

THE POSITIVE SIDE

HEALTH INFORMATION & VIEWS

SUMMER 2014
VOLUME 16 ISSUE 2

ANCHORED

Kath Webster's path to peace

AIDS icons

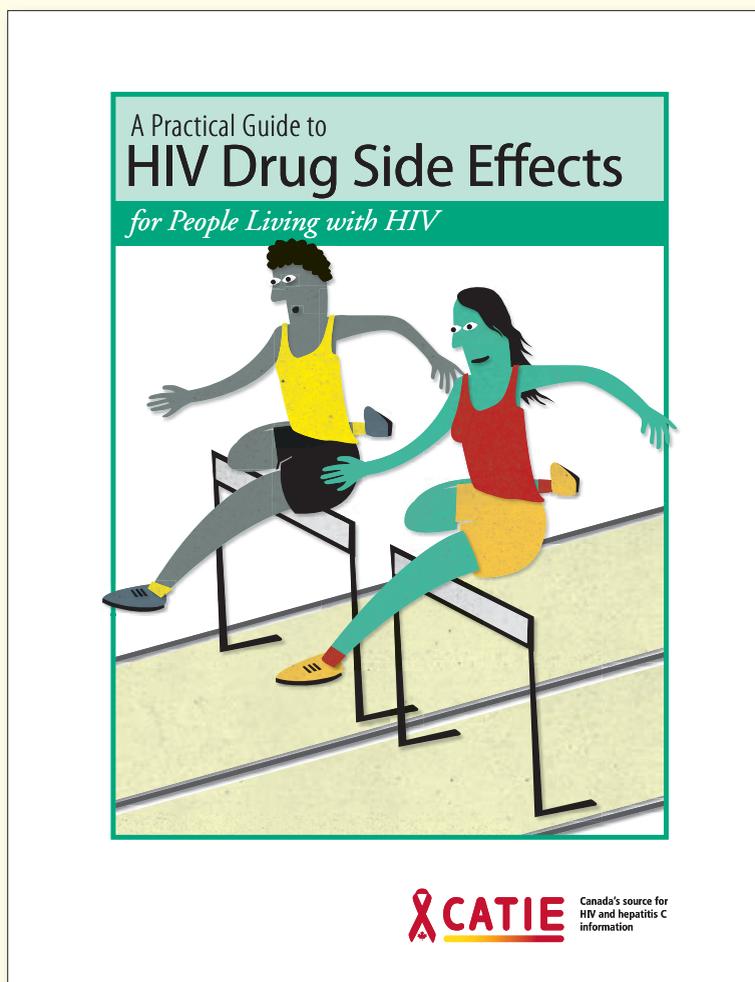
Peer power

Posters target stigma

The quest for a cure

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EDITOR'S LETTER

Artists know that light—and dark—play a crucial role in producing an engaging, inspiring work of art. Brightness draws the eye (or ear) and can be joyful or punchy, while darkness can provide restful contrast or challenge us to seek meaning in subtleties. Life with HIV certainly has its moments of light and dark. This issue of *The Positive Side* has a strong artistic sense that reflects that range.

The lineup kicks off with “From the Front Lines” reporting on art and art therapy programs for people with HIV. Artistic expression can be a fun way to pass some time, but it can also be a profound process of exploring thoughts and feelings. “Visual AIDS” shares the story of Peggy Frank’s seven-foot sculpture of a cocktail glass, which is at once whimsical and sobering.

The art of life with HIV contains bright threads, and we explore one of them in our article on peer mentorship programs, in which people with HIV help each other navigate the complexities of healthcare. Also, “The Push for a Cure” looks at the bright spots in ongoing cure research.

There are somber threads, too. In an extended instalment of “Ask the Experts,” Yvette Perrault talks to four people who know grief intimately about the impact of HIV-related grief. “In Your Face: AIDS Posters Confront Stigma” looks back at over 30 years of poster art to see how artistic expression—there’s that art theme popping up again—has evolved to counter the changing yet still devastating effects of stigma faced by people with HIV.

And there are threads that mix light and dark. This issue of “Chatty CATIE” asks people with HIV: Who is your AIDS icon? Several people highlight the inspiration they draw from those long gone despite their sense of loss and sadness. And the stories of Kath Webster, who graces our cover, and Joseph Babcock, our artist profile, reveal how these inspiring people refuse to let the dark overpower the light.

I hope you enjoy this issue of our little magazine. As always, send your stars and cherry bombs to dmclay@catie.ca. We love to hear from you.

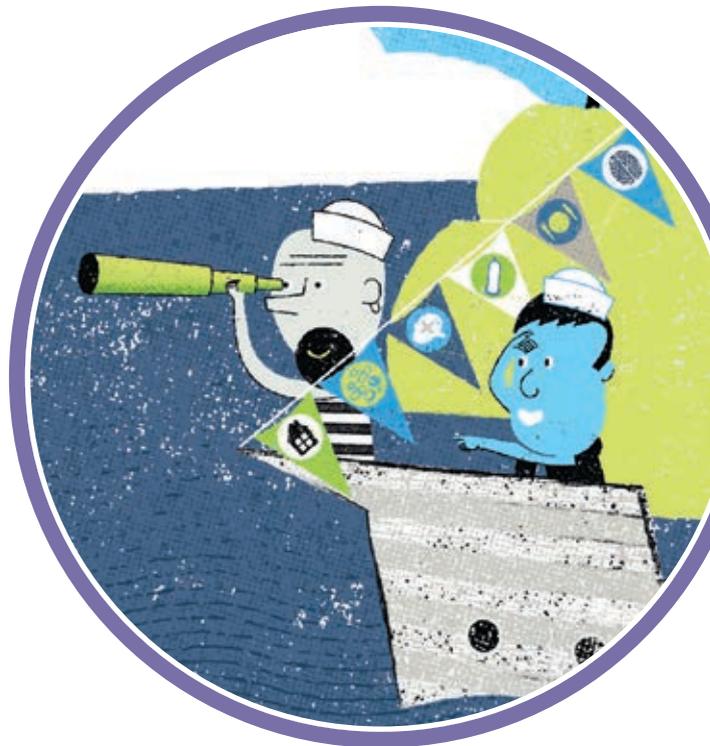
—David McLay

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Express Yourself

CATIE educator **Melissa Egan** highlights 4 programs that promote health and healing through art.

Whether you're artistically inclined or not, singing, dancing and drawing can allow us to explore our deepest thoughts and feelings. Creating and enjoying art can be therapeutic: It can offer an emotional outlet, inspire us to see things from a fresh perspective, even give us tools to work through deep-seated trauma. Or, it can simply be an enjoyable way to while away a few hours. Here are a few arts-based programs offered by AIDS service organizations across Canada. You do not have to be a Leonardo da Vinci or Frida Kahlo to join!



Drumming & Singing Circle

**Nine Circles Community Health Centre
Winnipeg**

The drumming circle is an important part of Aboriginal culture, as it offers people an opportunity to build community, get in tune with each other and make music. At Nine Circles, Peetanacoot Nenakawekapo works with people to create a powerful circle of healing. The collective drumming and singing creates a unity of sound that honours the spirit and allows participants to explore culture and music in a safe space. "It's like being in another dimension," Nenakawekapo says. "People feel warm and authentic in the welcoming atmosphere of the drumming circle."

To participate, call Peetanacoot at 204.940.6000. You can find out when this and other inspiring programming is scheduled by visiting ninecircles.ca and clicking on the event calendar.

Art Therapy

Toronto People With AIDS Foundation (PWA)

If you've ever lost yourself in the process of writing or drawing, or found calm in playing an instrument or dancing the night away, then you understand the power of art therapy. Since PWA began incorporating the arts into its programming a few years ago, clients have expressed growing interest and staff members have made note of "the healing power of engagement."

PWA offers art therapy in both spring and fall, in the form of either two full-day sessions or a series of evening sessions. The direction is always client-driven. Using different modalities—music, drama, body percussion, visual arts and poetry—participants explore their feelings around relationships, stigma and other challenges they may be dealing with. This helps them cope and feel more empowered. For many, it is an opportunity to play with paint and movement in a way that makes them feel safe and generates joy.

