Koop Foundation estimates \$100,000 per person in the absence of a transplant, while the BC Centre for Disease Control has estimated that the medical cost from time of diagnosis to death, including the economic loss for that individual, is \$1 million per patient.

What is clear is that we are facing an epidemic with an increasingly expensive impact. By 2018, rates of HCV-related liver decompensation are expected to increase by 430 percent, demand for liver transplants by 770 percent, and liver-related deaths by 336 percent, as compared to 1998.

The consensus is that we need to implement a coordinated strategy that includes better surveillance and data collection; greater public awareness, prevention, and testing; increased education and support to minimize disease progression; improved treatments; and more research.

However, given the nature of politics, where long term means this fiscal year and an eternity is the time between now and the next election, that which is obvious and fiscally prudent to most Canadians may yet again be silenced by the urgent bleating of today’s headlines.

It seems a lot like that old oil filter commercial: “You can pay me now...or you can pay me later.” ⊕

Ken Thomson is the chairperson of the Hub Team (working group) of the BC Hepatitis C Collaborative Circle.

Questions or concerns about your treatment or health?

BCPWA Treatment Information

You are welcome to drop by anytime Monday to Friday, 10AM to 4PM, at 1107 Seymour Street, Vancouver (down the street from St. Paul’s) and you can even email us at treatment@bcpwa.org

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LONG DISTANCE 1.800.994.2437**

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Wanted: AIDS treatment activists

by Paula Braitstein

People in other disease groups are often envious of the HIV/AIDS treatment and research infrastructure. In the twenty years since HIV surfaced, many drugs have been developed that have, for those with access to them, turned HIV into a chronic manageable illness. We have learned more about this virus (and the immune system) in twenty years than we have learned about any other virus or disease, including cancer. Dedicated HIV clinical trials groups have been established, and it is almost a standard of care for expanded access programs to accompany the development of new HIV drugs.

However, our governments and hospitals were largely dragged, kicking and screaming, into the process of addressing the HIV epidemic. Scientists in the Canadian government initially refused to conduct HIV testing because of their fear of catching the virus. St. Paul's Hospital in Vancouver evolved into the HIV centre for BC because the other major hospital, then called Vancouver General, refused to treat HIV-positive people. It took a great deal of effort to persuade the government to take HIV seriously and to fund research, the research infrastructure, and community-based programs.

Although many of these advancements were a result of the courageous, compassionate, and forward-thinking efforts of HIV-negative individuals such as the Sisters of Providence of St. Paul's, HIV-positive activists have driven the agendas of both the research and community worlds.

However, the number and quality of treatment activists is dwindling. Burnout

(it's hard and usually thankless work), death, and complacency (the irony of success) have taken their toll.

Without knowledgeable and committed activists, not only do we risk not moving forward, we also risk falling back.

If you think that we no longer need activism in HIV/AIDS, reread all the back issues of *Living+*! The HIV/AIDS issues have changed over twenty years—they have evolved from developing a research agenda and including people with HIV/AIDS in all aspects of research to today's complexities of drug pricing, formulary coverage, co-infections, harm reduction, and addiction treatment.

Without knowledgeable and committed activists, not only do we risk not moving forward, we risk falling back. Fewer innovative drugs are being developed. Criteria for accessing new drugs are becoming tighter. Death rates from addiction, viral hepatitis, cancer, and HIV (because of inaccessibility to antiretrovirals) are increasing. The people affected by HIV are increasingly marginalized and vulnerable.

What does it mean to be a treatment activist? It means giving a damn about people. It means making the time to learn and to apply what you learn to make a difference.

You don't have to be a scientist or even scientifically inclined. You can play many different roles. You can focus on the many restrictive and punitive policies that are rammed down our throats, such as HIV and hepatitis C reportability or the insufficiency of Canada's contribution to the Global Fund to Fight AIDS, Tuberculosis, and Malaria. You can face down pharmaceutical companies on any number of issues: provision of expanded or compassionate access to new medications; marketing techniques inherent in drug company research designs and presentations; or drug pricing. You can work with scientists on research advisory boards, argue for certain research priorities, or lobby for more money for community-based treatment information services.

We are where we are today because smart, passionate, and caring people made making a difference a priority in their lives. Our fore brothers and sisters had many successes, and they have left an important, albeit fragile, legacy.

If you are interested in being part of the next wave of HIV treatment activists, email the BCPWA Society's Collective Advocacy Committee at <collective@bcpwa.org> and type "treatment activism" in the subject line. ☺



Paula Braitstein is the senior policy advisor on health promotion for the BCPWA Society.



Flourish with fungi!

Medicinal mushrooms can boost the immune system

by *Katolen Yardley*

Herbal medicines and allopathic (prescription) drugs both have legitimate roles in the health maintenance and treatment of people with HIV/AIDS. Although some research has been conducted on the specific effects of herbal medicine on HIV, most available data discuss the benefits that plant medicine has on general immune system enhancement.

The hectic pace of North American living, emotional stress, poor nutrition, and “dis-ease” can cause our bodies to overfunction in an effort to maintain health. Extended stress over time can lead to exhaustion and increased susceptibility to further illness. When used as medicine, botanicals can provide nourishment in conditions of depletion, strengthen the body’s natural antiviral mechanisms, and assist in keeping HIV under control and asymptomatic.

Herbs and fungi that contain balancing, regulative, and tonic properties are called adaptogens (harmony-restoring agents). The term “adaptogen” is a Russian concept based on the daily use of herbs to prevent disease and enhance an individual’s current state of health. Numerous clinical studies have been conducted on herbal adaptogens since the 1950s, and medicinal mushrooms have been used therapeutically in Asia for centuries.

Adaptogens are of particular importance for supporting the health of people with HIV/AIDS, cancer, autoimmune disorders, and other chronic illnesses. Adaptogen herbs and fungi are used to increase physical and mental endurance, enhance vitality, and help the body cope with stress. They also improve resistance to infection and help maintain optimal organ function. Used in conjunction with allopathic medicine, adaptogens can often minimize side effects caused by many drugs.

