MAGNETIC LOVE

When opposites attract

STAND BY YOUR MEDS
THANKS FOR THE COMPLEMENTS
AN OUNCE OF PREVENTION
CANADIANS IN BANGKOK
**RESOURCES**

From massages to makeovers, ballet to baseball, dating to demo-ing—there are plenty of exciting opportunities to take advantage of in your community. After all, you are a person LIVING with HIV. Don’t forget that.

**Reach out & touch someone**

Thanks to the hetero HIV meeting group run by Montreal’s CRISS (Centre of Resources, Interventions and Services in Sexual Health), there’s no need to spend another Friday night in front of the TV.

When? Friday nights at 7 pm
Contact: Nathalie at 514.855.8991; nathalie@criss.org

Edmonton Persons Living Positively offers a support group/romance night for positive folks of all orientations. Meet other PHAs for friendships, relationships or more.

When? Tuesday nights from 7–9 pm
Contact: 780.488.5768; 1.877.975.9448; livepos@telusplanet.net

**Stir it up**

Voices of Positive Women (and the AIDS Committee of Toronto, Africans in Partnership Against AIDS, the Black Coalition for AIDS Prevention, and African Community Health Services) offers “The Kitchen,” an African and Caribbean women’s HIV group—for friendship, food and food for thought.

Where? For the location of the next Kitchen, call the number below.
When? 2nd Thursday of every month
Contact: Kaddu at 416.324.8703 (register in advance and tell her about any special dietary needs)

**Make your body hum**

The Toronto People With AIDS Foundation offers free yoga classes for PHAs. Strike a pose to strengthen your body and calm your mind. Yoga mats are provided; you bring comfortable clothing and an open mind.

Where? The 519 Church Street Community Centre
When? Wednesdays from 4:30–6 pm
Contact: 416.506.1400

**Paint the town**

All dressed up and nowhere to go? Several organizations offer tickets for local events and goodies.

**In Vancouver:**

From ballet to rugby, BCPWA’s Complimentary Tickets Program provides the opportunity for members, friends and family to attend a variety of events.

Contact: 604.893.2285; comptix@bcpla.org

**In Edmonton:**

Movie and bus passes, food vouchers and toiletries (funded by HIV Edmonton, The Ross Armstrong Fund and Edmonton Persons Living Positively) can be picked up by PHAs from 4–7 pm on the 2nd Tuesday of every month.

Contact: Edmonton Persons Living Positively
780.488.5768; 1.877.975.9448

**In Toronto:**

Whether you want to ride a roller coaster, catch the latest flick or attend the theatre, the Toronto People With AIDS Foundation, in partnership with local theatres and video outlets, provides clients with tickets to cultural events.

Contact: 416.506.1400

**Rub-a-dub**

Experience the healing power of touch. Members of the AIDS Coalition of Nova Scotia in Halifax can make an appointment for a free one-hour massage from a registered massage professional. Call in advance to book your rubdown—dates and times vary.

Contact: Cathy Giles at 902.425.4882; 1.800.566.2437; www.acns.ns.ca

**Glam it up**

Need a little pick-me-up? The Beauty Night Society will do the trick. Not only do these twice-monthly affairs provide the opportunity to meet other wonderful women, you’ll also get your hair, makeup and nails done! Access is by agency referral only. Other chapters are planned for across Canada. Check www.beautynight.org for more info.

**Vancouver Chapter**
Contact: Caroline MacGillivray; 604.601.1383; info@beautynight.org

**Toronto Chapter**
Contact: Ann Roche; 416.379.8456; colour_diva@sympatico.ca

**Get cheeky**

Tired of no longer recognizing yourself in the mirror? LIPO-ACTION Quebec is a grassroots movement that brings attention to the devastating impact of lipodystrophy by staging creative demonstrations. Call or e-mail for support or info on lipo treatments. Want to start a chapter in your community? LIPO-ACTION Quebec is happy to help out.

Contact: Martin Mailloux at 514.529.4750; lipoactionquebec@yahoo.ca

—Compiled by Cameron Ray and Susan Massarella
EDITOR’S LETTER

What do you get when one HIV positive person and one HIV negative person fall in love? Magnetic love.

Magnetic. It’s got a more sexy and romantic ring than its dry, clinical-sounding counterparts—serodiscordant and serodivergent. Discord, the opposite of harmony, has a negative connotation, and divergent means to extend in different directions, to differ. Magnetic suggests attraction, chemistry, sparks.

In the case of magnetic couples, the romantic cliché “opposites attract” is literally true. However, many partners in mixed-status relationships find that they connect not due to their HIV status but rather in spite of it. Speaking with the four magnetic couples I had the privilege of interviewing for the cover story reminded me of another cliché: “Love conquers all”—even in the face of HIV. Without a doubt, magnetic better reflects these four couples. Thanks to all of them for sharing with us the ups and downs of magnetic relationships and for spreading the love. Especially to Sue, one of the women interviewed, for bringing the phrase magnetic love to our attention.

Also in this issue: Five people with HIV/AIDS (PHAs) give kudos to their complementary therapies—from acupuncture for neuropathy to medical marijuana for nausea. HIV treatment guru Lark Lands gives a lesson on why it’s important to your immune health to avoid minor infections (colds, flus and sinusitis) and major ones (hepatitis)—and how to treat them if they do strike. And, just when you thought you’d heard everything about adherence, Derek Thaczuk gives his two cents on the topic, along with confessions and suggestions.

Thanks in part to feedback from you, our readers, we’ve streamlined production of The Positive Side and moved to a cleaner design we hope will be easier to read. Please take some time to drop us a line by mail or at info@catie.ca—write a letter to the editor, tell us what you think about our new look, or pitch an article or idea to us. Even better, fill out the attached subscription card and have The Positive Side delivered to your doorstep twice a year for free. Share the magazine, share your stories.

—Ronnilyn Pustil
You may experience many symptoms as an HIV positive person. Most of these do not mean you have a serious medical condition. Sometimes, however, they could indicate an acute and possibly life-threatening medical emergency. Get in touch with your doctor immediately if you experience any of the symptoms listed below:

1. **“I can’t keep any food or liquid down.”** This could lead to your body not getting enough water—dehydration. Vomiting is a common cause of dehydration, but if you can’t eat for other reasons (such as painful swallowing or severe nausea), you might need treatment with intravenous (IV) fluids.

2. **“My stomach hurts so much.”** When abdominal pain is beyond the point where you can tolerate it and/or is getting worse, it must be dealt with. If you’re on ddI (Videx), dDC (Hivid) or d4T (Zerit), severe pain in the middle of the abdomen could signify pancreatitis (a life-threatening inflammation of the pancreas gland) or lactic acidosis (a condition where high levels of lactic acid build up in the blood).

3. **“I can’t breathe normally/properly.”** If you can’t breathe well, you need medical attention—no matter what’s causing it. There are serious HIV-related conditions, such as PCP (Pneumocystis carinii pneumonia), other pneumonias, lactic acidosis or abacavir (Ziagen) sensitivity, which could be the cause of abnormal breathing or shortness of breath (dyspnea).

4. **“My chest is killing me.”** If you have chest pain, a feeling of tightness and shortness of breath that lasts more than a few minutes, you should see your doctor immediately or go to the emergency room. These can be signs of a heart attack.

5. **“My vision is going blurry.”** Especially if your CD4 cells are low (less than 50), this could be the beginning of cytomegalovirus (CMV) retinitis. CMV is a serious eye infection that can cause blindness if not treated. An ophthalmologist (eye doctor) should examine you as soon as possible.

6. **“I feel like killing myself.”** Depression and suicidal tendencies can increase in HIV positive people. This may be even more likely for people taking certain medications, such as interferon (for the treatment of hepatitis C) or the non-nuke efavirenz (Sustiva), because these drugs can have psychological side effects. Depression can be treated! If you feel like
you’re losing the battle with the blues, get help. [For more info on depression, see “Lady Sings the Blues,” The Positive Side, spring 2003.]

“**This is the worst headache of my life.**” Most severe headaches in HIV positive people have nothing to do with the HIV. Still, if this headache is worse than any you’ve had before, call your doctor.

“**I am passing blood in my stool (or vomit).**” A small fleck of blood is not necessarily an emergency. This can happen with a condition such as hemorrhoids. But if you go to the toilet and what comes out looks like actual blood, call your doctor.