For info about upcoming sessions, call Ed Argo at 416.506.1400 (ext. 207) or visit www.pwatoronto.org





Art & Music Therapy

Dr. Peter Centre, Vancouver

The art and music therapy sessions at the Dr. Peter Centre have become the heart of this beautiful space, which is the legacy of the late Dr. Peter Jepson-Young, a young Vancouver physician diagnosed with HIV in 1985. Nestled in the city's leafy West End, the centre provides comprehensive client-centred care and support to more than 400 residents and Day Health program participants each year.

The centre's music therapy program takes the form of both solo and group sessions. Clients can express themselves and develop musically, increase their self-esteem and, for those who jam in a group, connect with others.

In the art therapy program, clients, many of whom have experienced traumatic life events, can express themselves using various mediums—sculpting, sewing, pottery, painting or papier-mâché. Participants have a chance to explore repressed memories and work through their experiences of discrimination or social isolation with the support of a trained art therapist.

To learn more about these unique programs, visit www.drpeter.org

VIH des arts

Maison Plein Cœur, Montreal

There is something thrilling about sitting in a crowded theatre, nestled in your seat, waiting for the show to start. The anticipation of a captivating performance, witnessing artistic expression as a community and sharing in the enthusiastic applause as the curtain goes down all help to bring people together. VIH des Arts, at Maison Plein Cœur, creates opportunities for people living with HIV to attend arts events around the city by offering clients free tickets and passes to various cultural events, such as plays, dance performances and occasionally even concerts by the Montreal Symphony Orchestra.

This program is run entirely by a group of volunteers who have formed strong relationships with the city's arts organizations, which, in turn, donate tickets to some of the most sought-after shows.

For the volunteers and staff at Maison Plein Cœur, "breaking isolation and nourishing the mind are as important as taking care of the body."

If you would like to strengthen your connection to Montreal's thriving arts scene and get involved with a community of people who love it, contact Bastien Lamontagne at 514.597.0554 or visit maisonpleincoeur.org



Does your local ASO have arts-based programming? To let *Positive Side* readers know about it, email us a short description: contribute@positiveside.ca



Who is Your AIDS Icon?

5 PHAs pay tribute to the people who inspire them.



LOUISE BINDER, 65

Toronto

HIV+ since: 1994

Brian Farlinger was a lawyer who worked for the Canadian Bankers Association before he was diagnosed with HIV. He became a leader in the early HIV activist community and was one of the founders of AIDS Action Now! (which did much of the groundbreaking work for treatment access in this country). He passed away in 1995.

There's no question that Brian had a profound influence on me. He brought a unique integrity to the work he did. He clearly was not doing this work for himself; it was really selfless and he thought about it in terms of what would bring the best result for the most people. Brian came from a well-to-do family and could have done anything with the remaining years of his life; he didn't have to take on AIDS activism but, at great personal cost, he did.

One thing that will always stand out in my mind: When the first protease inhibitor trials were coming to Canada, the drug companies were not prepared to give any compassionate access to the trial. Brian held out, saying, "you can't bring these trials to this country unless you help out those who are really sick." He withstood some criticism at the time for what he did, but ultimately the companies did allow compassionate access and this became the gateway for all the compassionate

access programs that all the drug companies then put in place. That saved a lot of lives because protease inhibitors turned out to be so important to our treatment and survival.

Toward the end of his life Brian became blind with CMV and was very fragile, but he still travelled to conferences and speaking engagements, dragging an IV pole around with him. He gave this community everything he had. He sacrificed his own health and survival for the rest of us. And he was egalitarian—he didn't make distinctions between different groups of people with this disease. It didn't matter if you were a gay man or a woman or whoever you were, the important thing was your compassion and commitment to this cause.

Underneath Brian's businesslike demeanor and reserve was a great humanitarian and a selfless, compassionate human being who would go to any lengths to help people in need. My admiration for him is profound.

GOGO BOUKAR, 46

Ottawa

HIV+ since: 1997

My AIDS icon is a man called **Jean Marie**. I met him at the AIDS Committee of Ottawa when I was seeking support there. He was a handsome, elegant and alluring man. Jean Marie was proud of who he was and where he came from.

Jean Marie was a black HIV-positive gay man who experienced three-dimensional discrimination. Despite his situation, he never stopped fighting for his rights as a human being—he fought until his last breath. I consider him my icon because he showed me that no matter how much I can contribute, it will make a difference in someone's life.

Jean Marie told me, "Don't let my story be forgotten. You are a witness to how I was treated. Please tell the world what happened and that no one deserves to be discriminated against that way." He said that no one should have to suffer the way he did and that I have to remember that, so his pain wouldn't be in vain. From that day, I said to myself that Jean Marie's voice

would be heard through mine until my last breath.

Jean Marie's personality and his experience shape the way I advocate and stand up for people who are voiceless. He made me believe in my strength. If the work that I do won't ease people's pain and make their lives a little better, I have to stop and ask myself what I should do to make it right.

I am deeply sorry that I didn't have enough resources to help Jean Marie. I am sorry that I did not have more courage to fight hard for him. I am sorry that I didn't scream on the top of Parliament Hill so the decision-makers would listen. I am sorry that he had to endure all of those injustices. I am sorry that nobody cared enough for him because of what he represented. I am sorry that I didn't have the power to make decisions about health equity for all people, no matter where they come from or what their social status, gender or sexual orientation.

Although Jean Marie is not here today, he is remembered all the time because his legacy is the work that I and so many others are doing today.



DEBORAH NORRIS, 55

Edmonton

HIV+ since: 1991

There is one group of people that stands out in my mind as my icons in the HIV movement: Living Positive's **Edmonton Persons Living with HIV Society**. It was my lifeline when I was diagnosed.

I will never forget walking into one of their Monday night support groups in 1992 and being overwhelmed by

the joy and fun and compassion in the room. For the first time since being diagnosed, I felt like I was going to be OK. Sure, there were people there who were very sick, and there were limited treatment options—we only had AZT back then. But in spite of the fact that many people—our friends—were dying, we were there for each other. And not willing to give up.

There were activists like Dana King, one of the founders of Living Positive, who died in 1992; Ken Ward, who fights to this day for the care and support of Aboriginal people with HIV; Wayne, Maggie, Jim, Sherry, Chance, Cornie—the list is long—all people who showed me that it is possible to *live* with this disease and that if I fought for my life, I'd be OK. They taught me to question everything and to stand up for myself. They were, and are, HIV warriors. They fought—and some continue to fight—against the stigma and discrimination that continues to be leveled at people living with HIV.

I am fortunate to have had such strong mentors in my life and I credit them for my being alive today. I carry on their example by continuing to educate people about HIV and reduce stigma by speaking out. Their legacies live on.

BRUNO L., 31

Montreal

HIV+ since: 2002

It may not be very original, but my AIDS icons are **Bernard Hirschel** and the **Swiss Federal AIDS Commission**, which took a position in 2008 about the minimal risk of HIV transmission associated with an undetectable viral load.

Before 2008, I was afraid of starting antiretroviral therapy for various reasons: the cost, the fear of forgetting to take my meds, side effects, long-term problems related to travelling. Hirschel's announcement transformed my relationship not only with the medication (by helping me see it as a positive part of my life) but also with my body. Finally there was room to think of something other than the virus.

If I had the chance to meet him, I would want to thank him. I would say: Thanks to your research, I now have greater control over my life. Mainly, I feel that this knowledge allows me to reverse the power relationship and vulnerability I feel when disclosing to an HIV-negative partner. If I am rejected because of another's ignorance or fear, I can tell myself that I'm not the one who missed out. On the contrary, my self-knowledge allows me to experience relationships that are ultimately far more satisfying.



SANDY LAMBERT, 54

Vancouver

HIV+ since: 1998

My AIDS heroes are the **warriors** who have gone before us and the warriors on the ground who are now doing the work. The warriors who have left us, who died of AIDS and have gone into the spirit world, are the ones we can't forget. They are the ones who came before us and they had struggles like we do. When I have meetings, I usually invite them in to give me some guidance.

The warriors on the ground are all across Canada. They are living with HIV and doing very difficult, groundbreaking work—in education, HIV awareness, being the guinea pigs, trying out new drugs, fighting stigma and discrimination. Many of the warriors come from remote communities and are still dealing with that stigma.

All of the warriors have affected me. In the Aboriginal community, we're family. If I'm in Vancouver and another warrior is in Iqaluit, we still support each other, even if we're strangers.

I am one of the warriors. +



Standing Strong

20 years after HIV pulled her life off-course, Kath Webster feels more anchored than ever before.