A boost to the immune system

Medicinal mushrooms with adaptogenic properties such as *reishi* (*Ganoderma lucidum*) and *maitake* (*Grifola frondosa*) help to maintain healthy immunity in HIV-positive people. All medicinal mushrooms contain a compound called beta glucan. This complex polysaccharide contains adaptogenic and immunostimulant properties that support components of cellular immunity, stimulate production of interferon, and increase natural killer cell activity against viral infected cells. In animal studies, beta glucan has also been found to stimulate the activity of macrophages (the immune system scavengers that destroy foreign invaders). Medi-

cial mushrooms also contain chemical substances that inhibit viral, bacterial, and fungal infections, specifically oral and genital herpes, warts, shingles, viral hepatitis, and candida.

The immune system is the first line of defence against infection. When the immune system is impaired, bacteria, fungi, and viruses have free reign in the body, and cancer cells and other opportunistic infections can develop. Conventional treatment often includes broad-spectrum antibiotics to keep microbes in check. However, medicinal mushrooms can offer increased protection from infection.

Maitake is a precious and expensive variety of Japanese mushroom. Animal studies have found that maitake mushrooms stimulate interferon by increasing the number of macrophages. (Interferon stimulates T-cell division therefore assists in increasing anti-bacterial troops in the body). A considerable amount of research has been conducted on maitake mushrooms and their anti-tumour, anti-HIV, and anti-hepatitis benefits.

Strengthening the body's resistance to stressors

Otherwise known as *ling-zhi*, reishi mushrooms have been used for centuries in both China and Japan to treat deficiencies in vital energy. Their adaptogen qualities are used to strengthen the body's resistance to physical, mental, and environmental stressors. Some of the main chemical constituents in the plant include polysaccharides, triterpenes, germanium, and steroids.

Used in conjunction with prescription medicine, adaptogens can often minimize side effects caused by many drugs.

Polysaccharides are anti-tumor, immune-stimulating, adaptogenic, and blood-sugar balancing. Triterpenes (ganodermic acids) and germanium are free radical scavengers that inhibit histamine release, thereby reducing asthma and allergy symptoms. These chemicals also inhibit angiotension-converting enzymes, which narrow the blood vessels in conditions of high blood pressure. Triterpenes and germanium also decreases LDL ("bad" cholesterol). The steroid components (gandosterone) help to protect the liver and balance blood sugar.

Clinical studies reveal that reishi mushrooms have the following beneficial effects:

- ▼ Increases oxygen utilization of the cells and removed free radicals by acting as an antioxidant
- ▼ Improves resistance to fatigue and physical stress, enhances energy and endurance
- ▼ Significantly lowers blood pressure and the amount of low-density lipoproteins in the blood
- ▼ Inhibits the formation of thrombi (blood clots), which can lead to myocardial infarction and angina
- ▼ Improves immune response by supporting increased production of white blood cells in the bone marrow, increasing macrophage action and enhancing T-cell activity

- ▼ Acts as an antibacterial agent against staphylococci and streptococci bacteria

A wide range of therapeutic uses

Reishi mushrooms have been used to treat HIV/AIDS; arthritis (osteo and rheumatoid types), as well as auto-immune disorders, fibromyalgia, chronic fatigue syndrome and liver diseases, including cirrhosis and hepatitis. Reishi mushrooms are thought to inhibit cancer and sarcomas by inhibiting platelet aggregation, which impedes metastasis. Other applications include lung infections such as bronchitis and pneumonia; hyperlipidaemia, hypercholesterolaemia, and hypertension; allergies and allergy-induced asthma; and ulcers. By relaxing and strengthening the nervous system, reishi mushrooms can also help relieve insomnia and anxiety and improve concentration. By increasing platelets, hemoglobin, and tumor-fighting cells, it also helps to restore homeostasis in the body and enhance immune system function. It can even offer protection during chemotherapy and radiation by stimulating and protecting bone marrow function.

When you begin to use medicinal mushrooms, short-term side effects may occur until your body has a chance to adapt. Some adverse effects include increased bowel movements, skin rash, or constipation. These are normal signs that the mushroom is causing your body to excrete toxins, and will disappear with repeated consumption.

Do not self-treat. Chronic conditions are best treated while under the clinical care of a practitioner trained in botanical therapies. In a clinic, a practitioner designs a program specific to an individual's needs, taking into account the whole body, nutrition, and concurrent prescription medication. Most botanical therapies are used in combination rather than singly, and when used in this manner, they are most successful for treating the whole person. ⊕

Recommended reading

Boik, John. *Natural Compounds in Cancer Therapy*.
Mills, Simon and Kerry Bone. *Principles and Practice of Phytotherapy*.
Schar, Douglas. (1998) *Grifola frondosa and the Human Immuno-deficiency Virus*. *British Journal of Phytotherapy*, 5(1), 13-23.
Willard, Terry. *Reishi Mushroom: Herb of Spiritual Potency and Medical Wonder*.
Yance, Donald. *Herbal Medicine, Healing and Cancer*.



Katolen Yardley, MNIMH, is a medical herbalist in private practice at Gaia Garden Herbal Dispensary in Vancouver and the Tri City Natural Health Clinic in Coquitlam.



East meets West



Integrative medicine uses conventional drugs and alternative therapies

by Tom Mountford

In the last decade, health consumers became familiar with complementary and alternative medicine (CAM). As we entered the new millennium, the theory and practice of integrative medicine began to evolve. Integrative medicine (IM) is a healing-oriented system of medicine that takes the whole person—body, mind, and spirit—into account, including all aspects of the person's lifestyle. It uses all appropriate treatments, including conventional Western drugs and alternative therapies.

In 1997, Andrew Weil, MD, founded the Program in Integrative Medicine (PIM) at the University of Arizona. The program now has an Integrative Medicine Clinic in a university setting. Its research facility offers a two-year resident fellowship, a two-year Web-based model of distributed learning (associate fellowship) program, a one-month rotation in IM as a medical student, and resident electives.