“**My mouth is on fire.**” If you’ve had a rash, especially when starting a new medication (such as Bactrim), and then develop fever and nausea and notice that the lining of your mouth (mucous membranes) is becoming inflamed and seems to peel off, it could be serious. This condition, known as Stevens-Johnson syndrome (SJS), is a major allergic reaction to medications. Although it’s rare, if you don’t treat it, it could be fatal.


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### Top 9 Reasons to Call CATIE

1. **Newly diagnosed? We’ll give you the lay of the HIV landscape.** Whether you want to learn about the basics of HIV, the immune system, living day to day with the virus, HIV drugs or nutrition—or if you just need to talk to someone about what it means to have HIV—CATIE can show you the ropes.

2. **We’ll connect you with resources in your own community.** CATIE can hook you up with anonymous testing sites, AIDS organizations, clinics and other HIV resources.

3. **We’ll help you understand HIV treatment.** Drug combinations, starting, stopping, switching, drug interactions, resistance, complementary therapies—we’ll go over your options so you can make informed treatment decisions with your doctor.

4. **We’ll school you on the medical jargon and the alphabet soup of AIDS acronyms—and what they mean for you.** CD4 counts, liver enzymes, genotypic testing, co-infections, triglycerides, CMV, STIs, PCP—you name it!

5. **We’ll help you learn how to manage your health.** From eating well to monitoring your blood work, from side effects to supplements, from herpes to hep C, CATIE can dish up info and tips to help you take control of your health.

6. **We’ll talk to you peer to peer.** We know that treatment is more than taking medications and your health is more than CD4 counts and viral load. Living with HIV can affect your self-esteem, relationships and lifestyle. Most of us at CATIE can talk the talk with the voice of experience, helping you put it all into perspective.

7. **We’ll update you on the latest treatment information.** Call us to find out about new drug info, studies, clinical trials, dosing, side effects, availability, expanded access and more.

8. **We’ll research HIV treatment information for you.** Can’t find the facts on a particular topic? Looking for published medical studies? CATIE can help you find what you’re searching for and, where possible, direct you to it online or send it to you by mail or fax.

9. **We’ll dial you in to CATIE’s services.** Workshops, publications, treatment news, research library… it’s all at your fingertips, because it’s at ours.

Call CATIE’s treatment information line from anywhere in Canada at 1.800.263.1638 (toll-free) or 416.203.7122 (for collect calls from correctional facilities). Staff is available Monday–Thursday from 10 am to 6 pm EST.
**GEORGE CLARK-DUNNING, 42**  
Volunteer with AIDS PEI and GLBT collective, Internet service provider  
Diagnosed with HIV: 1991  
Viral load: undetectable  
CD4 count: 297  
Cavendish, Prince Edward Island  
I had car accident in 2000 and started seeing a chiropractor, Dr. Vince Adams, who’s also an acupuncturist. I had whiplash and stress on my joints and muscles. After a year, we saw some progress in pain relief but I was still walking with a cane, so we started doing acupuncture as well.

Most of the needles are done on my back. I lie on the table for 15–20 minutes and more often than not I fall asleep. Then Vince does the chiropractic side of the treatment and I’m out the door.

When I started acupuncture, I was also suffering from neuropathy—from my hips to toes. It felt like shards of glass being ground into my flesh. Every step and movement hurt. Vince said: “This isn’t car accident pain, this is HIV pain. I can work on that, so let’s go for it.” I went twice a week. Within a month I started feeling benefits. I stopped taking gabapentin for the neuropathy. The pain stopped and the acupuncture keeps it from returning. I have more energy for about four to five days after each session.

Vince recently asked about my liver function. It’s not good. I have a fatty liver and early stages of cirrhosis, so now he’s working on that organ, using trigger points related to liver function. I’m a firm believer in mixing East and West. What can it hurt? One needle in 10 hurts, but other than that I absolutely love it. It’s the best money I’ve spent for myself.

**Acupuncture is an ancient Chinese form of bodywork that uses special needles to stimulate energy points to help the body heal itself. For more info: Chinese Medicine and Acupuncture Association of Canada (519.642.1970, www.cmaac.ca).**

**REBEKKA VALIAN, 43**  
Yoga instructor and aromatherapist  
Diagnosed with HIV: 1991  
Viral load: undetectable  
CD4 count: 640  
Vancouver, British Columbia  
I’ve been doing yoga since I was 8 years old. I taught myself from a book. When I was diagnosed, being on the yogic path played an important role because I wasn’t petrified of death. I thought: “I can control my health, I can stay healthy, I can not get psyched out by this diagnosis.”

In 1998, I was hospitalized. I had only 10 T cells left and I was diagnosed with MAC. I had to quit work and was bedridden for four months. I realized I was going to die if I didn’t try antiretrovirals. It was a combination of the meds and yoga that brought me back to life. I went to Quebec to be part of a study on how yogic breathing impacts HIV. It worked for me. I was in a lot of pain and as soon as I did yoga, the pain disappeared. I got pretty depressed around that time and tried an antidepressant, but it didn’t work. Yoga brought me out of it.

Getting back to the yoga really built up my T cells—I’m at 640 now. A lot of that is the drug cocktail, but it’s also the complementary therapies—aromatherapy, massage, meditation and especially yoga.

Yoga keeps the muscles strong and the ligaments juiced up. It seems to keep everything healthy and flexible and out of the pain zone. I feel strong because of my practice. There’s the whole mind-body-spirit connection. A healthy mind keeps the immune system healthy. And everyone can afford yoga because once you know the poses you can do it in your own home. Just tune in to the rhythm of your breath and let it guide you through the stretches. +

Yoga, a form of mind/body exercise from ancient India, involves breathing, meditation and postures. For more info: Canada’s Ascent magazine (www.ascent-magazine.com), Yoga Journal (www.yogajournal.com) and “Introduction to Yoga,” The Positive Side, fall/winter 2001.

**SHARI MARGOLESE, 42**  
Community activist and writer  
Diagnosed with HIV: 1993  
Viral load: 1,500  
CD4 count: 700  
Mississauga, Ontario  
In 1995 I tried medical marijuana. It helped relieve my HIV-related nausea and vomiting. When I started meds the next year, I tried it again and it was really helpful. I didn’t use it regularly because I didn’t have a medical license or regular access to it. So I tried over-the-counter and prescription meds, which made me pass out. I was so exhausted I couldn’t do anything.

In 2001, they changed the medical marijuana legislation. It became a little easier to get a license. I needed to try something else for the nausea, so I got one. I’ve been using medical marijuana since then and it’s helped me considerably. I get better pain relief for my neuropathy from marijuana than I did from amitriptyline. It’s made it easier for me to get on with my day and has helped me stay on HAART.

But it’s expensive and there’s no way to recoup the expense. It’s difficult with kids in the house—you have to hide and sneak around. And it’s not really socially acceptable. Some days I feel so sick that I can’t smoke, so I take a Gravol and go to bed.
Plus, I have asthma and there are days when I just can’t get a breath.

With medical marijuana, you have control over your dose. I can give myself just enough to do what it needs to do so I’m not passed out all the time. Sometimes I need more, sometimes less; sometimes one puff is enough, sometimes I smoke two joints in a row.

At first I get a buzz, and after a few minutes, the buzz goes away but the beneficial effects stay. +


TOM HAMMOND, 39
Support services coordinator at the AIDS Committee of Guelph and Wellington County
Diagnosed with HIV: 1992
Viral load: undetectable
CD4 count: 210
Guelph, Ontario

“I get better pain relief from marijuana.”

Last November a coworker who was training in cranial sacral therapy wanted to practice on people, so I decided to give it a shot. I’d never heard of it before, but I’ll try anything.

She starts with a guided meditation to help me clear my thoughts and get my breathing on track. Then she puts her hands on my sacrum (just above the butt) and moves them up my body, touching lightly. You don’t even really feel it. After 10 minutes, I fall asleep.

When I started, the first thing I noticed was that it reduced my stress level. For a week after the treatment I’m very focused instead of being spaced out from my meds. I have increased energy. I can think clearly and sleep better. Before that I had insomnia, probably from my meds and stress, but now I sleep right through the night. I also have gastrointestinal problems from my meds, and the therapy soothes my stomach.

When the session starts and I do my breathing, I pay attention to my whole body and visualize the virus in my system and how my body could make the medication work better. Before I started this therapy, my CD4 count was 168, and it had been there for several years. But after four sessions it went up to 210. It could be a coincidence, but I don’t think so. It’s not a big jump but to see any change at all was “wow!”