PHOTOGRAPH BY KAMIL BIALOUS

I never went for an HIV test. All I wanted that day back in 1995 was to donate blood to the Red Cross. Instead, a week later I received the diagnosis from my doctor. I was shocked: “HIV? What are you talking about? I’m a lesbian! Lesbians don’t get HIV!” Well, as I learned, some of us do.

At first, I was completely baffled as I had been in a monogamous relationship for seven years (my partner tested negative shortly afterwards). I racked my brain to try to make sense of it: Was it that blood product I had received in Lesotho, Africa, in the 1980s? Or the one time I had sex with a man while there? Ultimately, how I got it doesn’t matter; it was what it was and I had to accept it.

Today, at age 50, after nearly two decades of life with HIV, I feel strong, optimistic and more anchored than perhaps ever before. But it hasn’t always been this way. I’ve worked hard to get where I am since that day when HIV first pulled my life off-course, sending me downstream into unknown waters.

The first few years following my diagnosis were about keeping my head above water as my CD4 count hit rock bottom and my health declined

quickly. I developed MAC (*Mycobacterium avium* complex, a life-threatening infection that can affect people with severely suppressed immune systems) and severe wasting syndrome, which resulted in a feeding tube to my stomach that may well have saved my life.

Right from the start, I felt an urgent need for support from other people living with HIV. The HIV-positive gay men’s community in Vancouver welcomed me with open arms. Back then I often felt more kinship with my queer poz brothers than with the predominantly straight community of HIV-positive women. Although that support was invaluable, I still often felt alone. Queer women were few and far between in the HIV community and I was the only woman with HIV I knew in my own lesbian circle, so I didn’t feel completely at home in either.

In 1997, once I was well enough, I travelled to a women’s HIV retreat near San Francisco, where I happily met at least a dozen dykes with HIV. This was important in those early days to affirm my identity as an HIV-positive lesbian. Today my community of support has evolved into a rich blend of wonderful people from all orientations and backgrounds. Support from others living with HIV has been key to helping me cope and feel more anchored.

But following my diagnosis back in ’95, I was anything but anchored. Anxiety burst to the surface and I was engulfed by fear. I had trouble sleeping, eating and focusing. And then there were the panic attacks. My anxiety was about more than HIV. Some of it stemmed from long ago. When I was four years old, my brothers and I experienced the sudden violent death of both of our parents. My deep grief has been a part of my emotional fabric ever since. It became lodged within me and I have had to continually find healthy ways to address it.

I’ve come to realize that—contrary to the old adage—time does not heal all. The passing of time definitely helps, but I have had to continually work hard to overcome anxiety and maintain a sense that I can handle what may come my way. For years, this sense of confidence was elusive, or tentative at best. The idea of losing grasp of my ability to cope still terrifies me, but I’m finally learning to trust myself.

The anxiety brought on by HIV propelled me to do much healing work. Along with therapy, spending time in nature, doing yoga, reiki and meditation have all helped me immensely. I learned firsthand that it’s not just what happens to us that counts but also, and perhaps even more importantly our *response* to what happens.

I wouldn’t go so far to say that HIV has been a gift, but the healing and lessons I have received certainly are. Ironically, in order to feel grounded, I’ve learned that I need to feel OK letting go and accepting life’s uncertainties. So I strive to go with the flow and accept that I can’t always control what will happen next.

As my overall health improved, I began venturing outside the comfort zone of the HIV community more often and increasingly found myself in situations where I had to decide if and how to disclose my HIV status to others.

A few years ago, when I was single for the first time since being diagnosed and was considering dating, I asked my friend Eve hypothetically if

she would ever date a woman who is HIV positive. In her brutally blunt way, she quickly said no.

“Why not?!” I shrieked. “Worried you’ll get it?”

“No, because I want to grow *old* with someone.” At first I felt discouraged and deflated, but I quickly realized that was ridiculous. For starters, with proper treatment, people with HIV can, and do, grow old. Plus, how could Eve ever know for sure how long she or anyone else would live?

So I forged ahead and tried online dating. I struggled with knowing when to disclose my status. In my personal ad? No. When emailing back and forth? No. During the first coffee date? No. On our second date, when walking around the Seawall? That didn’t feel right either. It seemed there was never a good time to disclose.

A wise friend said, “Kath, you want to find someone who sees HIV as an asset, not a strike against you.” That seemed like a stretch, but how about someone who completely accepts it? Someone who sees HIV as a challenge I have met, that has strengthened me. I had the simple yet powerful realization that if someone doesn’t want to be with me because I’m HIV positive, they are clearly not the one for me. HIV would help weed them out!

Ultimately, I had great success in my quest for love and I have been happily partnered for the past two years. Ironically, I didn’t need to disclose my status to Laura, who has worked in the HIV field for many years and already knew my status. A mutual friend who thought we would be a good match set us up on a date, and the rest is history. We now have plans to share a home.

I no longer need to worry about how to disclose my status to a prospective partner, but figuring out if and how I want to tell people I meet in my day-to-day life still occasionally poses a challenge. The typical small-talk question “what do you do?” can catch me off guard. I don’t have a stock answer like “nurse” or “bus driver.” And I don’t like the sound of “I’m on long-term disability” because it doesn’t reflect my life. So I refer to some aspect of my

Whether I disclose or not, I try to remember my mantra: “What others think of me is none of my business.”

vibrant volunteer career instead: “I do HIV community-based research.”

If the person I’m talking to probes further (“how did you get into that?”), I never know what’s going to come out of my mouth. Sometimes it’s full and confident disclosure: “I’m very well qualified. In fact, I’m HIV positive.” Or, if I’m feeling cheeky: “Well, you see, I have a touch of AIDS.” Other times, for whatever reason, I want nothing more than to change the subject: “Isn’t this chipotle bean dip *incredible*?”

Whether I disclose or not, I try to remember my mantra: “What others think of me is none of my business.”

In addition to figuring out disclosure, seeking the support of fellow PHAs and benefitting from the many wonderful services out there, an invaluable anchor has been my active engagement in the HIV community. Not long after I was diagnosed, I realized that I didn’t want to simply receive services, I wanted to help deliver them, too.

So I started facilitating HIV treatment workshops and teaching people leadership skills. Over the years, I have at times been overwhelmed by the opportunities that have piled up—requests to speak publicly, sit on committees, present at conferences and take paid jobs. Many of them pique my interest but I continually strive to maintain a balance between my

volunteer work and my self-care, keeping in mind that the latter is essential. Staying healthy with HIV is definitely about more than taking medication—it requires a commitment to putting my health at the top of the priority list. So now when someone calls to ask if I’d like to get involved in an exciting new project, I take a careful look at the stress/joy ratio before jumping in.

I’m currently involved with a community-based research project, the CHIWOS study, investigating the healthcare needs of women living with HIV in Canada. And I work with the Positive Leadership Development Institute, helping people with HIV explore their personal values, build community awareness and develop their skills. Witnessing participants gain confidence and ultimately step into leadership roles in their community inspires me.

Last December I attended a holiday dinner organized by Positive Living BC, along with about 150 people with HIV, mostly gay men in their 60s. A feeling of warmth came over me as I looked around the room and recognized many of the wonderful men who had buoyed me when I was newly diagnosed. All those years ago, I was often the only woman in a sea of gay men—at retreats, acupuncture groups, tai chi classes.... Many of us had witnessed each other’s physical decline and likely imminent death. In the throes of AIDS, we had bonded together and fought for our lives. And nearly two decades later, here we were, still kicking—grey hair and all! It was a bittersweet moment that I couldn’t have imagined in 1995 when I was only able to look a few months or even weeks ahead. Who would have thought we’d be sitting here in a room full of HIV-positive seniors?

If I had to get a life-threatening illness, I definitely got the best one. The HIV community is dynamic, political, engaging, fun, and full of smart and fascinating people from all walks of life. Even if I wasn’t HIV positive, I would want to be a part of it. +

Take a Load ff

9 tips for how to stress less.

A stress epidemic seems to have swept across the country: According to Statistics Canada, nearly 1 in 4 Canadians report that most days are quite or extremely stressful. And an HIV diagnosis can bring with it its own set of stressors—you might be dealing with health concerns or stigma, or maybe you're biting your nails over how you're going to tell your loved ones that you're HIV positive... All of these things can ratchet up a person's stress level.