The program defines the basic principles of IM, beginning with a partnership in the healing process between patient and practitioner, using appropriate conventional and alternative methods to facilitate the body's innate healing responses. It takes into consideration all factors that influence health, wellness, and disease, with a philosophy that neither rejects conventional medicine nor accepts alternative medicine uncritically.

IM recognizes that good medicine should be based in good science that is inquiry-driven and open to new paradigms, with the use of natural, less invasive interventions whenever possi-

ble. It incorporates the broader concepts of health promotion and prevention of illness, as well as the treatment of disease with practitioners as models of health and healing committed to the process of self-exploration and self-development.

The Foundation for Integrative AIDS Research

The Foundation for Integrative AIDS Research (FIAR) is one of many new organizations in the US devoted to IM. Operating without pharmaceutical or nutraceutical funding, this non-profit organization addresses issues relevant to both the prevention and treatment of HIV and chronic hepatitis. Currently, it is conducting clinical studies on the dietary supplements that are now widely used to help delay progression, offset anti-retroviral side effects, or extend structured treatment interruptions. Using clinical questions selected by the infected and affected communities, it is evaluating the benefits, risks, limitations, and costs of dietary supplements. This research will enable people to make more informed treatment decisions.

FIAR also conducts evaluations of commonly available products to assess their purity and potency, provides background on interventions, and performs statistical analyses on completed studies. It presents this information in peer-reviewed journals, AIDS newsletters, and on the FIAR Web site, which provides links to many other CAM studies.

Currently FIAR is conducting two NIH-approved studies in conjunction with New York City's Mount Sinai Medical Cen-

ter. The first study is evaluating the safety of milk thistle among people with HIV and hepatitis C. The research will seek to obtain preliminary efficacy data concerning the effect of milk thistle on liver enzymes and other markers. It will also record any problematic interactions with antivirals.

The second project is exploring the study of Siddha medicine in a southeastern Indian state. This indigenous medicinal system has been used safely for thousands of years and is the only access to care for the large HIV-infected population in the region. The project will provide new opportunities to strengthen ties between the local practitioners and Western partners and to develop local skills in clinical trial research methods. It will develop a "FIAR Trade" agreement to ensure that, should the intervention prove effective, any commercial value will reside with the community to meet local needs such as conservation, prevention programs, wider access to antivirals, and more opportunistic infection treatments.

There was no mention of complementary and alternative medicine among the 47 recommendations in the Romanow Report.

Other FIAR projects include a pilot study created by two Traditional Chinese Medicine practitioners, Mark Kuebel and Fred Blair, to evaluate the anti-HIV effects of a Chinese medicine protocol. The researchers hope their formula of herbs will extend structured treatment interruptions by reducing viral activity to a low level while detoxifying the body and preventing major AIDS symptoms from developing during the interruption.

A fourth FIAR project involves the development of an STD clinic and enhanced access to prevention programs and treatment in Nepal. Eventually this project will include clinical trials. Stakeholders are being identified to conduct a study of Ayurvedic treatment of HIV disease in Nepal. The study will also allow researchers to address other significant infrastructure issues such as developing local access to more affordable diagnostic techniques.

Integrative medicine in Canada

In Canada, the increased use of CAM necessitated a review of the current regulatory framework. An advisory group developed a discussion paper on complementary and alternative healthcare for the Health Human Resources Strategies Division of Health Canada. It defined expected outcomes, core values, and key concepts of an integrated health system. The paper also identified challenges and suggested strategies. This process led to the formation of a new Natural Health Products Directorate and a new regulatory framework. New natural health products regulations took effect January 1, 2004.

The final report of the Commission on the Future of Health

Care in Canada, called *Building on Values: The Future of Health Care in Canada*, makes no mention of CAM in all its 47 recommendations. Also known as the Romanow Report, it proposed sweeping changes to healthcare in Canada to "achieve a more effectively integrated and a more accountable world class system that helps to make Canadians the healthiest people in the world."

The report did, however, recommend that the various levels of government, regional health authorities, and healthcare providers should continue to develop programs and services that address the diverse healthcare needs of Canadians, including visible minorities, people with disabilities, and new Canadians. It also recommended that "the Health Council of Canada should review education and training programs and provide recommendations to the provinces and territories on more integrated education programs for preparing health care providers, particularly for primary health care settings."

Elsewhere, the Canadian Strategy on HIV/AIDS directs the development of a strategic approach to care, treatment, and support. The preamble to its action plan identifies "the need for access to alternative therapies, including marijuana."

The need for community activism

Unfortunately, with changes at all levels of government, it is hard to predict how new leaders and political parties will deal with issues associated with the integration of healthcare delivery.

We need community activism in Canada to direct and assist health consumers, practitioners, and non-profit organizations in becoming involved in research that will lead to a more integrative system of healthcare delivery. Any movement toward this integration of healthcare delivery will be very complex. The political dominance of conventional medicine carries the values, culture, and conceptual framework into which it expects CAM to assimilate. It operates from the assumption that each CAM intervention, once tested and proven effective, can be incorporated into conventional care as now practiced.

It is an immense challenge to merge a system so entrenched in our society with CAM systems, which diagnose and treat patterns of dysfunction within the entire person as an indivisible system, rather than isolated problems in separate bodily subsystems. Differing world views and the values placed on different outcomes must be accepted in order to find common ground and create patient-oriented research rather than disease-oriented research. ☺



Tom Mountford is a volunteer with the BCPWA Society's Treatment Information Program.



Entrevista con Byron Cruz

por Sergio Plata

Byron Cruz es Presidente de la Sociedad Multicultural de Servicios de la Salud, también es trabajador de extensión para el Centro de Control de Enfermedades, en el área de enfermedades de transmisión sexual y actualmente es coordinador del proyecto de prevención de la hepatitis C en la comunidad latinoamericana y vietnamita.

Cómo surgió la idea de crear un proyecto de prevención de la hepatitis C dirigido a la comunidad latina y vietnamita y en que consiste este proyecto?