I’m still going, once a week for four weeks, and then I take a break. It’s more affordable this way. I’ve done lots of other kinds of therapies, but this really gives me the best bang for my buck. +

Cranial sacral therapy is a form of massage that focuses on the head and spine to release tension and energy blocks.

MARTIN MAILLOUX, 45
Volunteer Taoist Tai Chi instructor
Diagnosed with HIV: 1994
Viral load: undetectable
CD4 count: 760
Montreal, Quebec

In 1995, one year after my HIV diagnosis, I got meningitis. My immune system was almost destroyed; I had 18 T cells. Back then meningitis was considered terminal for people with HIV, but there was a new treatment protocol and I was one of the first patients to be saved.

Then I had to live again. I had to learn how to walk again. The recovery period was about two years. In October 1998, I went to a Taoist Tai Chi class for people with HIV organized by Maison Plein Coeur. Despite being so weak, I enjoyed it and kept going because I realized how powerful it was for me.

Tai Chi has really improved my circulation, balance and coordination. It’s helped reduce the side effects of the meds and some HIV symptoms. After each class I felt very hungry and started to gain weight. My headaches went away. Tai Chi stretched out my muscles, which were stiff from meds. It helps reduce lipodystrophy by gradually rebuilding my legs and bum.

Tai Chi also relaxes me—I’ve stopped worrying all the time. I trust my body more now. Because I almost died, it was something to trust my body again. I have strength now and I feel it.

At first I was the worst student, but the instructor was very patient. I had other people with HIV around me who were doing their best to improve their health. It was really motivating. After a while I realized: “I’m not bad at this. I feel really good.”

One day my instructor asked me to teach. “What are you talking about? I’m a sick person.” She said that’s what they were looking for. I became an assistant in 1999 and a volunteer instructor in 2001. I now help other instructors in two HIV classes.

Generally, when you have a disease like HIV, you’re overly concerned with yourself. Tai Chi helps: You have to look at others to adjust your movements and you feel it as a group. You become “one” for a little while. That’s the magical part. Slowly, you get less worried, improve your strength and enjoy just being with others. +

Tai Chi is an ancient style of mind/body exercise made up of a series of slow, therapeutic movements. For more info: Taoist Tai Chi Society (www.taoist.org) or Martin Mailloux (see Resources page).

“For more info see CATIE’s Practical Guide to Complementary Therapies at www.catie.ca/comp_e.nsf.”
When positive and negative attract, HIV often takes a backseat to that crazy little thing called love. Four couples tell all about negotiating the serodivergent terrain.

MINNEH, 36, HIV positive for 11 years
HIV educator, part-time janitor
RYAN, 26, HIV negative
Computer programmer
Together since June 29, 2003
Victoria, British Columbia

When Minneh met Ryan:
RYAN: We participated in a lot of the same advocacy groups, like the Cannabis Buyers’ Club of Canada, and freedom marches and anti-discrimination groups.
MINneh: We’ve been friends since 1999. We met fighting oppression. Ryan used to take me to lunch from time to time. On June 29, 2003, he asked me out and I needed to stop by my place first. When we got there, it just happened. We were sitting together; we drew to a kiss and touched. When we went for lunch that day it was different—it was a date.

Did you know that Minneh had HIV?
RYAN: I’d known since I first met her.
MINneh: I was involved in HIV and open about my status.
RYAN: At first I was concerned. I didn’t really know about HIV or if a relationship was even possible. But once Minneh educated me I wasn’t so worried. We take reasonable precautions.

What kind of role does HIV play in your relationship, if at all?
MINneh: Not a very big part, but we’re reminded of it all the time. Ryan’s very good at helping me take my meds, reminding me or even getting them for me. It’s hard to say that HIV isn’t completely in our lives, because it’s really right there, but it doesn’t affect us that much.
RYAN: HIV is a very, very small part of this relationship.

Are there any issues that have arisen from being in a mixed-status relationship?
MINneh: It’s a good thing I’ve always been outspoken, because when we visited Ryan’s family, they’d already

For information on HIV prevention, see HIV and HCV Transmission: Guidelines for Assessing Risk, Fourth Edition, 2004, published by the Canadian AIDS Society at www.cdnaids.ca. The views expressed in the following interviews are solely those of the people interviewed and do not reflect the policies or opinions of CATIE.
read articles about me and my HIV so it wasn’t really a big deal.

Ryan: The only people I’ve encountered who had any problem with it whatsoever is Immigration Canada.

Minneh: I was refused permanent residence because of AIDS, and I’m fighting it. I just got a temporary resident permit, so I can stay in Canada for three years. Then I need to renew it and apply again for permanent residence. If I didn’t have HIV, I’d already be in the country, which would make mine and Ryan’s situation quite easy. It’s very frustrating.

Are there any rewards from being in a serodivergent relationship?

Ryan: It’s inspired us to start SAN-FAN Educational Group, which stands for “See A Need, Fill A Need.” I organize presentations at schools, churches and other public areas, and Minneh educates people about HIV. She talks about prevention and technical information about HIV, and also about what it’s like to live with HIV and how it affects your self-worth.

What contributes to the success of your relationship?

Minneh: The best thing that ever happened to me was finding Ryan. Being spiritual has really helped us. I was waiting to die, but now I’m actually living and wanting a family—something I never thought was possible. I will die one day, but I will die a truly happy woman.

Ryan: Minneh and I are both very close to God and that is the foundation of our relationship.

How do you deal with the fear of HIV transmission?

Minneh: We use condoms faithfully.

Has HIV affected your sex life or intimacy?

Ryan: I don’t think so.

Minneh: No. Putting on a condom has become part of having sex.

How do you deal with the grey areas when it comes to transmission?

Ryan: Because Minneh has such a low viral load, I don’t worry about oral sex. We just go ahead, really.

Are there other kinds of fears you deal with in a mixed-status relationship?

Minneh: They have to do with the medications I take for my bipolar condition. In order to get pregnant, I’d have to stop those meds and I don’t know if I’d be emotionally stable enough to be able to carry a pregnancy. That’s something we think about. I’d love to have another child. But we’d like to get married first.

Ryan: We’re getting married on May 21, 2005.

Minneh: We don’t know if my immigration will be settled by then, but we just go on with life. There’s HIV, there’s Minneh, and there’s immigration—in no particular order. I must carry on, moment by moment, otherwise it would be such a waste of time just sitting around worrying about it.

Ryan, how involved are you when it comes to Minneh’s treatment?

Ryan: I’m pretty much there every step of the way. I go with her to the doctor. I don’t actually suffer the side effects with her or anything like that, but I’m fairly involved.

Minneh: I feel very well supported. I remember walking to the lab by myself, going to the doctor’s office and getting all confused. Now Ryan goes with me, and we talk about it later and I understand more what the doctor was saying. He’s a great friend as well as a good lover.

Are your families and friends supportive of your relationship?

Minneh: Very much. We’re very fortunate that way.

Advice for other magnetic couples:

Ryan: Educate yourselves and be very communicative.

Minneh: Before HIV is the person themselves. That’s how you should approach your relationship—as human beings. Then HIV and other issues come in later. Remember that you are people first and foremost.

For workshops contact:
SAN-FAN Educational Group
250.661.7357; www.SAN-FAN.com
**THE CONCEPT OF NOT HAVING**

**BRIAN, 43, HIV positive for 14 years**  
Outreach and partnership coordinator  
**NEAL, 31, HIV negative**  
Footwear product manager  
**Together since October 20, 2002**  
Toronto, Ontario

When Brian met Neal:  
**NEAL:** Brian was a one-night stand.  
**BRIAN:** We met online and decided to meet at a bar.  
**NEAL:** I met him for a drink, but then I had to run home to see *Alias*.  
**BRIAN:** We got along really well, so I invited him back to my hotel room to watch *Alias* and I promised I wouldn’t do anything—and I didn’t.  
**NEAL:** That’s the absolute truth. I was really intrigued with Brian. He was here on business for two weeks and each night we’d have dinner, then go back to his hotel room and watch TV. We didn’t have sex for two weeks after we met.  
**BRIAN:** We went on a date for two weeks.  
**NEAL:** It was total dating. Is that unheard of?  
**BRIAN:** It was a first for both of us.  
**NEAL:** Brian moved to Toronto a few weeks later. He said, “Let’s get a two-bedroom. If things don’t work out, we can just be roommates.” There’s been no need for a second bedroom—it’s my shoe room.