If the source of your stress is something you have control over, addressing it is obviously key. But while you work through those bigger issues, here are some things you can do to lower your stress levels now:



1 Breathe.

Concentrate on taking slow, steady breaths. Breathe in to the count of four, pause, and breathe out to the count of four. Repeat. Find some time every day to focus on your breathing and slow it down.

2 Relax. Tense up each muscle in your body, one at a time, then release it to see how a relaxed muscle feels. Taking a hot bath with aromatherapy oils or Epsom salts or getting massages can also relax your muscles.

3 Laugh.

Studies show that laughter reduces stress. Watch your favourite comedian or a silly movie that will make you split your sides laughing.



4 Appreciate the good things.

Every day, count five things in your life that you are grateful for. Practicing gratitude can help you cultivate a positive outlook.

5 Talk about it. Keeping your fears bottled up makes them worse; getting them off your chest can be surprisingly cathartic. Find a friend, a group, a counsellor or an Elder you can talk to about your fears and worries. You might find that “talking it out” in a journal can also help you gain perspective and release tension.

6 Learn about stress reduction.

There are many complementary therapies that involve teaching people about relaxation and stress reduction. Some AIDS service organizations offer free massage, yoga and meditation classes.



7 Exercise.

Regular physical activity improves not just your physical health but also your emotional well-being, and can be a great stress reliever. Joining an exercise group, dance class or gym can also reduce loneliness by connecting you with a community of people.

8 Concentrate on one thing at a time.

For example, when you are out for a walk, turn off your cell phone and focus instead on the sights, sounds and smells around you.

9 Live in the here and now. Life with HIV can be all about living in the past with regrets or in the future with worry about what lies ahead. Find some time every day to try to let go of both the past and the future and to live in the moment. +

Someone Who's Sailed the Same Seas



Logan Broecker reports on peer programs that help PHAs navigate HIV and HIV care.

ILLUSTRATIONS BY IAN PHILLIPS

When **Matthew Beasley** was diagnosed with HIV in 2012, he had many questions about the illness and needed support. “I didn’t know what a CD4 cell was. I didn’t know what ‘viral load’ or ‘undetectable’ meant,” says the 32-year-old graduate psychology student from Vancouver. And Beasley isn’t alone. Most people newly diagnosed with HIV face a steep learning curve: There’s much to know about the virus, treatment, how to disclose, how to stay healthy, safer sex and self-acceptance. Who better to help than someone who has sailed the same waters?

The nurse who diagnosed Beasley did what most diagnosing clinicians in Vancouver now do: He told Beasley about **Peer Navigator Services**, a program of Positive Living B.C. The program—the first of its kind in Canada—pairs people who are newly diagnosed, or who were diagnosed a while back but haven’t been linked to services for some time, with peer navigators. Peer navigators are HIV-positive individuals who have been trained to make information about HIV, treatment and other related health issues easier for clients to understand. They’ve also been trained to provide emotional support and help the person they’re paired with to navigate a healthcare system that can be bureaucratic, fragmented and overwhelming.

“I was shy going in there...a little nervous,” says Beasley about his first meeting with his peer navigator. But he knew from his experience as a recovering addict how beneficial it can be to talk to somebody about his concerns. For Beasley,

being able to interact with someone with HIV who was living a full and healthy life was critical to his own self-acceptance and to how he viewed his future. “I didn’t have to live in the closet about being HIV positive,” he says. “It helped confirm for me that HIV wasn’t going to be a crippling disability.”

Peer navigation gets at the heart of what a person living with HIV needs when engaging in care: someone who knows what you are going through and can walk alongside you through the process. This relationship has had the effect of providing invaluable support to clients, as well as the unintended consequence of benefitting navigators, too.

Nicole Bachynski, who coordinated a peer navigator program in Regina, says that for clients, having a peer makes the whole process of getting healthcare a bit more comfortable and less daunting. “To have that peer beside them, walking them through what can be a scary experience, can be critical.”

Peer support in one form or another has probably been around forever. Peer navigator programs (a formalized version of that relationship) have their roots outside of HIV. One of the first comprehensive programs was introduced in 1990 at the Harlem Hospital Center in New York City by Dr. Harold Freeman. The program was developed to improve breast cancer screening and diagnosis rates among low-income, mostly black, women who were more



likely to receive late cancer diagnoses and inferior health-care. The impact was dramatic: As a result of the hospital's patient navigator services and other factors, the likelihood of breast cancer patients being alive five years after their diagnosis increased from 39 to 70 percent.

Since then, similar programs have been established to improve the health and wellness of clients and patients in other areas: mental health, diabetes care, palliative care, treatment for substance use—and HIV care.

Canada currently has three comprehensive HIV peer navigator programs. In addition to the program at Positive Living B.C., the **Peer-to-Peer Program** in Regina provides peer support for people living with HIV in Saskatchewan, and at **ASK Wellness** in Kamloops, BC, peers (and HIV-negative social workers) provide navigation services to people living with HIV, hepatitis C and other chronic conditions.

Peer support has been a mainstay of HIV work since the beginning of the epidemic, and HIV peer navigator programs are built on that long history. They provide the added

benefit of being integrated in the healthcare system, making it more accessible for people with HIV. Another major difference is that peer navigators are paid—for some, it's their full-time job.

Peer navigator programs are built on the premise that people living with HIV have the best understanding of what it means to live with HIV. Peers (sometimes called navigators or mentors) use their lived experience to support and counsel other people living with HIV. What this looks like for each client varies: Some clients need someone to talk to. Others need a navigator to help them find a doctor, accompany them to their medical appointments or advocate on their behalf.

We know that a lot of people living with HIV could use some extra help navigating what can sometimes be a complex and unfriendly healthcare system. Somewhere between being diagnosed and receiving effective treatment,

many people living with HIV stop seeking regular care. There are many reasons for this. Some are personal—for example, someone who feels healthy might not want to see a doctor and be reminded of their status, or an individual from a small community may worry about their family and friends discovering their status. And some of the reasons are structural—such as a lack of stable housing or health-care that doesn't accommodate the needs of newcomers and people with limited literacy. When people are dealing with pressing issues in their lives, their health can sometimes take a back seat.

Statistics confirm that a significant portion of people diagnosed with HIV are falling through the cracks. If we take a basic measure of the success of HIV care (by no means the only or best measure), in the United States only about 25 percent of people living with HIV have an undetectable viral load. This indicates that there are serious gaps in HIV services. In British Columbia—the only Canadian province that has published comparable numbers—about 34 percent of people living with HIV have an undetectable viral load. We know that many people are not linked to care, and some are linked to care but don't continue to receive the care and support they need.

Glen Bradford, who coordinates Peer Navigation Services in Vancouver, notes that getting people from diagnosis to care can be challenging. When Peer Navigation Services was started in 2010, the average time between a person's diagnosis and their entry into care was three years. "People were out there spiraling on their own," he says, but "the emergence of peer navigation services in Vancouver helped reduce the time between diagnosis and entry into care from three years to three weeks."

When asked about the program's other successes, Bradford laughs and says: "Are you ready?"

The list is impressive for a program that's a little over three years old: more than 300 clients; nine full-time and part-time navigators who serve a diverse client population; people getting the care they need faster; more people on treatment; a satellite office for peer navigators at St. Paul's Hospital, so clients can drop in on a navigator whenever they need one; and fewer silos between clinics and community organizations like Positive Living B.C., which means that clients have better access to more services.

For clients, having a peer navigator means they have access to someone who can relate to what they are going through. Like their clients, many navigators have struggled or may still be struggling with addiction and recovery, mental illness, stigma, disclosure, homophobia and feelings of isolation or uprootedness. This allows them to empathize with clients and offer practical advice based on their lived experience. This can alleviate some of the stress of getting a diagnosis or starting treatment and makes people feel less isolated.

Having a person who can model good spiritual, emotional and physical health can make a world of difference.

"My navigator was someone who was very physically and socially active," Beasley says. "It helped me to see a really healthy person sitting across from me talking about his own experience being diagnosed and navigating the health-care system."

As a client, Beasley received one-on-one counselling and learned about the basics of HIV as well as the impact that treatment could have on his physical health. He was also connected to alternative health services—massage, acupuncture and reiki—to help with his emotional and spiritual health, and to social groups like Suits, a dinner group for poz gay men in Vancouver.

Peer navigator programs such as the ones in Vancouver, Regina and Kamloops are designed to strengthen the confidence and ability of clients to manage their own care. Ultimately, the goal is to improve clients' health, appointment attendance and adherence to medications.