El origen vino cuando diferentes trabajadores de salud nos dimos cuenta de que algunos inmigrantes al realizarse el examen médico de migración sus resultados daban positivo en la infección de hepatitis C, también nos percatamos que no existía ningún material escrito en español tampoco en vietnamita sobre las medidas de prevención, al mismo tiempo Health Canada hizo un llamado para hacer prevención sobre hepatitis C en British Columbia la BCMHSS yo y Francisco Granados creamos la propuesta.

El proyecto consiste en tres etapas: la primera es de concientización.- cuyo objetivo es dar a conocer que la hepatitis C esta también presente en la comunidad latina y vietnamita y que se puede prevenir. Creamos un grupo de trabajadores comunitarios, cubriendo diferentes medios de comunicación, pláticas comunitarias, distribución de folletos, elaboración de materiales escritos en español y vietnamita, entrenamiento de educadores, y seleccionamos cuidadosamente las comunidades de alto riesgo.

Me he dado cuenta que la mayoría de las personas infectadas son hombres, es verdad esto?

En el caso de la comunidad latina el porcentaje es mayor en hombres, y también la comunidad de inmigrantes que tenemos es mayormente masculina.

Cuales son las estrategias y las prácticas de prevención de la hepatitis C?

Tratar de alcanzar la mayor comunidad posible a través de la concientización, dando pláticas y distribución de folletos también promoviendo el examen de sangre para la hepatitis C. Alcanzar a la comunidad de alto riesgo, localizar a los recién lle-

gados en Vancouver, dar alcance los adolescentes en escuelas y los padres de familias.

Y las formas de prevención son; no compartir jeringas u otros instrumentos en el uso de drogas, usar condón o prácticas de sexo seguro, tener cuidado de que se encuentren esterilizadas las agujas utilizadas para perforaciones de aretes y tatuajes

El problema de la hepatitis C es serio, usted cree que sea un problema de salud, social o educativo?

Es un problema integral y que tiene mucho que ver con las condiciones de pobreza, por ejemplo, se ha dicho que en abril la asistencia social será reducida o eliminada y eso conllevará a mayor consumo de drogas y por lo tanto a conductas de riesgo. En el campo de la salud, lo es, porque es una enfermedad infecciosa que puede ser transmitida, y también genera depresión y baja autoestima (salud mental). Es un problema educativo por la falta de información y social por los mitos y estigma que existe.

Cómo una persona puede aprender a vivir con la hepatitis C?

La persona puede pasar por diferentes etapas emocionales, como es el duelo, la negación, la culpa, el enojo y finalmente la aceptación de su condición. Se tiene que dar empoderamiento a través de la educación y la información y por supuesto cuidarse porque esto permitirá a la persona llevar una calidad de vida, hacer ejercicio, buena dieta, dormir bien, evitar el estrés y evitar las conductas de riesgo para no coinfectarse o infectar a otros. Es importante acudir a sus citas médicas y el apoyo de amigos y la familia son vitales. ⊕

BCPWA Treatment Information Program (TIP)

Ofrece información sobre tratamientos del VIH/SIDA.

Todos los miércoles 1:00PM a 5:00PM.

1107 Seymour Street, 2nd Floor, Vancouver, BC V6G 5S8

Llame a la línea directa: 604.893.2243

email: treatment@bcpwa.org

Co-infection study looks at preventing depression

by Jim Boothroyd

A newly approved Canadian study will examine whether people co-infected with hepatitis C (HCV) and HIV are better able to tolerate interferon HCV therapy if they take antidepressants before starting interferon. (Depression is a common side effect of interferon.)

Many people with hepatitis C are prescribed a combination of pegylated interferon plus ribavirin. Previous studies involving HIV-negative people indicate that this combination eradicates HCV in 60 percent of cases overall among those receiving therapy for 24 to 48 weeks.

However, one in three people who go on this combination develop depression. Most experience tiredness, lack of appetite, and irritability. These side effects may limit the effectiveness of the HCV treatment. For example, patients suffering depression may not be able to take their medication properly or may need to stop their hepatitis C treatment early.

Depression that develops from interferon can be treated successfully with antidepressants called selective serotonin reuptake inhibitors (SSRIs). Normally, doctors prescribe these antidepressants once symptoms of depression appear. This study will test whether giving the SSRI citalopram hydrobromide (Celexa) to people before they develop symptoms reduces depression and anxiety. It will also assess whether this strategy allows better adherence to pegylated interferon plus ribavirin and, ultimately, better responses to this HCV treatment.

This trial is entitled “A randomized, placebo-controlled trial of citalopram (Celexa) for the prevention of depression

and its consequences in HIV-hepatitis C co-infected individuals initiating pegylated interferon/ribavirin therapy.”

Sixty patients will be enrolled at different centres across Canada, up to 15 of them at the Downtown Infectious Diseases Clinic (IDC) in Vancouver. The principal investigator is Dr. Marina Klein of McGill University. Her Vancouver co-investigator is Dr. Brian Conway of the University of British Columbia and Downtown IDC.

Treatment will last for up to 48 weeks. Participants will then continue to be watched by study staff for another 24 weeks. One group will be given citalopram hydrobromide, the other a placebo.

Candidates must be both HIV-positive and HCV-positive and must not have been previously treated for hepatitis C or recently diagnosed with depression.

“The treatment of co-infected people is often undermined by depression, yet until now few studies have looked at ways of preventing this side effect,” said Dr. Marina Klein. “So we think this study is highly relevant and will enroll swiftly.”

Researchers expect the study to begin enrolling later this year. ☺



Jim Boothroyd is the communications manager at the Canadian HIV Trials Network.