How did you disclose your HIV status to Neal?  
**BRIAN:** I disclosed to Neal online, so he knew from the minute we met. I always disclose because it’s a trust issue right up-front for me. When we started to discuss moving in together, we talked about me being positive and what it could mean down the road. I told Neal, “There could be a time when I get sick. I don’t know when, so now’s the time to say you don’t want to do that part.” I can handle rejection up-front, but I don’t want to be with somebody who leaves me when I’m sick. You want to make sure the person you commit time to isn’t going to bolt at the first sign of trouble. Financial trouble is one thing, relationship stuff is one thing, but if you’re sick that’s another thing.  
**NEAL:** I couldn’t believe Brian was putting this to me, but I’m glad he did. I thought: “Just because he’s HIV positive doesn’t mean I can’t love this man. Does he not deserve to be loved? And why can’t I be loved by him? I don’t care if he gets sick. We’ll deal with that when the time comes.” I don’t know if I verbalized that to him, but I know I did say “shut up.”

**What kind of role does HIV play in your relationship?**  
**BRIAN:** HIV helps me not waste a lot of time, which is probably why we moved so fast in living together. If I wasn’t positive, I might have taken more time.  
**NEAL:** HIV plays a bigger role for Brian. For me, it’s a very minute aspect in our lives. But, for instance, if Brian’s having a tired day, we have a slower, more relaxed day than one that’s go-go. It’s not a big deal, it’s just about balance.

Are there any issues that have arisen from being in a mixed-status couple?  
**BRIAN:** I’ve been fully disclosed and very public about my HIV status, so it’s not an issue for me. But I worry about Neal because it’s difficult when I’m with his family. I’m not sure who knows. I have to let him tell people at his own pace.  
**NEAL:** I’m very protective of me, in terms of how I’m bombarded with questions from my family. Coming from an ethnic family, just being gay was a huge thing. When I came out to them, their biggest fear was: “You’re going to get HIV and die.” I could only do one hurdle at a time. I wasn’t capable or willing to jump the other hurdle. I guess I got complacent. Certain family members know about Brian’s HIV and others don’t need to know. Brian’s part of the family, he’s accepted as my other half—my better half, maybe.

Are there any rewards from being in a serodivergent relationship?  
**BRIAN:** You’re a bit more grown up about a relationship.  
**NEAL:** It exposes me to a lot more than I would have known on my own. That’s definitely a plus. Because of that, I’ve become a board member with a local AIDS organization, where I can help promote awareness.

What contributes to the success of your relationship?  
**BRIAN:** Being honest. For me, disclosure was honesty right up-front, and that sets the pattern for a relationship. Also, the idea that we’re not in it for the short term—if there’s an issue, we try to talk and work our way through it. I think we’re slightly successful in that, but I won’t say we’re 100%.  
**NEAL:** We respect each other’s lives and there’s an open flow of communication that’s always there. So, we’ve got communication, respect and honesty.
SAFER SEX WAS NEVER AN OPTION. IT’S NOT EVEN A DISCUSSION THAT EVER HAPPENS.”

BRIAN: I have a lot of respect for Neal. There are a lot of people who would run scared in the other direction for the smallest of reasons, and this is one big reason. I’ve had rejection around my HIV status. An HIV negative person who runs in the other direction is probably doing you a favour because they’re going to run eventually anyways.

How do you deal with the fear of HIV transmission?
BRIAN: I know that condoms work when you use them consistently and correctly, so that’s just become a part of life. The concept of not practicing safer sex was never an option, it’s not even a discussion that ever happens. I don’t have a huge fear in terms of HIV transmission, but I’m the positive person. I fear being exposed to other STDs, so honesty is really important because other STDs could be a big threat to me.

NEAL: I grew up in the era of safe sex. The safe-sex campaign was full-blown when I was at the most impressionable age, becoming aware of my sexual identity and freedoms. I’ve never had sex without a condom. It’s a natural course of life and I’m very comfortable with it. I’ve never had an STD or anything to worry about, so for me it’s not a concern.

Are there other fears that you deal with in your relationship?
BRIAN: Every time I come back from the doctor, if there are any changes in my health I discuss it with Neal. My counts have been the same for seven years, but I make sure in my health I discuss it with Neal.

NEAL: My counts have been the same for the doctor, if there are any changes in my health I discuss it with Neal. We’re slowly starting to talk about longer-term things, like buying a place. I never would have done that at one time because having HIV limits your view into the future. Planning a holiday next year isn’t one of my strengths. Neal likes to plan longer term, so it’s a good balance. I don’t let him go beyond a year and he tries to get me up to a year.

Has HIV affected your sex life or intimacy?
BRIAN: I don’t think so.
NEAL: Because I knew from Day One that Brian was HIV positive, it hasn’t hindered our sex life in any way. Not sleeping with him in the beginning wasn’t because he had HIV. It was because I thought I liked him and I wanted to see if it would work, if there was any substance there. And there was.

How do you achieve intimacy while protecting yourself from HIV?
NEAL: F—ing isn’t everything there is to sex. We achieve intimacy on so many different levels—cuddling, holding hands while we walk down the street, the special gaze we have in each other’s eyes.

BRIAN: We have date night once a week, no matter how busy we are, when we go to dinner and spend time debriefing. It’s going to the movies and all the other things you do together that make your relationship.

Sex is just one piece of intimacy. There’s so much more.

What about the grey areas when it comes to transmission?
NEAL: I’m going to get a little graphic here: When it comes to oral sex, we take pleasure in it and we enjoy receiving and giving it. In terms of transmitting fluids, we’re a lot more cautious and aware of our actions, and we let each other know what’s going to happen next.

BRIAN: After many years of being positive, talking to other people, doing prevention workshops and knowing the guidelines, I know that the grey areas are just that. Sometimes you live your life in the grey areas. Crossing the street between lights is a grey area for getting hit by a car, but it doesn’t stop you from doing it. So, looking at oral sex, knowing the facts and being aware of the precautions you can take is common sense. It’s no longer a grey area anymore. You just do it and you know. It’s lack of knowledge that creates grey areas.

Neal, how involved are you when it comes to Brian’s treatment?
NEAL: Not in the least. Brian’s so self-sufficient and organized that I don’t see a need to step in at this point. When there is, I’ll be ready to.

Have your families and friends been supportive of your relationship?
NEAL: One hundred percent.
BRIAN: Yeah, me too.
NEAL: If they could, I think my family would trade me in for Brian.

Advice for other magnetic couples:
NEAL: Be yourself. Don’t be self-conscious. Life is too short. You just need to live it.
BRIAN: HIV is just one aspect of life. It doesn’t make a person a different person; it’s just a part of who you are. As long as nobody’s trying to infect someone else and there’s no power imbalance, enjoy and be yourself.
Gary, 48, HIV positive for 3 years
Engineer
David, 32, HIV negative
Medical writer
Together for 10 years
Montreal, Quebec

When Gary met David:
Gary: We met 10 years ago at a coming-out group at McGill University.

When you were diagnosed, how did you deal with it together?
Gary: I was first diagnosed in London, England, in December 2001. I’d gone to see a doctor about an STD, and they performed an HIV test as part of the lab tests. I’d tested negative in September 2001, so I thought it would be OK. I got the result a couple weeks later—the antibodies had come back positive. I was in total denial. I was traveling, David was in Montreal, and I wasn’t able to tell him over the phone. We met up in Europe a couple weeks later and I told him. The HIV test was repeated in January 2002 in Montreal with the same result.

David, what was your reaction?
David: I was numb. My immediate reaction was to reach out to the man I loved who was having such a hard time telling me. When we returned home, I tried to make life as normal as possible. But a few months later, I couldn’t deny it any longer—I needed some help. I went to a counsellor.

Gary: I was also in therapy to deal with the HIV and some childhood issues. I went for a year and then we decided to see a couple’s counsellor. Now we have our couple’s counsellor and I’m in a support group with other positive men at ACCM [AIDS Community Care Montreal].

To what extent does HIV factor into your relationship?
David: Most importantly, it’s impacted our life as a couple—emotionally, socially, sexually.
Gary: It has impacted all aspects.