Instead of delivering one-size-fits-all solutions, support is tailored to the needs of each client. A care plan is developed based on what the individual sees as their priorities. Navigators are there to help clients reduce the barriers that many people living with HIV face when seeking healthcare—no barrier is too small or too large. Many people living with HIV, like Beasley, need basic information about HIV, treatment and the supports that exist in the community. Others need more intensive, long-term support—finding housing, dealing with substance use or mental health issues. Newcomers, people who speak English as a second language and people with literacy challenges often face a plethora of linguistic and literacy barriers. In a nod to Vancouver's ethnic and linguistic diversity, Peer Navigation Services employs one peer who speaks five languages. This has reduced barriers for clients who speak English as a second language.

Bradford says that a lot of people mistrust the healthcare system: "They want their healthcare provider to give them treatment information, but they don't necessarily trust that it's going to work." That's where the navigators come in. Clients "need to hear it from someone else: 'Yes, HIV really is different now. The meds are better. You will live a longer life.'"

Though the successes and benefits are undeniable, these programs are not without their challenges. For one, they require ongoing funding and resources, and enough navigators to meet the demand. This may explain why there are so few such programs in Canada despite their benefits. Also, it can take time to build trust and foster open communication between clinicians and peers, especially in situations where a peer is also a patient of the healthcare provider with whom they are working.

Bachynski, former coordinator of the peer navigator program in Regina, can attest to that. "Some of the mentors have had conflicts with clinic staff in the past, so for both the mentor and the staff, there can be hard feelings." But Bachynski says that having navigators on-site some days to provide drop-in services for clients helps both navigators and clinicians see the navigators as professionals.



HIV peer programs

People living with HIV were some of the first people to provide support services to others living with the virus. Here's a roundup of some of the peer programs that help people with HIV navigate treatment and care.

PEER NAVIGATION PROGRAMS

Peer Navigator Services

Positive Living B.C., Vancouver

604.908.7710

www.positivelivingbc.org/services/peer-navigator-services

Peer-to-Peer

Regina Qu'Appelle Health Region, SK

306.766.6727/306.766.6883

Chronic Health Navigation Program

AIDS Society of Kamloops (ASK), BC

250.376.7558 ext.232

www.askwellness.ca

Maintaining good self-care is also a constant challenge for peers. Gloria Tremblay, an HIV-positive woman in her 70s who mentors at the Regina program, says that one of the biggest lessons she's learned in her work is that "you can't help someone if you don't take care of yourself." For Tremblay, that means spending time with family, volunteering in her daughter's French immersion class and making sure she always looks as good as she can when she leaves the house. Glen Bradford echoes Tremblay's belief that peers need to take care of themselves. "Peers give it their all to help others," he says. "They'll sacrifice their own well-being to help."

For the first while after his diagnosis, Beasley met with his navigator weekly, but, he says, "it pretty quickly became a check-in once every few weeks. And then I became a peer navigator myself." Both the Vancouver and Regina programs have seen former clients graduate to become peer navigators. "Because [my diagnosis] is pretty new for me," Beasley says, "I have a lot of empathy for others who are newly diagnosed. It's still fresh in my mind—what it's like to get the news, what it's like to tell friends and family and people you're dating."

Although Canada's HIV navigator programs were established to help clients improve their lives, one of the unintended consequences has been that they help navigators, too. Beasley became a peer navigator to give back to a

Peer support takes different forms in other parts of the country:

My Life with HIV

AIDS Community Care Montreal

A 6-session workshop for people who are newly diagnosed, treatment-naïve or having trouble staying on treatment. This treatment-readiness program is developed and delivered by PHAs, for PHAs.

514.527.0928

[email: treatment@accmontreal.org](mailto:treatment@accmontreal.org)

Peer-Supported Treatment Decisions

Toronto People with AIDS Foundation

HIV-positive gay men are paired up with other gay men living with HIV for one-on-one counselling. Over the course of 4 sessions, motivational interviewing is used to help clients prepare for treatment, adhere to their medications and improve their health outcomes.

Circle of Care Peer Support

Toronto People with AIDS Foundation

A peer support program that helps women with HIV navigate social services, accompanies them to appointments, offers interpretation services and other supports. www.pwatoronto.org

If you know of other HIV peer navigator programs in Canada, please share them with us: contribute@positiveside.ca

Unfortunately, peer navigation is not available in many parts of the country. If you are looking for information or support, call CATIE's toll-free line at 1.800.263.1638. Your call will be treated as private and confidential. You can also check out our many resources on living with HIV, starting treatment and emotional wellness at www.catie.ca

program that he says helped him immensely. But he found that in his role as navigator, the program continued to help him: "Just being able to see other people live healthily with HIV helps me on my journey of self-acceptance."

Tremblay says she gives a lot to the Peer-to-Peer Program. She pauses and then adds: "But I think I am getting even more. That's what keeps me going. I think I'm getting more than I am giving and I'm giving 150 percent." +

Logan Broeckert is a researcher/writer at CATIE. Before joining CATIE, Logan worked on research and knowledge exchange projects for the Canadian AIDS Society and the Ontario Public Health Association.



In Your Face

AIDS Posters Confront Stigma

BY DARIEN TAYLOR



In

the late 1980s, AIDS activist groups, like AIDS ACTION NOW! here in Canada and ACT-UP (the AIDS Coalition to Unleash Power) in the United States, mounted powerful protests against institutional responses to the AIDS crisis. They confronted political indifference and demanded that governments and pharmaceutical companies take action against an epidemic that was killing people. Activists took their provocative messages to the streets with bold graphic posters, creating images that are indelibly linked to our understanding of AIDS and our memories of the urban landscape of that time.

While the heyday of confrontational demonstrations and direct action campaigns—and their associated in-your-face graphics and AIDS posters—may be largely over, campaigns continue to educate people about HIV and work to

eliminate stigma and prejudice. For example, AIDS ACTION NOW!'s recent and acclaimed Postervirus project (postervirus.tumblr.com) challenges the judgment, marginalization and criminalization of people with HIV and urges people to **"Look After Each Other."**

Early political postering

AIDS first made headlines in 1981. In North America, the '80s was a decade ruled by a right-wing agenda. U.S. president Ronald Reagan was silent about AIDS, AIDS research went unfunded, and AIDS was seen by many as "God's punishment against gays." AIDS education campaigns that were deemed to "encourage or promote homosexual activity" were prohibited.

ACT-UP responded, creating chapters throughout the United States. ACT-UP New York, at the centre of the epidemic, became a master of media manipulation. Its propaganda arm, Gran Fury, a collective of artist-activists, sought to retaliate against the institutions and individuals responsible for making people with HIV invisible and the AIDS catastrophe negligible. In a 1987 poster by Gran Fury member Donald Moffett, the words **"He Kills Me"** appear over a photo of an amused-looking Ronald Reagan. 1987 was the year that Reagan, after years of silence, publically uttered the word AIDS for the first time. By then, nearly 60,000 Americans had already been diagnosed with AIDS and half had died of the disease.

Two years later, the poster **"Kissing Doesn't Kill: Greed and Indifference Do"** was, in the words of member Tom Kalin, Gran Fury's first "high-stakes opportunity." It consisted of a video campaign and mass mailing of postcards, along with large posters on the sides of city buses in New York City, Chicago, Washington, DC and San Francisco. Exploiting the look of popular Benetton ads of the time, the campaign featured three couples of various races and sexual identities, playfully kissing. The flipside of the postcard read: **"Corporate Greed, Government Inaction and Public Indifference Make AIDS a Political Crisis."**

Like many early AIDS groups, ACT-UP did not let a lack of resources stop them from shining a light on the inadequate response to this public health catastrophe. Gran Fury strategically combined the approaches of the media and advertising worlds, aimed at reaching a broad audience, with their own targeted political messages. Papering New York City with their sexy, angry, provocative posters, they used images and guerrilla dissemination tactics that other activist groups like Canada's AIDS ACTION NOW! would later adopt. Member Loring McAlpin reflected in a 2003 interview that Gran Fury's goal was to "drive a wedge into public discourse and open a space where AIDS could be talked about in all its dimensions." They succeeded.