Trials enrolling in BC

- CTN 147** — Early Versus Delayed Pneumococcal Vaccination
BC sites: St. Paul's Hospital and Downtown Infectious Disease Clinic (IDC), Vancouver
- CTN 157** — Fenofibrate & L-Carnitine for Elevated Triglyceride Level; BC sites: St. Paul's Hospital and Downtown IDC, Vancouver
- CTN 164** — STI (Structured Treatment Interruption)
BC site: Downtown IDC, Vancouver
- CTN 167** — OPTIMA: Options with Antiretrovirals
BC sites: Downtown IDC, and St. Paul's Hospital, Vancouver, and Cool Aid Community Health Centre, Victoria

- CTN 169** — DAVE: D4T or Abacavir plus Vitamin Enhancement
BC site: St. Paul's Hospital, Vancouver
- CTN 171** — Ziagen plus Cellcept (Mycophenolate Among Patients with HIV Receiving Abacavir)
BC site: St. Paul's Hospital, Vancouver
- CTN 178** — Rosiglitazone maleate (Avandia)
BC site: St. Paul's Hospital, Vancouver
- CTN 183** — Continuous Treatment versus Intermittent Treatment
BC site: St. Paul's Hospital, Vancouver
- CTN 189** — 3TC or No 3TC for HIV with 3TC resistance
BC site: St. Paul's Hospital, Vancouver

To find out more about these and other trials, check out our trials database at <www.hivnet.ubc.ca/ctn.html> or call Sophie at the CTN (1.800.661.4664).



Crossing that bridge now

Part 1 of a report on end-of-life decision making

by Irene Goldstone and Mary Petty

Ideally, as adults living well-organized lives, we would complete a series of tasks referred to as end-of-life (EOL) decisions. These tasks include making a will, appointing a power of attorney, appointing someone to direct our medical affairs, identifying preferred locations for living our final days and for our death, and leaving directions for a celebration of our life. In British Columbia, many of these aspects can be dealt with in a representation agreement (See the Nov/Dec 2003 issue of *Living+*, as well as www.trustee.bc.ca).

As part of the annual survey conducted by the BCPWA Society and the BC Centre for Excellence in HIV/AIDS (BCCfE), a self-administered questionnaire was mailed to 1508 BCPWA Society members between May and September 2002. Questions addressed socio-demographic characteristics, clinical and functional status, antiretroviral therapy use, and end-of-life issues. Statisticians at the BCCfE did the analysis. The findings were first reported in April 2003 at the 12th annual Canadian Conference on HIV/AIDS Research in Halifax.

Half of the members returned completed surveys. Of the returned surveys, 91 percent answered the questions on end-of-life decision-making. The majority (89 percent) were men, median age 44; ten percent were women, median age 40; and one percent were transgendered. The 85 percent of all respondents who had considered EOL decision-making were much more likely to be born in Canada and to be Caucasian, and most (86 percent) had taken antiretroviral therapy. Twenty-nine

percent had at least a bachelor's degree. Relative to those respondents who had not considered end-of-life decisions, they also had a higher current income median (\$17,000), an earlier year of infection (1992), and a lower median nadir CD4 count (150). No difference was found with respect to gender, age, functional status, most recent CD4 count, or viral load.

Few have made end-of-life decisions

In the survey, 41 percent had completed a will, 36 percent had appointed someone to direct their medical care, and 36 percent had appointed a power of attorney. Only 29 percent had made a living will (which has no legal status in BC but in practice guides care). Twenty-nine percent had given direction for a celebration of their lives, and 25 percent had identified a preferred location for the final weeks or days of care (with the vast majority preferring palliative environments, in particular in a home). Only a small percentage had completed a representation agreement.

The findings are consistent with a 1995 study of HIV-positive persons living in Vancouver entitled "Patterns of Care in Advanced HIV Disease in a Tertiary Treatment Centre."

These data suggest that limited EOL decision-making has occurred, even among more advantaged PWAs. Healthcare professionals and HIV/AIDS service providers need to develop strategies to increase EOL decision-making among all PWAs, especially among the disadvantaged.

Broaching the issue can be difficult

Raising the issue of EOL decision-making is highly sensitive. Thirty-two percent reported having considered it on their own initiative, while over one-half reported others had raised EOL issues with them (generally, family, friends, a partner, or healthcare professionals). Thirteen percent reported they wished someone would raise the issue with them. The most commonly preferred choice was their partner, counsellor, or lawyer.

Respondents were hoping that their caregivers would introduce EOL discussions. Many caregivers who emphasize the importance of EOL discussions in theory consistently fail to initiate them with patients. As both caregivers and patients, we are reluctant to talk about death and dying. The impulse to fight for life can be strong under adverse conditions. We avoid thinking and talking about the inevitable, as if we can push death away by not recognizing it.

Advanced medical care represents the very essence of this fight for life and against death; it is focused on cure and on prolonging life. Within the structures of modern medicine, it is challenging to find a space where we can comfortably talk about death. At best, we miss opportunities because people are not deemed sick enough.

An empowerment model of health care includes anticipating and planning for future needs, including the end of one's life... .

As a way of talking about these issues, we use the terms “EOL decision-making” or “advance planning” to imply a task to be completed, a check list of sorts. In fact, these discussions are complicated human interactions in which people experience intense emotions. Having one conversation with a patient about a “do not resuscitate” order should not be perceived as speaking with them about how they wish to live at the end of their lives.

PWAs need to plan in advance

HIV disease has challenged the conventional approach to palliative care with cancer patients whose course of disease progression has been more predictable. In the early pre-treatment days of the HIV/AIDS epidemic, physicians advised patients to get their life affairs in order from the time of diagnosis. Such advice was warranted since the median life expectancy between an AIDS diagnosis and death was nine months.

Now, with highly active antiretroviral therapy and prolonged life expectancy, disease progression is difficult to predict. Complicating the prognosis are co-infections such as hepatitis C.

Healthcare providers may postpone discussions—or become more occupied with complex treatment regimens—until it is evident that available treatment has failed the patient. EOL discussions, if they occur at all, take place past the point of constructive action, in which case PWAs lose the opportunity to talk about the end of their lives.

An empowerment model of healthcare includes anticipating and planning for future needs, including the end of one's life. End-of-life decision-making should be an integral part of collaborative planning and continual discussions between PWAs and their healthcare providers. Talking about death and dying is difficult, but a good relationship between a healthcare provider and a patient increases the possibility that these discussions will occur.