Was your relationship pre-HIV very different from your relationship now?
Gary: Yes. Definitely.

What are the main issues you’ve had to deal with as a mixed-status couple?
David: On a daily level, there is living with not being 100% well and having to be flexible around that. If Gary’s not feeling up to doing something, we both get frustrated. As well, disclosure is an issue for us.
Gary: More recently sex has become an issue. Our sex is totally different now.

How do you deal with the sex issue?
Gary: Mostly by not having sex. A couple of weeks ago I decided I didn’t want to have sex because I don’t want my partner, who I love, to become infected.

David: I know Gary will do absolutely everything in his power to protect me from becoming infected. I can feel no safer than that. When it comes to our sex life, HIV has done some really great things and some terrible things. Over the last two years our sex life has fluctuated. There have been times when we feel close sexually. There was a period when the sex was very good, more intimate and emotional than ever.

Recently, we’ve come to realize how scared we are of having sex with each other because of the HIV. I’m dreadfully afraid of becoming infected. And now that it’s at the surface, we have to deal with it. Our sex life for the last six months has been non-existent. It hurts, disappoints and frustrates me, but I believe that by working through the issue we’ll come back together. We’ll get the fear out, get over it and get to a place where we’re comfortable playing again. That’s happening now, but it takes a lot more communication. Though it happens less frequently, we have good sex.
Gary: I hope that with lots of communication and support we’ll get closer again and I’ll be more comfortable having sex without always being afraid of infecting David.

How do you achieve intimacy while protecting each other from HIV?
David: We’ve always had a creative sex life, so it’s easy to keep exploring areas that are safe in terms of HIV transmission. There hasn’t been a big shift away from high-risk to low-
risk behaviours. As for emotional intimacy, that comes from us plucking up the courage to be frank and honest with each other. That is bringing me much closer to Gary. 

**GARY:** It's made me enjoy life more, at least try to, even though sometimes it's hard because the HIV is always in the background. It pops up and sometimes puts you down. I'm trying to see the positive side of life.

**DAVID:** It's really made me appreciate having Gary around. You can either bemoan the fact that you're not going to be around forever or you can do the best you can with every day you have. And we try that every day. We're not always successful, but we try.

What other fears do you deal with in a mixed-status relationship?

**DAVID:** The day my man's not going to be here. Because Gary has been fairly healthy up until now, HIV as an illness rarely affects us. He's been in the hospital a couple of times, and that's when it really hits me that this is a disease.

**GARY:** Right now, sex is important but not as important as bringing us together emotionally.

Has being in a mixed-status relationship placed certain roles on each of you?

**DAVID:** Up until Gary seroconverted, he was the caregiver. Now it's become plain that Gary can't always be the caregiver, nor should he have to be. It's allowed us to both be caregivers.

You mentioned something about disclosure being an issue.

**GARY:** Over the last two years we've almost ended the relationship at least twice. Every so often I still think to myself, "I'm out of here. This is too much." I'm in a support group at ACCM for the negative partners of serodiscordant couples. It's been an amazing help to share with people who are going through the same thing.

Advice for other magnetic couples:

**GARY:** See a good therapist.

**DAVID:** For us, it comes down to one word: **communication.** Each couple has to come up with their own set of words. Ours are: communicate, be patient and have respect.

**GARY:** And be honest with each other.
SUE, 37, HIV positive for 15 years
Administrator

JEFF, 38, HIV negative
Insurance adjuster
Married for 10 years
Ottawa, Ontario

When Sue met Jeff:
SUE: We met in high school and then dated off and on for 10 years because Jeff was living in Toronto. There were gaps when we weren’t in touch, but then we’d spend a weekend together and it was like we were never apart. We got back together in 1993 and married in ’94. On September 7th we’d been together for 20 years!

What happened when you told Jeff you had HIV?
SUE: I told him on the phone because he was in Toronto. I didn’t know how to tell him. Back in the early ’90s things were a lot different. I didn’t know how he would react.

JEFF: I saw it as an illness. I wasn’t taken aback by it. I was very concerned and supportive. She was my sweetheart, my love, and it didn’t matter.

Does your daughter know you have HIV?
SUE: She’s known since she was 8, when she asked why I take so many pills. I told her I have a virus, and she said, “like in the computer?” I figured I could work with that. I told her that when there’s a virus in the computer all the programs don’t run properly and sometimes the computer shuts down. If the virus in my body is making my body not work properly, at some point my body is going to shut down. I also told her that the virus was asleep and we’d worry about it if the virus woke up.

Are there any issues that have arisen from being in a mixed-status relationship?
SUE: We’ve had people assume that Jeff and our daughter also have HIV, but I’m the only one who does. Other issues have been pretty much medical—starting new drugs, side effects, throwing up first thing in the morning. If I’m not well or I’m moody or lacking physical energy, it’s hard on the family because everyone has to do more around the house.

JEFF: But that’s not a major issue. Like any family dealing with any illness, the other family members would pick up the slack.

Are there any rewards from being in a serodivergent relationship?
JEFF: My life before Sue didn’t involve anybody who was HIV positive. I didn’t know or care about HIV. But from being with Sue I’ve learned that there is more to life than being... I don’t know how to say this...

SUE: A white, heterosexual male? (laughter)

JEFF: It’s opened my eyes to a whole real world out there that I’d never seen. I’ve met so many fascinating and informative people in the HIV community.

SUE: This relationship has given me the calmness and security of knowing that Jeff will be here for our daughter if I’m not. That has helped me medically because I’m not stressed out about what will happen to her. I also know every day that I’m loved and cared for.

JEFF: Sue having HIV has shown me that there’s more to a relationship than just good times.

What contributes to the success of your relationship?
SUE: He makes me laugh.
JEFF: Golf. And lots of it. (laughter) I’m kidding. We always find time for us. There are times where we’re apart and I may not like it, but the quality
time turns out great. We also don’t dwell on the HIV factor.

SUE: HIV doesn’t overwhelm our lives at this point. We can’t make it go away, but we can try to control it and live our lives to the fullest.

How do you deal with the fear of HIV transmission?

JEFF: It’s no different from when I was single. I was aware of sexually transmitted infections when I was younger, so protecting myself from HIV didn’t invoke any fears.

SUE: When Jeff re-entered my life, he knew full well that I was HIV positive. It was his choice to come back to this relationship. I still have that underlying fear, but he’s still negative.

JEFF: I’ve had two HIV tests. My general practitioner convinced me to get tested just to ensure that I was OK.

SUE: We do have unprotected sex. It happens. I don’t know what else to say.

JEFF: It’s happened a few times. The moment just takes over, and because we attempt to live as a healthy couple we sometimes have sex just as any healthy couple would. We do try very hard to have protected sex though.

Are there other kinds of fears you deal with in a mixed-status relationship?

SUE: I know that one day I’m going to end up a client at the agency where I work. I know I’m going to be sick one day.

JEFF: I know that one day Sue could get very ill and that’s going to hurt our family in a lot of ways. We’re a two-income family and taking away half of the income would hurt. Sue is a strong figure in our family, and it would be hard to replace her contributions, both physically and mentally.

SUE: I was on disability for a while. And I see how hard it is for people on government disability plans to make ends meet. So, it’s a financial burden that we fear.

Has HIV affected your intimacy?

JEFF: No, Sue having HIV does not affect our intimacy. Just like any other couple that works full-time and raises a family, in our busy lives intimacy is hard to come by.

How do you deal with the grey areas when it comes to transmission?

SUE: We didn’t have sex for the longest time when my viral load was high. And we don’t have sex when I have my period, even protected sex. It’s not a place we want to go. Why put that risk out there? It’s only a week . . . he can go without!

JEFF: We’ve been having oral sex since Day One.

SUE: It was actually Day Three, hon. (laughter)

So you weigh the risks and benefits.

SUE: Absolutely.

JEFF: I’ve decided what I’m doing in this relationship. My goal is to have a “normal” relationship. I know that by having unprotected intercourse and oral sex with Sue I could get infected, but I can walk out of my house and get hit by a car. I love Sue and I want her to enjoy her life to the fullest.

You seem pretty informed about HIV.

JEFF: If I have a question, Sue answers it. She’s a walking encyclopedia. And I trust her. I’m very fortunate in that sense.

How involved are you when it comes to Sue’s treatment?

JEFF: Marginally.