GRAN FURY, "KISSING DOESN'T KILL," 1989. COURTESY OF CREATIVE TIME

© DONALD MOFFETT, 1987. COURTESY OF THE ARTIST AND MARIANNE BOESKY GALLERY, NEW YORK

An AIDS poster for everyone

Using a palette of bold colours and simple, almost child-like images of urban street life, artist Keith Haring also put his prodigious talents to work, creating the graffiti-influenced poster “**Ignorance = Fear, Silence = Death.**” This poster borrows and bends the traditional Japanese imagery of the wise monkeys who hear, see and speak no evil. (AIDS ACTION NOW! would later use this imagery in a 1996 poster campaign calling for a national AIDS strategy from then-Prime Minister Jean Chrétien.)

Whereas Gran Fury’s messages were angry and political, Haring’s style was so joyful and celebratory that it seemed at odds with the message. While Gran Fury’s message and tactics appealed to the activist, Haring’s spoke to the masses. Referencing break-dancing, comic books and hip hop culture, Haring’s famous poster is accessible and easily reproduced. In fact, Haring encouraged the reproduction and dissemination of his work, first through promotional giveaways and then by creating the Pop Shop, in New York’s Soho neighbourhood, where T-shirts, buttons, posters and other items were sold.

Haring’s work has been criticized for its mass appeal. Nonetheless, it brought issues of drug use, AIDS and sexuality into popular consciousness during a politically repressive time. Diagnosed with AIDS in 1988, Haring died in 1990.

Turning point

When protease inhibitors appeared in the mid-90s, the treatment and lives of people living with HIV were transformed, and the visibility of the AIDS crisis faded. For many of those left standing, adrenaline dissipated in burnout and exhaustion. The often politically charged activist campaigns of the ’80s and early ’90s largely gave way to tools of AIDS awareness and promoting access to social services.

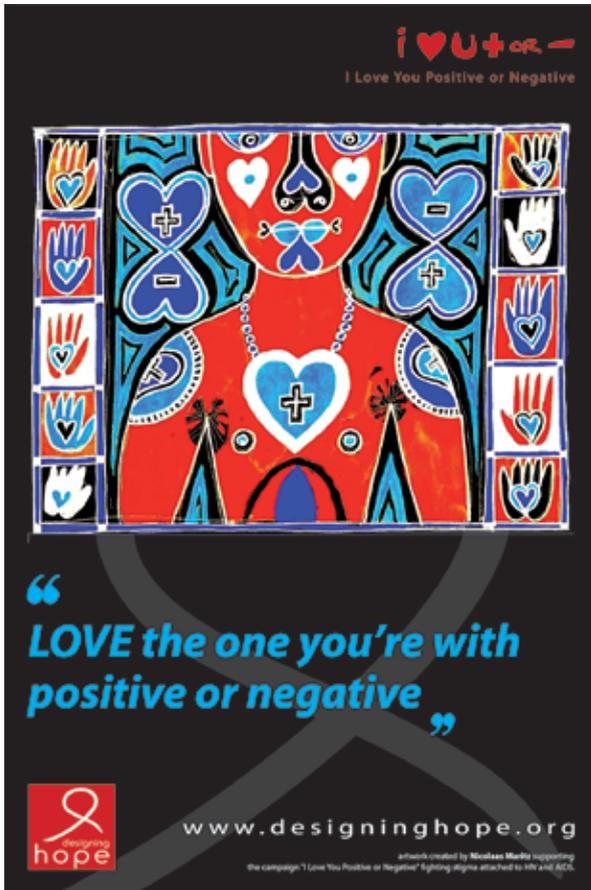
But the AIDS crisis has not been resolved. And AIDS posters continue to be used as tools for education and anti-stigma work. Today, in industrialized countries, AIDS posters often act as tangible, real-world conductors to the virtual world of online technologies.

A savvy anti-stigma campaign by COCQ-SIDA, a Quebec coalition of community organizations, illustrates this point. Based on a highly successful campaign by the French organization AIDES, the 2013 campaign features Quebecers who live proudly with HIV, such as Emelyne, an articulate and composed young African woman who works in a Montreal drug prevention program and attends school at night. These vibrant individuals talk about their lives, their



dreams and the ways in which they contribute to their communities. Each concludes: “*C’est le sida qu’il faut exclure, pas les séropositifs*” (“It’s HIV that needs to be excluded, not the people living with it”).

With their messages of inclusion and respect for people living with HIV, the posters also act as a portal into an innovative online anti-stigma campaign—people can watch videos or download an app to create a personalized poster



What is Stigma?

HIV stigma refers to negative attitudes toward people living with HIV. UN Secretary-General Ban Ki-Moon said: "Stigma is a chief reason why the AIDS epidemic continues to devastate societies around the world."

Just as stigma takes many forms, so do the strategies used to stop it. Here are just a few:

- squashing stereotypes and challenging misinformation
- talking about HIV rather than staying silent
- putting a human face on HIV
- showing that people with HIV are not defined by their serostatus or sexual orientation but are three-dimensional people
- demanding that governments and institutions take action and protect the rights of people with HIV

and message, then share it on Facebook and Twitter, or join an online discussion at www.jesuissero.org.

The struggle continues

Stigma and discrimination continue to take not only a psychological toll on those who live with HIV, but in many countries where HIV is endemic, they are the main barriers

to physical health and well-being. Antiretroviral treatment is now available to many people in most African countries, for example, but the stigma of testing for HIV and acknowledging one's status as HIV positive prevents people from accessing medications that could save their lives and the lives of their children.

Since 2005, the French NGO Dessine l'Espoir (Designing Hope) has led a number of creative initiatives through the UNESCO-sponsored "I Love You, Positive or Negative" campaign, aimed at reducing HIV stigma. Like Quebec's COCQ-SIDA, Designing Hope ties its graphic images by contemporary artists to anti-stigma testimonials from local personalities and to opportunities to initiate dialogue with affected communities. They work predominantly with African communities in France, with children and families in Romania, and in African countries including Burkina Faso, Swaziland, South Africa and Zimbabwe.

In 2011, South African Nicolaas Maritz won Designing Hope's poster competition. Maritz describes the need to speak to a broad spectrum of people: "With more than 111 languages spoken and as many tribes of different ethnic origins, the word 'diverse' doesn't even cover it." Hence, his simple and unthreatening message: **"Love the One You're With, Positive or Negative."**

In an effort to reach out to women, Maritz used colourful visuals inspired by the fabric prints worn by many South African women as well as some men. His vibrant style has been called "ethno-centric punk" for its mixture of traditional, tribal and modern design. Maritz was happy to have his work associated with Designing Hope's anti-stigma work: "It's wonderful when you create something that assists in making change." In addition to posters, his work was featured on condom packages, stickers and tote bags.

Throughout the epidemic and across cultures, posters have played an important role in promoting AIDS awareness and in combatting stigma against people with HIV. Highly politicized messages and graphic images characterized the early response to the AIDS crisis in North America. More than a decade of political activism produced great changes. AIDS generally became less of a guerrilla battleground and more of a scene of aftercare and reintegration. HIV campaigns reflected this new reality, promoting services and HIV awareness. The poster, cheap and locally reproducible, has proven to be highly adaptable and accessible in these changing contexts. In recent years, the poster has forged an important alliance with social media, assuring its continued relevance in years to come. +

Darien Taylor is CATIE's former Director of Program Delivery. She cofounded Voices of Positive Women and is a recipient of the Queen Elizabeth II Diamond Jubilee Medal, awarded to honour significant contributions and achievements by Canadians. Darien has been living with HIV for more than 20 years.

The Push for a Cure

The search for an HIV cure is ramping up. So, just how close are we?
Ann Silversides reports.

ILLUSTRATION BY AARON MCCOMY

Ten years ago, it wasn't getting funded. Sure, there was lots of basic research into HIV—how it mutates, where it hides, why it is so damn elusive and tricky. But funding aimed specifically at finding a cure—a way to clear HIV completely from the body? It just wasn't happening.

Yet we know how badly a cure is needed. Most of the millions of people in the world who are living with the virus aren't getting treatment. And those who are on treatment know the downsides: a lifetime of drug-taking, side effects, the risk of long-term negative health consequences, not to mention the stigma still attached to being HIV positive.

The good news is that there's a relatively new concerted global push to search for a cure. For example, the International AIDS Society (IAS) convened a global scientific conference in 2013 to focus more attention and energy on cure research. "Towards an HIV cure: people focused, science driven" was the slogan for the IAS effort.