Developing good relationships with healthcare providers can be challenging for all PWAs. For those who are poor and otherwise disadvantaged, keeping appointments with multiple providers, organizing and taking medications—even eating nutritious food, getting enough sleep, and avoiding violence—are beyond reach.

HIV/AIDS care providers work with increasing numbers of people with multiple barriers to healthcare. For many, a continuous good relationship with one doctor is unrealistic. The opportunities for even the most disadvantaged people to be able to talk about death and dying can come through the conscious efforts of hospital providers, community healthcare workers, and a diverse array of activists and volunteers. Within the often chaotic and adverse living conditions of many PWAs, we need to create these opportunities to talk comfortably and safely about hopes and fears for the future.

People living with HIV in BC come from many different cultural backgrounds where attitudes toward death and dying vary widely. Many PWAs are disadvantaged and marginalized. Many use injection drugs. HIV/AIDS caregivers need to develop an understanding of and sensitivity to those differences if we are to have meaningful EOL discussions with PWAs. ⊕

Part 2 will explore how healthcare providers and others can respond to the needs of all PWAs as they approach the end of their lives. As well, it will look at existing hospital and community resources and discuss increasing needs for hospice and palliative care.

Irene Goldstone (l) is the director of professional education at the BC Centre for Excellence in HIV/AIDS in Vancouver.

Mary Petty (r) is a social worker with the AIDS Program at St. Paul's Hospital in Vancouver.





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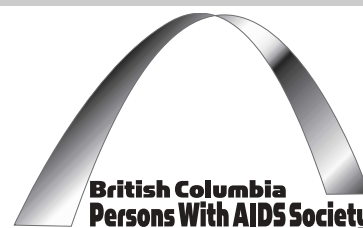
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Volunteering at BCPWA

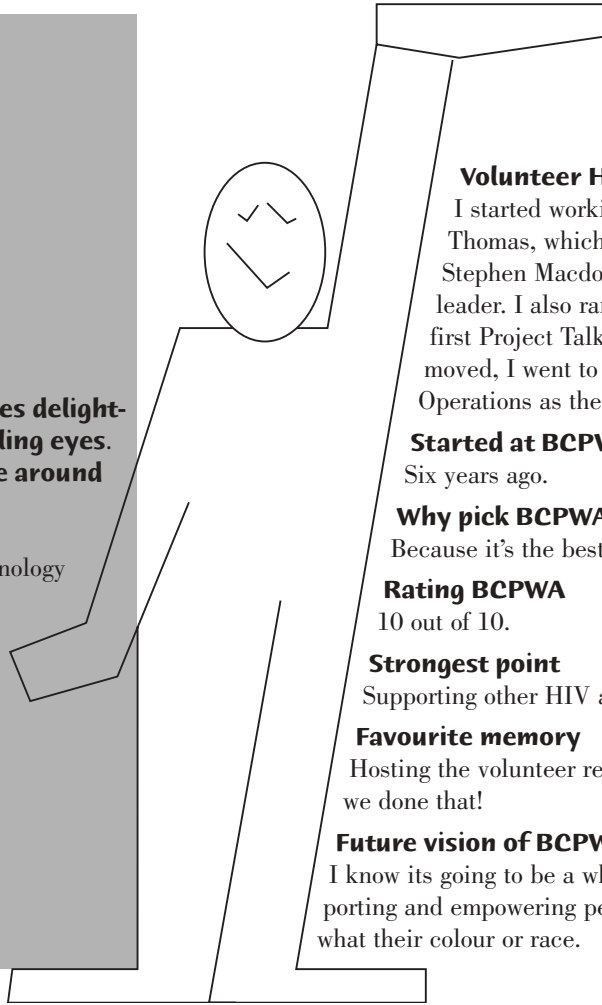
Profile of a volunteer:

Billie Bowman



Billy's exuberance shines delightfully through his twinkling eyes. He is a pleasure to have around and work with!

Ruth Marzetti
Manager, Information Technology



Volunteer History

I started working in Member Volunteer Resources with Peter Thomas, which became Member Volunteer Services under Stephen Macdonald and Ruth Marzetti. I was the front desk leader. I also ran the lunch program and helped design the first Project Talk database for MVS. When the department moved, I went to Support and Operations. Now I volunteer in Operations as the Project Talk leader.

Started at BCPWA

Six years ago.

Why pick BCPWA?

Because it's the best AIDS organization in Vancouver.

Rating BCPWA

10 out of 10.

Strongest point

Supporting other HIV and hepatitis C community members.

Favourite memory

Hosting the volunteer recognition event last year. Never in history have we done that!

Future vision of BCPWA

I know its going to be a while before they ever find a cure. To keep supporting and empowering people with HIV and/or hepatitis C, no matter what their colour or race.



Interested in writing?

We need articles on HIV-related prevention, advocacy and treatment. Volunteer for living+ magazine...

Volunteers should possess the following skill sets:

- Ability to analyze and distill information
- Excellent research and writing skills
- Ability to work independently

Here's what one of our writer's had to say: "I find the whole process challenging and rewarding, not to mention the "feel good" feeling after finishing a piece."Volunteering for living+ provides the flexibility to work from home.

If you are interested in becoming a volunteer writer and/or to obtain a volunteer application form, please email volunteer@bcpwa.org, call 604.893.2298 or visit www.bcpwa.org.

where to find help

If you're looking for help or information on HIV/AIDS, the following list is a starting point.