SUE: If I want to go on a structured treatment interruption, the choice is mine and I have to weigh the risks and benefits. Jeff and I discuss it, but I’m the one who goes to the doctor and says “I want to go off meds,” because that decision is mine.

Has being in a serodivergent relationship placed certain roles on each of you?

JEFF: When I go to HIV conferences I’m known as “Sue’s husband,” and I’ve grown accustomed to that.

SUE: Since I’ve been giving workshops on serodivergent relationships, I seem to have fallen into a role where I’m asked by people I’ve never met before how the relationship and the sex work. I tell people that magnetic relationships like mine and Jeff’s can work well with lots of hard work.

Magnetic?

SUE: The title of my workshop is “The Magnetic Couple: The Positives and the Negatives in the Serodivergent Relationship.” Serodiscordant assumes that there’s discord in the relationship, so I really try not to use that term. Divergent means different.

Are your families and friends supportive of your relationship?

SUE: He’s the only boyfriend my mother ever liked.

JEFF: For the most part, my family’s been supportive. However, some of my family and friends found out through the grapevine and were very obtuse.

SUE: “Don’t use a glass that she used, don’t smoke that joint with her,” stuff like that.

JEFF: Sue’s mother, stepmother and father are very supportive, as is the rest of her family.

Advice for other magnetic couples:

JEFF: Live for today and love the one you’re with, because love is the best medicine.

SUE: You can’t let HIV overrule everything in your life. It’s a component of your life, but it can’t be the overwhelming force that absorbs everything else.

To contact Sue about workshops:

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sasp@cheerful.com
A re you like me—sick and tired of the same old song: “Take all your pills, all the time”? This mantra is shoved down our throats so often, who can blame a person for saying, “Take ALL your pills and shove ‘em!”? The problem is that playing loose with HIV therapy can lead to drug resistance, causing treatments to fail. Why do we PHAS have to walk such a tightrope, and how do we manage to pull it off?

Drug adherence (or compliance) means taking your HIV medications exactly as prescribed—in the right number, at the right time, with or without food, every time. Understanding why adherence is crucial can help you stick to the pill drill.

**Drug Resistance 101**

Once HIV is in your body, it’s there for good (until medical science finds a way to exterminate it). Drug therapy—antiretrovirals, HAART, the cocktail, whatever you call it—is not a cure, but it can reduce the risk of life-threatening infections and improve survival.

HAART (highly active antiretroviral therapy) keeps HIV under control—throwing monkey wrenches into the “assembly lines” the virus uses to reproduce. But a dose here and there won’t succeed: It takes constant, adequate amounts of drugs to keep HIV under control. Think of HIV as a gushing river, and HAART as the dam holding it back. Half a dam won’t work—it’s either high enough or not. Biologists describe antiretroviral drugs as a “genetic barrier” to HIV reproduction. If you don’t keep enough meds in your body, all the time, that barrier wears away under viral pressure and eventually breaks, allowing HIV to reproduce.

HIV is sneaky, finding weak points in our defenses, such as low drug levels. The virus can change shape to sneak around a drug: The change is called a **viral mutation**, and the mutated virus may be **drug resistant**. Once a certain drug no longer works for you, drug-resistant HIV can reproduce and grow, even if you keep taking the drug. Even worse, **cross-resistance** can sometimes make the virus resistant to other drugs in the same class—even if you’ve never taken them before.

Prime example? Moi: I started mono-therapy (single-drug therapy) with AZT back in 1995, before we knew that taking just one med was a recipe for drug resistance. We did a lot of things wrong back then—adding on 3TC (Epivir) and then Crixivan (indinavir) only made me resistant to them as well. Thanks (or no
thanks) to cross-resistance, many other new meds became useless too, and for a while my prospects didn’t look good. Luckily, the five antiretrovirals I switched to in 2000 finally got my viral load under control, but believe me, you don’t want to paint yourself into that corner.

What does all this have to do with adherence? Simple: 

**drug levels.** Whether you’re taking too few meds or taking enough but not often enough, the result is the same: inadequate drug levels. Your body is constantly clearing medications out, so you have to keep putting them in to maintain sufficient levels. Hence, once-, twice-, or even (bleah!) three-times-daily pill-popping schedules.

**WE’RE ONLY HUMAN**

As you can see, there’s good reason to be adherent—it’s not just doctors being bossy. In fact, one often-quoted study found that chances of keeping the virus suppressed for a long time start to slide if you miss more than 5% of your doses. If you pop your pills twice daily, that means not missing more than two or three doses a month; for three-times-daily poppers, not more than one dose a week.

Taking 95% of your doses for peak effectiveness is an incredibly high target. Most negative people don’t come anywhere near it. So what are we PHAs supposed to do out here in the busy and messy human world?

Take my less-than-perfect self: I can spout stats ‘til the cows come home, but I still find missed doses in my carefully organized pillbox. My own personal pitfalls?

- Falling asleep before pill time (because, dammit, I’m tired!).
- Being depressed and not feeling like eating, which makes a “with-food” dose a problem.
- Losing track of one of my nine prescriptions, and either forgetting to get one of my HIV ’scripts refilled or running out of repeats.

**COMPLIANCE CULPRITS**

Working at the Toronto People With AIDS Foundation for eight years, I’ve found that there are as many different adherence challenges as there are people on meds. Laura, a single mom whose kids don’t know she has HIV, has to keep her meds hidden. Luis went for weeks taking only half-doses because he thought that would lessen the side effects. Jimmy does really well until he lights up his crack pipe, then it’s game over for the next three or four days. And I can’t even begin to count the people who show up at our agency, out of meds and panicked, because their drug coverage plan has screwed up—again.

Out of this assortment, some common culprits emerge:

- **Side effects.** Who wants to feel sick? If the side effects are nasty, switching meds may make adherence easier. Talk to your doc about how to deal with them.
- **Depression or anxiety.** Ever ask yourself “why bother?” Because your life is worth it, that’s why. Depression can be treated in a variety of ways. Don’t be ashamed or afraid to seek help.
- **Lack of structure.** This is often tied to alcohol and drug use or mental illness. Or just trying to hold a hectic life together—as any single parent can tell you.

- **The “oops” factor.** “I just forgot” or “I was late”... hey, it happens! Finding some stable point amid the daily chaos can be the key (see “Forget-Me-Nots” for practical pointers).
- **Access issues.** You can’t take your meds if you can’t fill the ’script—and too many coverage schemes have cracks that people fall through. You may need to work with your health care team or AIDS agency to get the drugs you need.

**GETTING AHEAD OF THE GAME**

While there’s no single magic solution, take heart—most people can handle the challenge of adherence once their issues are addressed. Best up-front advice? Be prepared. Going from no pills a day to any pills every day is a big leap. If you’re thinking about starting HAART, work through your feelings about taking HIV drugs. Be aware of any potential side effects before you start taking meds and practice with jellybeans or Smarties to see where the trouble spots may lie. Talk with other HAART takers.

Once you’re on HAART, adherence problems can sneak up—even eager beavers may drift after awhile. If you feel like you’re slipping, don’t wait: Talk with your doctor, pharmacist or clinic nurse—your health is their job. Simpler schedules, such as once-a-day dosing, often make adherence easier, but they may not work for everyone.

If you do miss the occasional dose, don’t beat yourself up. Nobody’s perfect; just do the best you can. If you space out, don’t double up your next dose to make up for it—get back on track by taking your next dose on schedule.

I’ve been taking HIV drugs for a long time now and, like everyone else, there have been times I’ve wanted to ditch ’em. But in the end, while taking meds may be complicated, one thing is simple: My life is worth the trouble.

Derek Thaczuk tested positive 12 years ago. He provides treatment information at the Toronto People With AIDS Foundation and as a freelance writer. His pill schedule can’t keep him off the bike trails.

**Web Wee-minders**

- CATIE’s Practical Guide to HAART, [www.catie.ca/PG_HAART_e.nsf/](http://www.catie.ca/PG_HAART_e.nsf/) (see the sections on “Issues to consider before starting treatment” and “Continuing Treatment: making it work long-term”)
- “The Importance of Adhering to Your Treatment Regimen,” [www.aidsmeds.com/lessons/Adherence1.htm](http://www.aidsmeds.com/lessons/Adherence1.htm)
- “Adherence: Keeping up with your meds,” [www.projectinform.org/fs/adherence.html](http://www.projectinform.org/fs/adherence.html)
Research into HIV drug adherence may produce ways to make it better and will hopefully help doctors and scientists see the point of view of the people taking the medications. However, considering how heavily HIV is studied, there’s less research on drug adherence than you’d expect. One reason is that it’s so complex, says Laura Park-Wyllie, a Toronto pharmacist and researcher with St. Michael’s Hospital’s Inner City Health Program: “A huge number of factors affect people’s adherence. As a researcher, you have to make sure you’re doing the science carefully, but it’s important to remember you’re dealing with real human beings.”