Late last year, Canada joined the international effort. Two Canadian teams were awarded \$10.7 million from the Canadian Institutes for Health Research (CIHR) and the Canadian Foundation for AIDS Research (CANFAR). This will fund research over five years in key areas related to a basic understanding of the human immune system, how the virus persists and what might be done to stop it.

One of the teams, led by Montreal microbiologist Eric Cohen, will research a particular group of immune system cells, their role as reservoirs for HIV and (it is hoped) strategies to eliminate the virus from these reservoirs. The other team, led by fellow Montreal microbiologist Hugo Soudeyns, will be examining the medical profiles of Canadian children now on HIV treatment for clues about how these children might live well without lifelong treatment.

"This research is not about stabilizing HIV at a low level through treatment," emphasizes Marc Ouellette, scientific director of the CIHR's Institute of Infection and Immunity.

"It is about getting rid of the virus completely, or at least controlling it without the need for daily treatment."

Community advocates—people who are HIV positive and belong to the communities that will be directly impacted by the research—sit alongside Ouellette as members of the CIHR HIV/AIDS Research Advisory Committee. The research underway will involve translating the knowledge into clinical and/or commercial applications, the committee decreed. Both research teams hope to hold community forums to share their findings.

WHY NOW?

Why all this excitement about a cure for HIV now? What's changed is that a body of scientific knowledge has accumulated that makes it possible to organize research for a cure, says Robert Reinhard, the community representative on the steering committee for Cohen's research team.

That body of knowledge includes the examples of very unusual experiences that a few HIV-positive people have had before and after stopping antiretroviral therapy (ART) and at least two documented cases of individuals who no longer take ART being effectively "cured" of HIV. One, known as "the Berlin patient," has had HIV eradicated from his body. And the other, often referred to as "the Mississippi baby," no longer requires treatment and has experienced no viral rebound so far, though very small amounts of HIV can still be detected in her body (this is known as a "functional cure").

These events are, in everyday language, game-changers. In scientific lingo, they're known as "proof of concept" that a cure is possible.

VISCONTI AND GENE THERAPY

In 2012, hopes for the development of a cure for HIV were raised by the implications of the Visconti Study. By searching several databases, a group of French researchers, led



by Christine Rouzious, was able to find 14 individuals who had started ART very soon after contracting HIV (during primary infection) and then years later, for unknown reasons, stopped treatment. Despite stopping treatment, they had very low levels of HIV—and the virus did not rebound. This raised the hope that a functional cure may be possible.

There have also been small-scale gene therapy trials. These studies usually involve modifying CD4 cells to knock

out a co-receptor needed by HIV to infect these cells. After this modification, the cells are multiplied and then injected into people. So far the results from this mode of intervention have been modest. This therapy needs to be further refined and additional studies are required to demonstrate the safety and efficacy of such a strategy.

But the two most often-cited events that have given rise to this new hope are the cures of the two individuals.

Q+A

Peggy Frank

Do you think we'll find a cure for HIV in your lifetime?

It seems like we're close. And I'm going to live another 40 years, so I do think we'll find a cure in my lifetime.

The worst thing that could happen would be if we in North America become complacent because we can treat and control the virus so well that we forget how important a cure would be for people in those parts of the world where it is still hard to access treatment.

Once we have a cure, we will have millions of people to thank—those who did the research, those who tracked down the dollars, those who acted as guinea pigs...

If we do find a cure, how would it impact your life?

If I was no longer HIV positive, I imagine that I would have more energy to tackle the global issues I'm passionate about. I would love to return to Africa, to work with people whose hope swells seeing others survive AIDS. I would love to set a few new life goals and get out there and break ground. I would take a moment each day to be grateful for what HIV has taught me.

[See Peggy Frank's 7-foot martini glass on page 34.]

BERLIN AND MISSISSIPPI

When the so-called "Berlin Patient," Timothy Brown, went for HIV monitoring tests in 2009, his doctors found no evidence of HIV. Brown had been HIV positive for several years when he developed leukemia. After two bone marrow transplants from a person with a rare form of genetic resistance to HIV, and after chemotherapy and radiation as well as treatment for graft-versus-host disease (when the grafted cells attack the tissues and organs of the graft recipient), the virus was no longer found in Brown's blood. Nor was it found in any of the reservoirs where HIV usually sits dormant, ready to rebound when treatment is ceased. In addition to being cured of his leukemia, Brown became the first person in the world to have HIV eradicated from his body.

Then, in late 2013, it was announced that "the Mississippi baby" may have been "functionally cured" when HIV did not rebound after her treatment stopped. This baby girl was born HIV positive to an HIV-positive mother. Treatment of the infant with ART began 30 hours after birth. About 18 months later, for unknown reasons, the mother stopped her child's HIV treatment. And the child has had no signs of HIV since then. (Her health and HIV status need to be followed closely for any resurgence of HIV.)

More recently, the case of another child who appears to be free of HIV was announced at this year's Conference on Retroviruses and Opportunistic Infections (CROI 2014), though this child is still taking ART. The HIV-positive mother had not taken drugs to prevent transmission, and DNA and RNA of HIV were detected in her infant's blood. Four hours after birth, the infant was treated with potent triple drug therapy, and nine months later no virus can be detected, researchers have reported.

But very clearly, none of these can be considered a recipe for curing HIV. Replicating Brown's medical treatment—which was costly both financially and in terms of the huge toll it took on his health and well-being, not to mention being life-threatening—is by no means a blueprint for the cure of millions of people already infected. And any move to deliberately withdraw treatment from children for the purposes of research would require extremely careful ethical scrutiny and medical attention. Nevertheless, the findings are hopeful.

A NOTE OF CAUTION

Sean Hosein, CATIE's science and medicine editor, warns that "it's still early days—these are small steps being taken toward a cure." Scientific research does not always proceed in a straightforward manner. For example, until the advent of effective ART in '96, hopes for effective treatment were regularly raised and dashed. These days, premature news about HIV cure research risks creating a similar emotional rollercoaster for people living with HIV. Overhyping an HIV cure also risks diverting attention away from efforts to make those treatment and prevention strategies that we already have and we know work readily available.

"It's a very big deal" that two Canadian teams have been funded to pursue this type of HIV research, says Robert Reinhard. He warns that a cure is not on the immediate horizon and that continued research into other important areas—such as new treatments, hepatitis co-infections, vaccine research—are no less important than cure research.

As encouraging as these examples are, "nobody knows *why* Timothy Brown or the baby were cured," Reinhard stresses. "We have educated guesses and suspected answers, but nobody knows. We know a couple of things about what are *not* the reasons, because of the Boston patients."

He's referring to an attempt to replicate much of Brown's treatment—bone marrow transplant and chemotherapy—in two people with HIV in Boston who had also developed lymphomas, cancers of the immune system. But the treatment did not have the same results: After HIV therapy was withdrawn, the virus rebounded in both individuals.

Q+A

Robert Reinhard

Do you think we'll find a cure for HIV in your lifetime?

Just as we couldn't foresee that it would take so many years to find an effective vaccine, we can't predict the success of cure research. But we now know a lot about the biological obstacles to eliminating HIV and have strong agendas to attack them. I'm more hopeful than ever before.

If we do find a cure, how would it impact your life?

More than 35 million people worldwide have HIV. While each person would be able to enjoy their right to health and to a good life, the social impacts would be enormous and collective. To quote the poet John Donne: "Every man is a piece of the continent, a part of the main."

Do you think we'll find a cure for HIV in your lifetime?

From an existential perspective, I believe we will. I have to hope. Otherwise it's too difficult for my activist heart to make sense of these past 30 years.

If we do find a cure, how would it impact your life?

Well, it won't bring my dead friends back. And would a cure prevent my dear friends who are very sick right now from dying? It is a certainty that everyone will face death sooner or later (those of us who are HIV-negative too), but a cure would at least level the playing field somewhat.

Once a cure has been found, I imagine it will be like when a war ends: We will be able to count our dead, complete our mourning and wonder why some of us made the cut and others didn't. I think I will finally exhale deeply and deal with whatever waves of deep sadness and rage surface. I will step back and pay careful attention to the memories of the past 30 years, which demand that I stop, reflect, make meaning and find ways to share stories with others who lived through this time. I'll be looking for the legion hall-equivalent for weary AIDS activists!

[See Yvette Perreault's *Ask the Experts* about grief on page 24.]