BC Persons With AIDS Society

1107 Seymour St, Vancouver BC V6B 5S8
604.893.2200 or 1.800.994.2437
e info@bcpwa.org www.bcpwa.org

A Loving Spoonful Location

Suite 100 – 1300 Richards St,
Vancouver, BC V6B 3G6
604.682.6325
e clients@alovingspoonful.org
www.alovingspoonful.org

AIDS Memorial Vancouver

205 – 636 West Broadway,
Vancouver BC V5Z 1G2
604.216.7031 or 1.866.626.3700
e info@aidsmemorial.ca www.aidsmemorial.ca

AIDS Prince George

1–1563 2nd Ave,
Prince George, BC V2L 3B8
t 250.562.1172 f 250.562.3317
e ogodwin@bcgroup.net; www.AIDSPG.ca

AIDS Resource Centre – Okanagan and Region

101–266 Lawrence Ave.,
Kelowna, BC V1Y 6L3
t 250.862.2437 or 1.800.616.2437
e arc@arcok.com; www.arcok.com

AIDS Society of Kamloops

P.O. Box 1064, 437 Lansdowne St,
Kamloops, BC V2C 6H2
250.372.7585 or 1.800.661.7541
ask@telus.net

AIDS Vancouver

1107 Seymour St, Vancouver BC V6B 5S8
604.893.2201
av@aidsvancouver.org
www.aidsvancouver.bc.ca

AIDS Vancouver Island (Nanaimo)

201 – 55 Victoria Rd, Nanaimo, BC V9R 5N9
t 250.753.2437 f 250.753.4595

AIDS Vancouver Island (Victoria)

1601 Blanshard St, Victoria, BC V8W 2J5
250.384.2366
info@avi.org; www.avi.org

ANKORS (Nelson)

101 Baker St, Nelson, BC V1L 4H1
t 250.505.5506 or 1.800.421.AIDS
f 250.505.5507 e info@ankors.bc.ca
http://kics.bc.ca/~ankors/

ANKORS (Cranbrook)

205 – 14th Ave N Cranbrook,
BC V1C 3W3
250.426.3383 or 1.800.421.AIDS
f 250.426.3221 e gary@ankors.bc.ca
http://kics.bc.ca/~ankors/

AIDS Vancouver Island (Cowichan Valley)

1 Kenneth Place, Duncan, BC V9L 2Y9
t 250.701.3667 f 748.3509

Asian Society for the Intervention of AIDS (ASIA)

210 – 119 West Pender St,
Vancouver, BC V6B 1S5
t 604.669.5567 f 604.669.7756
e asia@asia.bc.ca; www.asia.bc.ca

Dr Peter Centre

1100 Comox St,
Vancouver, BC V6E 1K5
t 604.608.1874 f 604.608.4259
e info@drpeter.org; www.drpeter.org

Friends for Life Society

1459 Barclay St, Vancouver, BC V6G 1J6
t 604.682.5992 f 604.682.3592
e ffl@radiant.net www.friendsforlife.ca

Healing Our Spirit

Suite 100 – 2425 Quebec St,
Vancouver, BC V5T 4L6
t 604.879.8884 or 1.800.336.9726
e info@healingourspirit.org
www.healingourspirit.org

McLaren Housing Society

200 – 649 Helmcken St,
Vancouver, BC V6B 5R1
t 604.669.4090 f 604.669.4092
e mclarenhousing@telus.net
www.MCLARENHOUSING.com

North Island AIDS (Campbell River) Society

684B Island Hwy,
Campbell River, BC V9W 2C3
t 250.286.9757 or 1.877.650.8787
f 250.830.0784

North Island AIDS (Courtenay) Society

355 6th St, Courtenay, BC V9N 1M2
250.338.7400 or 1.877.311.7400

North Island AIDS (Port Hardy) Society

8635 Granville St, Ground Floor,
Port Hardy, BC V0N 2P0, t 250.902.2238
niac@island.net ; www.island.net/~niac

Okanagan Aboriginal AIDS Society

101 – 266 Lawrence Ave.,
Kelowna, BC V1Y 6L3
250.862.2481 or 1.800.616.2437
oas@arcok.com; www.oas.ca

Outreach Prince Rupert

300 3rd Ave. West
Prince Rupert, BC V8J 1L4
t 250.627.8823
f 250.624.7591
aidspr@rapidnet.net

Pacific AIDS Network c/o AIDS Vancouver Island (Victoria)

1601 Blanshard St.,
Victoria V8W 2J5
t 250.881.5663 f 250.920.4221
erikages@pan.ca; www.pan.ca

Positive Living North West

Box 4368 Smithers, BC V0J 2N0
3862 F Broadway, Smithers BC
250.877.0042 or 1.886.877.0042
plnw@bulkley.net

Positive Women's Network

614 – 1033 Davie St, Vancouver, BC V6E 1M7
604.692.3000 or 1.866.692.3001
pwn@pwn.bc.ca; www.pwn.bc.ca

Red Road HIV/AIDS Network Society

804 – 100 Park Royal South,
Vancouver, BC V7T 1A2
604.913.3332 or 1.800.336.9726
info@red-road.org; www.red-road.org

Vancouver Native Health Society

441 East Hastings St, Vancouver, BC V6G 1B4
604.254.9949
vnhs@shaw.ca

Victoria AIDS Resource & Community Service Society

1284 F Gladstone Ave, Victoria, BC V8T 1G6
t 250.388.6620 f 250.388.7011
varcs@islandnet.com
www.varcs.org/varcs/varcs.nsf

Victoria Persons With AIDS Society

#330-1105 Pandora St., Victoria BC V8V 3P9
t 250.382.7927 f 250.382.3232
support@vpwas.com; www.vpwas.com

Wings Housing Society

12 – 1041 Comox St, Vancouver, BC V6E 1K1
t 604.899.5405 f 604.899.5410
info@wingshousing.bc.ca
www.wingshousing.bc.ca

YouthCO AIDS Society

205 – 1104 Hornby St.,
Vancouver BC V6Z 1V8
604.688.1441 1.877.968.8426
information@youthco.org; www.youthco.org

For more comprehensive listings of groups, societies, programs and institutions in British Columbia serving people touched by HIV disease and AIDS, please visit the Positively Happening section of the BCPWA Society website at www.bcpwa.org.