Different strokes
Park-Wyllie, along with Dr. Elizabeth Phillips of Sunnybrook and Women’s College Hospital, recently reviewed the research on adherence for the Canadian Journal of Clinical Pharmacology. Examining why people have trouble sticking to their regimens, they found everything but the kitchen sink: depression, stress, unstable living conditions, recreational drug use, complex and demanding medication schedules, side effects, the number and frequency of daily doses, poor or inconsistent medical care, travel, changes in daily routine, and just plain forgetting.

This grab-bag of troubles led to the notion of a “toolkit” of support techniques: working closely with each individual to assess what’s most likely to help, then drawing on existing tips and tools to form a highly customized adherence support program.

Pharma karma
A recent study from the B.C. Centre for Excellence, published in AIDS Care, found that pharmacists can help with adherence. People who got their meds from pharmacies in hospital clinics, where pharmacists work very closely with PHAs, were most likely to be highly adherent and have lasting viral suppression as a result.

STAART before HAART
Psychologist Louise Balfour and others at Ottawa Hospital are currently studying a program they call “Supportive Therapy for Adherence to Anti-Retroviral Treatment” (STAART). Providing psychological and educational support before people pop their first pill is proving useful to head off potential problems with adherence, especially for PHAs suffering from depression.

A full-time job
Other Canadian researchers say that adherence has a lot to do with how we as PHAs feel—about ourselves, our medicine and what we have to do to stay healthy. Eric Mykhalovskyi and colleagues at Dalhousie University in Halifax use the term “health work” to describe the ongoing daily effort demanded of PHAs, recognizing that just getting through a typical day, with its medication and other health demands, requires constant effort.

Mind over meds
James Gillett and colleagues at Hamilton’s McMaster University are talking to PHAs about their views of drug treatments and all that they symbolize. The McMaster team calls this a “rarely straightforward” headspace where treatments may symbolize hope, health and a future—or intrusiveness, toxicity and “feeling like a lab rat.”

A fine balance
Sergio Rueda, from the (now-defunct) Community Research Initiative of Toronto, found that while some people sing the praises of their meds, many more see them as, at best, a necessary evil. This “stoic” view reflects an ongoing struggle: to keep HIV and taking pills from ruling your life. +
—Derek Thaczuk

Forget-Me-Nots
- Piggyback. Pick something you do habitually every day—brushing your teeth, watching the nightly news, putting contact lenses in. Get in the habit of taking your pills at the same time.
- Get your ducks in a row. Dosettes—daily or weekly pillboxes with different compartments—can be had from the drugstore or perhaps your local AIDS organization. Doling out your doses at the beginning of the week saves time and bother.
- Put drugs in your pocket. Keep a dose or two on you in case you come home late (or not at all).
- Stockpile. It can’t hurt to have a little extra stash on-hand in case a prescription renewal hits a bump.
- Don’t be afraid to ask. For help, that is. Your doctor, pharmacist, AIDS organization, PHA pals—somebody is bound to have suggestions. You don’t have to go it alone.
- Put yourself in charge. Nobody likes being told what to do. Ditch “Yes sir, took my pills, sir”—do it for yourself.
- Come clean. Be honest about adherence problems. Your doctor should be able to help you, not scold you.
- Put it in perspective. If you’re bummed out about meds running your life, here’s how one PHA puts it: “I think about being HIV positive for 15 seconds a day—when I take my pills.” It takes longer than that to shower and shave!
For people living with HIV/AIDS (PHAS), a "minor" infection—think cold, flu or sinus infection—can have some major consequences. Avoiding infections, and treating them effectively when they sneak up on you, is a good idea. Here’s why:

- It’s much easier for your body to knock out an infection when your immune system is strong. Anti-infection drugs (antibiotics, antifungals and antivirals) don’t work alone—they need a hard-working immune system to help them eliminate bugs and germs. If you let an infection drag on, you’ll have more trouble fighting it off further down the road if your highly active antiretroviral therapy (HAART) fails and your immune strength diminishes. And with decreasing immune function, the infection may get worse and could cause more serious problems. Treating an infection as early as possible increases the chances of completely eliminating it.

- Every time your body has to crank up your immune system to fight an infection, the HIV living inside the immune cells gets cranked up, too. "HIV replicates most effectively within immune-competent cells..."
when these cells are activated,” says Anthony Fauci, MD, director of the National Institute of Allergy and Infectious Diseases at the U.S. National Institutes of Health. “When a person gets another infection, the immune system gets activated, or ‘turned on,’ to fight this infection. This activation puts the immune system in a more vulnerable state for the replication of HIV.” So, although the fever and aches and pains related to an infection may be all you’re feeling, what’s going on beneath the surface may include rapidly growing HIV.

This issue is not just a concern for those not on HAART. Although HIV activation is definitely greater in someone with unsuppressed virus, even people on HIV meds who have undetectable viral loads may have problems. Dr. Fauci says that although HAART generally lessens the increase in HIV activation that another infection can cause, if your immune system has to work overtime to fight other infections that activity can end up making your meds less effective at suppressing HIV. So preventing (where possible) or otherwise quickly treating infections may help preserve HAART’s ability to keep HIV in check.

Which infections are of most concern? In general, the infections most likely to boost HIV replication are those that cause body-wide (systemic) symptoms: fever, muscle aches, fatigue and “malaise”—that all-over yucky feeling. You know how you feel when you get a cold or flu or your sinusitis starts acting up? That’s what we’re talking about. These symptoms are indicators that your immune system has been activated enough to likely increase HIV activity.

Those are some reasons why it’s important to prevent infections—and treat them quickly when they do occur. Read on for tips on how to avoid and treat four common infections that can activate HIV: colds, flus, sinus problems and hepatitis.

Colds and flus

Achy all over, feverish, sniffing, coughing and just generally miserable—that’s probably how you felt the last time you had a nasty cold or flu. Even worse, the flu can lead to pneumonia, and the risk of this is greater in the immune-compromised. Plus, the infection can stress your immune system and may activate HIV. Here’s what you can do to prevent or quickly knock out these misery-makers if they occur. If you notice you’re getting colds and flus a lot more than usual, tell your doctor.

Prevention: “Start with what your mother always told you: Wash your hands and otherwise practice good hygiene,” says Ottawa Hospital’s Curtis Cooper, MD. Indeed, research has shown that the biggest factor in the transmission of colds and flus is touching contaminated surfaces. A classic example: grabbing a doorknob that an infected person touched after blowing his nose. Bingo. His cold becomes yours when your hand later touches your eyes, mouth or nose.

Avoid directly touching surfaces in public places that are likely to be contaminated—stair rails, doorknobs, faucets, toilet handles—or use a tissue when doing so. Wash your hands when you return home from a public place. If someone’s ill in your own household, extend those rules to the home-front.

Avoid eating anything that you or anyone else has touched with unwashed hands or that’s been in contact with an unwashed surface. Don’t drink or eat from the same containers that someone with a cold or flu has used.

It may not sound friendly but try to avoid being around people with a contagious illness like colds or flus as much as you can, and try not to touch any surfaces they’ve touched when you are around them.

When the flu vaccine becomes available every fall, get in line to get yours. The small amount of immune activation that a vaccination may cause is nothing compared to the effects of a full-blown infection. To prevent pneumonia, check with your doctor about getting the pneumonia vaccine (Pneumovax).

Treatment Tips: Rest, plenty of fluids and a fever med are the standard recommendations for colds and flus.

Rest, plenty of fluids and a fever med are the standard recommendations for colds and flus. Many people who’ve tried beta-glucan supplements say that they greatly shorten the duration of colds and flus (2–3 500-mg capsules taken when first symptoms appear, followed by 1–2 capsules every hour...
or two until symptoms disappear, usually within a day). Long-term use is not advisable because beta-glucans may end up activating HIV, just the thing we’re trying to avoid here, but a couple days’ worth to head off a viral infection appears to be safe.

- **Vitamin C.** Several studies have shown that vitamin C—2–6 grams (2,000–6,000 mg) daily, with doses spread throughout the day—can help prevent or shorten colds and alleviate symptoms. It works best if taken when symptoms first appear. Different people can tolerate different amounts of C, so start with a low dose and build up gradually. Too much C can cause sudden, very watery diarrhea. Once you stop taking it the diarrhea should go away.

- **Echinacea.** This herb has long been recommended by naturopaths to treat colds and flu, usually in doses of several capsules or drops of a tincture daily from the very beginning of the infection until it’s gone. Long-term use is not recommended because the herb may promote the production of potentially harmful immune system chemicals that are already too high in PHAs. Echinacea has the potential to interact with certain HIV and other drugs, so check with your pharmacist before using it.

- **Zinc acetate lozenges.** Several studies have shown a shortening of the duration of colds if one of these lozenges is held in the mouth and allowed to dissolve slowly every two hours until symptoms disappear, followed by use every 4–6 hours the day after symptoms disappear to help prevent recurrence. They work best if used at the very beginning of the infection. The lozenges may cause nausea if taken on an empty stomach, so have a snack before popping one.

**Sinus Problems**

Achy face, stuffy nose dripping yellow or greenish goo, wretched headache and fever—not exactly the recipe for a happy day. For many PHAs, it’s a combo of misery that happens too often as the result of sinusitis, an inflammation of the sinuses. And the symptoms are an indication that HIV is probably being activated. Sudden-onset (acute) sinusitis usually stems from an infection that may be bacterial, viral or fungal. Long-term (chronic) sinus problems may be allergy related but also frequently result from persistent infections. Sinusitis can return more often or linger longer in people with compromised immune function.

The focus in the past has been on bacteria as the most likely cause of sinus infections. However, recent research from the Mayo Clinic has shown that in most people the more likely culprits are fungi. The air is filled with fungal spores that we breathe in. This causes no problem in most people, but in the extra-sensitive extra-sensitive there’s a hyped-up immune system response which results in the typical symptoms.

Seasonal and other allergies (to dust, mold, etc.) contribute to sinus problems in many people. When caused by allergies, the most common symptoms are watery mucous production, sneezing, wheezing, itchy nose or eyes, headaches and swelling of the nasal membranes.

**Prevention:** If allergies are the suspect, check with your doctor about allergy testing, followed by desensitizing allergy injections, if appropriate. There are reservations about using such allergy shots in people with uncontrolled virus (due to the risk of HIV activation), and they may not work in those with seriously compromised immune function (low CD4 cells). In the case of pollen, dust, mold and other airborne sources of allergies, keep your living space as clean and free of them as possible. Air filters can help.

**Treatment Tips:** Specialists recommend a thorough diagnostic work-up to determine exactly what is causing your symptoms. This can include an endoscopy of the nose and a sinus CT scan.

- If a bacterial infection is diagnosed, appropriate antibiotics usually clear up the infection, although lengthy treatment is sometimes required. It’s important to accompany such treatment with acidophilus (either via supplements, 1–2 capsules several times daily, or regular consumption of live-culture yogurt) in order to replace the “good” bacteria that are inadvertently killed off by antibiotics. These good bacteria serve important functions, including aiding in digestion and helping prevent various infections and yeast overgrowth.

- If a fungal infection is found, an antifungal nasal spray (amphotericin B, usually used twice a day for three months or longer if necessary) has been shown by Mayo Clinic researchers to successfully eliminate the problem in some people. Although amphotericin B is not approved for this purpose, it can be prescribed off-label and prepared by a compounding pharmacy.

- Frequent use of a saline spray can help eliminate infections by keeping the area cleaned out and less hospitable to infectious organisms.

- If there’s serious congestion that makes it impossible to effectively

The air is filled with fungal spores that we breathe in.
Hepatitis viruses A, B and C can all activate HIV as well as cause serious symptoms.
I seroconverted early in the pandemic, when this illness did not yet own its final name. No one knew how to deal with it. I believed my life was over. I was terrified, confused and suicidal. The question was: Could I find a way to live with AIDS?

Diagnosed in 1985, not knowing who to talk to about it and fearing that my life would soon end, I was lost in a fog of loneliness and despair, until I began to speak about my condition with Dr. Andrew Zysman, my late cousin, who was also HIV positive. He encouraged me to turn my photographic interest toward documenting the history of AIDS.

There was much to be learned by following this path. By attending AIDS conferences around the world, beginning in 1989 at Montreal, I developed a career as a photojournalist. That surprised me, because I didn’t believe that I could do anything with a death sentence imposed upon me. My interest in life was rekindled. I learned how to better cope with my illness.

Though I grieve for all the people I’ve met, known, loved and lost in this struggle for survival, I am at once a member of the global AIDS community and a recorder of the evidence we witness in AIDS health care issues, politics, activism, business and society. This makes the spectre of AIDS easier to bear.

Any person living with HIV/AIDS can empower his or herself by cultivating their personal means of expression. This may benefit the psyche and strengthen the will to live. We all have a point of view about the subject of AIDS, and it is important for everyone who can to make their voice heard, whether in the arts or by helping others.

This past summer, at the 15th International AIDS Conference in Bangkok—the 10th one I’ve attended—I had the opportunity to meet other Canadians who actively dedicate their human talent to fight HIV/AIDS and its terrible effects. Here are some of them.

1 Buddha. 2 Craig McClure & Ian Grubb. 3 Dr. Mark Wainberg. 4 Dr. Jonathan Luetkehoelter & Dr. Tom Lampinen. 5 (clockwise from left) Glen Brown, Bill Flanagan, Ron Rosenes, Louise Binder. 6 Ron Rosenes & Brian Huskins. 7 Stephen Lewis. 8 Rolake Nwagwu & Ian Grubb. 9 Jacob Peters.
Here are some other CATIE publications you may find useful:

✚ **A Practical Guide to HAART**
The latest on what is known about the various aspects of treatment, including a description of the virus and the immune system, the stages of HIV disease, the tests used to assess health status, and anti-HIV medications.

✚ **A Practical Guide to HIV Drug Side Effects**
The latest on what is known about various side effects related to treatment, from appetite loss to sexual difficulties, and tips for countering or preventing them.

✚ **A Practical Guide to Complementary Therapies for People Living with HIV/AIDS**
This guide provides an overview of many CAM therapies used by PHAs. Included are descriptions of several forms of massage, mind-body medicine and an introduction to complementary medical systems such as Ayurveda and homeopathy. This guide also offers lists of resources where people can find more information about the various therapies in Canada.

✚ **A Practical Guide to Herbal Therapies for People Living with HIV/AIDS**
This made-in-Canada reference tool provides PHAs with information regarding non-pharmaceutical treatment options.

✚ **Fact Sheets & Supplement Sheets**
Concise overviews of conditions, symptoms, medications, side effects, complementary therapies, vitamins, herbs and other treatment issues.

✚ **Managing Your Health, 1999 edition**
A must-read guide for PHAs which addresses social, legal, health-related and practical issues comprehensively and from a national perspective.

✚ **Pre*Fix**
A harm reduction booklet for HIV+ drug users.

To order any of these publications or to subscribe to *The Positive Side*, please contact us at: 1.800.263.1638 or download an order form from our Web site at: www.catie.ca/pdf/Publicationsorderform.pdf

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**HIV POSITIVE?**

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**CATIE is Canada’s national provider of treatment information for people living with HIV/AIDS, their care providers and community organizations.**

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Read or download treatment publications and current news or find links to other Internet sites with information about HIV/AIDS.

**E-mail treatment questions to:** questions@catie.ca
Ask questions of our knowledgeable Treatment Information Service Representatives when it is convenient for you.

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**MISSION:** The Canadian AIDS Treatment Information Exchange (CATIE) is committed to improving the health and quality of life of all people living with HIV/AIDS in Canada. CATIE serves people living with HIV/AIDS, and the people and organizations that support them, by providing accessible, accurate, unbiased and timely treatment information. CATIE works in partnership with a network of other information providers to ensure that people have access to the information they need, in the form they desire, to make informed health care choices.

This publication is available in English and French, on-line at www.catie.ca, or by calling 1.800.263.1638.

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**DISCLAIMER:** Decisions about particular medical treatments should always be made in consultation with a qualified medical practitioner knowledgeable about HIV-related illness and the treatments in question.

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