Upcoming BCPWA Society Board Meetings:

Date	Time	Location	Reports to be presented
March 17, 2004	1:00	Board Room	Written Executive Director Report — Executive Committee — Director of Support Services
March 31, 2004	1:00	Board Room	Financial Statements / February — Standing Committee
April 14, 2004	1:00	Board Room	Written Executive Director Report — Director of Development
April 28, 2004	1:00	Board Room	Quarterly Department Reports — Executive Committee — Financial Statements / March
May 12, 2004	1:00	Board Room	Written Executive Director Report — Standing Committee —
May 26, 2004	1:00	Board Room	Director of Prevention

The BCPWA Society is located at 1107 Seymour St., 2nd Floor, Vancouver.

For more information, contact: **Alexandra Regier, Office Manager** Direct: 604.893.2292 Email: alexr@bcpwa.org

BCPWA Standing Committees and Subcommittees

If you are a member of the BC Persons With AIDS Society, you can get involved and help make crucial decisions by joining a committee. To become a voting member on a committee, please attend three consecutive meetings. For more information on meeting dates and times, please see below for contact information in the respective committee that you are interested.

Board & Volunteer Development

Contact: Adriaan de Vries
 t 604.893.2298 e adriaand@bcpwa.org

Collective Advocacy

Contact: Lisa Gallo
 t 604.983.2298 e lisag@bcpwa.org

Education & Communications

Contact: Lisa Gallo
 t 604.983.2298 e lisag@bcpwa.org

Fund Development

Contact: Alasdair Hooper
 t 604.893.2264 e alsadairh@bcpwa.org

IT Committee

Contact: Ruth Marzetti
 t 604.646.5328 e ruthm@bcpwa.org

Living + Magazine Subcommittee

Contact: Jeff Rotin
 t 604.893.2206 e jeffr@bcpwa.org

Prevention

Contact: Peter Hall
 t 604.893.2225 e peterh@bcpwa.org

Support Services

Contact: Jackie Haywood
 t 604.893.2259 e jackieh@bcpwa.org

Treatment Information & Advocacy

Contact: Tarel Quandt
 t 604.893.2284 e tarelq@bcpwa.org

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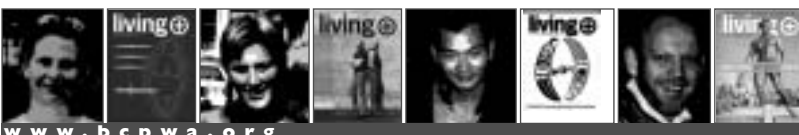
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I have enclosed the following for 6 issues of living+

- \$25 Canadian (non-BCPWA members) \$40 USA \$45 International
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- I am a PWA in BC and can not afford the full subscription price
- Enclosed is my donation of \$_____ for living+
- Please send me more information about Planned Giving
- I want to become a member of BCPWA

Cheque payable to BCPWA



www.bcpwa.org

living+

1107 Seymour Street, 2nd Floor
 Vancouver, BC
 Canada V6B 5S8



by *Francisco Ibáñez-Carrasco*

Recently, a friend assured me that we should take our cues for a positive prevention strategy in queer communities from gay men over 30 living with HIV.

I thought that the problems with prevention were promiscuity and our new millennium obsession with body cavities, fluids, insertions, ingestions, and injections. My friend says the challenges are the endemic indifference and self-righteousness gay men feel about each other. The intense traffic of “positive” gay stereotypes creates an illusion of inclusion. Still trapped in archaic and exploitative heterosexual contracts of romantic love, we forget the value of promiscuity and other elements of queer culture. We need to revisit poz men’s reasons to engage in consensual activities involving potent drugs, sometimes S&M, and the reshaping of bodies at once pneumatic, infused with chemicals, and riddled with lipodystrophy—reasons that are not always apparent but that evidence a search for a new identity as barebackers who are practicing a form of community ethics and even harm reduction.

That night, surrounded by a tribe of HIV-positive leather gargoyles, I had nightmares of Ashley MacIsaac in a tight rubber outfit commanding, “Drink it!” and Sue Johanson wielding a didactic finger, advising me to “put it in a cup and sip it slow, dear.” I woke up frazzled. My friend’s convoluted argument was the wailing of addicted, aging positive white gay men looking for excuses to glorify irresponsible acts that alienate the innocent, young, and healthy.

Livid, I called the slut back. So what’s wrong with a bit of a reality check? he said. Don’t we alienate poz guys from the diagnosis day? Barebackers do practice harm reduction in the face of the most rabid self-righteousness of the young and healthy. Educators are missing the beat. Merchants are *not*—see all the Web sites targeted at them. Young queers are only picking up on the external cues and not on the values of our sexual culture. Bareback is not shorthand for irresponsible fucking deluded by the straight romance of Harlequin paperbacks—I was aghast, but kept on listening—love *does* happen between queer

men. It is distinct and equal but separate.

We have overprotected our young and failed to tell them that sex is good, drugs are great, and that both kill, he concluded. Blinded by a commercial brand of liberation, we ignore the aging AIDS survivors—those barebackers—because the sexuality of the disabled, ugly, and retarded is uncomfortable.

We hang up. I took research into my own hands and let my fingers do the work. Hooked into the Internet, I parachuted myself into the bustling global sexual market. Armed with airbrushed photos of myself in implausible positions and costumes to convey either fierce maturity or candid youth, I made my entrance.

As my friend predicted, new meat is hot, so I got hit upon a lot. In the seeming safety of my house, where I was supposedly free to manage my identity, silence, smoke, and mirrors con-founded these exchanges.

However, this apparent openness that will save us from infection and loving monogamous relationships is deceiving. People are still telling lies to themselves and to others—the lies of straight marriage and monogamous sex, for example.

The polite, conventional, optimistic, and complacent have triumphed. The etherland is a new closet where virtuality is not virtuosity. Queer sex does not infect more than straight sex, just differently. Our perverse sexual ways really do protect the disabled (HIV or otherwise), honour age, and celebrate sexual knowledge instead of the rights of the clean and healthy, the arrogance of the beautiful and young, and the opulence of “normal” queers—their condos, SUVs, adopted babies, and blessings of their straight contemporaries. ☪

Francisco Ibáñez-Carrasco's collection of short stories (many of them about living with HIV) will be published in August 2004 by Suspect Thoughts Press, San Francisco.