THE CANADIAN NICHE

Canada has a distinguished history of HIV research, beginning with the development of the antiretroviral drug 3TC and later on with early attempts at cure research. Back in 2005, researchers across Canada attempted to cure HIV infection by adding the anti-seizure drug valproic acid to the regimens of some people who were taking ART. Unfortunately, that attempt did not result in a cure.

Because many studies are investigating the role of CD4 cells as viral reservoirs, Eric Cohen's team is going in another direction—looking at myeloid cells, another type of immune system cell infected by HIV. These cells are found in many tissues, including the testes, brain and guts, where antiretroviral drugs do not penetrate well, explains Cohen, who has conducted research into HIV since 1986. Myeloid cells are more resistant to HIV after they are infected—the virus does not kill them as rapidly as it kills CD4 cells—so they also play a role in HIV reservoirs.

Cohen's team brings together scientists and clinicians from six universities and research centres across the country. The team aims to identify and characterize the properties of these cells in animals and humans; determine the mechanics that govern HIV latency (when HIV-infected cells are “hiding” and not actively reproducing HIV but can be reactivated); develop strategies to eliminate HIV reservoirs; and, eventually, conduct clinical trials to test the effectiveness of strategies.

Soudeyns' team, comprising researchers and doctors who care for HIV-positive children, will be studying the 243 Canadian infants and children who were born with HIV

and are on ART. The effort, called the Canada Child Cohort study, was inspired in large part by the Mississippi baby reports. The team aims to discover if starting ART early can lead to a functional cure, a discovery that would mean “the standard practice for treating children can be changed,” Soudeyns notes.

Like Cohen's team, these researchers will use several different tests to detect and measure HIV that may sit dormant in reservoirs. If no virus is detected, treatment interruption would be discussed—and any decision would be subject to rigorous ethical and informed consent guidelines.

Of the Canadian children being followed, only a handful started ART early—in the case of all these children, therapy was initiated within 72 hours of birth. Most of these children are now school aged.

In Canada few infants are born with HIV—since 2005, fewer than 10 a year, and in 2012, none. These cases are typically the result of the mother not knowing she was HIV positive and not having appropriate prenatal care. The risk of transmitting HIV to an infant is very low—less than 1 percent provided specific steps are taken. (During pregnancy, the mother takes ART to lower her viral load to less than 50 copies/ml and goes for regular checkups. After birth, the baby is given ART for a few weeks and is fed formula rather than breast milk. Once the infant is older, it is important that the mother not pre-chew the child's food.)

The discovery of a functional cure for infants would affect a relatively small proportion of people living with HIV in Canada, but it could have a significant impact internationally, as more than 90 percent of HIV-positive children live in Africa and only a minority have access to ART.

LIGHT AT THE END OF THE TUNNEL

It's been more than 30 years since HIV was isolated by scientists, and at least 35 years since people around the world began dying of a mysterious wasting disease.

The past three decades have been punctuated with news of promising approaches to a cure—most of which have not borne fruit. But knowledge about the virus has been accumulating and scientists who have spent their lives studying HIV are excited about the present state of research.

Although it might not be right around the corner, a cure for HIV seems more and more possible. In fact, what will be needed is likely not a single cure but instead multiple cures. As Reinhard points out, an approach that might work for long-time survivors—people who have been living with HIV and taking treatment for many years—would likely differ significantly from a cure for newborns with HIV or a cure for recently infected adults. +

Ann Silversides is the author of *AIDS Activist: Michael Lynch and the Politics of Community*. She writes regularly about health policy issues and her article “First Do No Harm” in *Maisonneuve* magazine, about a Brockville, Ontario, coroner's inquest into prescription painkiller related deaths, won the Canadian Medical Association award for excellence in in-depth feature reporting.



Learning to Live with Grief

Yvette Perreault explores the impact of HIV-related loss and what helps survivors through their sorrow.

Just as AIDS has challenged us to rethink much about individual and community health, so too has it expanded our understanding of grief. For those of us who are long-term survivors and those of us who have been connected to communities ravaged by AIDS, we may know multiple losses.

While there seem to be certain common responses to death, there are also unique factors associated with HIV-related deaths. The impacts of stigma and discrimination, disenfranchisement, lack of spiritual support, fear of contagion,

multiple losses, illness-related complications and survivor guilt are tremendous.

In our grief, those of us who survive may feel a greater than usual amount of rage, fear, shame, unresolved grief, guilt, helplessness, insecurity, numbness and pessimism. We may be more likely to experience a loss of intimacy. We may develop new physical symptoms or those we already have may worsen. For some of us, grief can affect our will to stay healthy—we may lose the motivation to adhere to HIV treatment and take care of ourselves. To some, these reactions might

be viewed as “symptoms” that signal pathology, but they can also be seen as normal responses to catastrophic events.

At the same time, there are many stories of incredible resilience—of people who are transformed by their loss yet remain steadfast in their determination to continue to love and courageously engage with community. This, too, is part of the legacy of AIDS-related grief.

According to the Public Health Agency of Canada, 76,275 people in Canada have

tested positive for HIV since 1985. And, yes, many are doing just fine. But we also know that at least 14,030 Canadians have reportedly died of AIDS-related causes. And there are others in our communities of people living with HIV who have died from other causes—such as cancer, heart attacks, organ failure and overdoses. With

Many of us find ourselves immersed in what feels like unending waves of loss.

each death, a network of family, friends, colleagues and healthcare providers is left behind to grapple with the impact of loss. Many of us find ourselves immersed in what feels like unending waves of loss. This becomes our new normal: We are challenged to live and cope with our loss, with our altered hopes and dreams.

I asked four people with both professional expertise and lived experience to offer their thoughts on grief and grief support. These individuals know a lot about life and loss—and, I believe, about love.

AL McNUTT

HIV+: 27 years, Chair of the board,
AIDS Coalition of Nova Scotia
Truro, NS

When my partner Gary died 21 years ago, I felt guilty that I was still alive. And I still do. I can tell you exactly what he did before he died. There was a poster from *Longtime Companion* (a movie about the early years of the AIDS epidemic) on the wall, showing a scene where everyone reunites at the end. Gary and I had talked about that scene, about how when he died, everyone in his life would be reunited—his mother, me, Rob and Doug, Ralph and Ian, and his ex-partner John. (From the four couples who spent a lot of time together, I'm the only one left.) Before Gary took his last breath, he looked at me and smiled, touched my cheek, touched the poster, and then stopped breathing.

Initially I didn't feel worthy and took unnecessary risks because I didn't think I mattered. But then I realized that I had to stay healthy to contribute to society. I decided not to give up. Many of us already feel so beat up and are dealing with lots of pain in our lives, but we have to find our own unique ways of moving beyond that pain.

I have to love HIV in order to love myself. It's part of me now. We have to co-exist. It's no longer a loss but an opportunity to live in a fuller, more meaningful way. Life is too short to be dragged down by it all.

As people living with HIV, we have so much to offer. My advice is: Try to step out and face the world head on. Be yourself. Speak out. Your story is valuable. People will listen. Try not to stay in a place of fear. We need you to become the advocates of tomorrow.

Spend time with your photo albums and journals—and keep your vodka and orange juice handy! I have a video of Gary and me line-dancing that I replay, that still makes me cry. I know that pain can stop us from looking back, but the more you visit your story, the more crying you can do and the easier it becomes to remember. Crying is good therapy. It's important to think about our relationships and who we were in those relationships. What we shared with our loved ones matters.

I have Gary's urn on the mantle in my office, so I see him every day, along with my dad's urn and my sister Bonnie's, who died 40 years ago of cancer. Sometimes I look at the stars and wonder if my dad is up there and whether he's found Gary and Bonnie. Pain can be unbearable but facing it gives us our own teachable moments, our own therapy. Talk is also good therapy. We're not so alone in our grief if we can share our stories.

As far as my own death goes, I'm not afraid of dying but I worry about leaving my kids (even though they're now 30 and 34). When they ask, "What are we going to do without you?" I tell them: "Get on with your lives. Carve out your niche in the world. Take on your own advocacy pieces. Never forget the wonderful moments we shared—the hugs, the stories, the laughter....

Those memories are going to keep you going through the hard periods. When my time comes, rejoice in the fact that I've had a wonderful journey."

DR. ALEJANDRO PERALTA

Counsellor, Dr. Peter Centre
Vancouver

I have seen people deal with grief as they live with chronic health challenges and deal with losing loved ones. We learn to deal with loss with the inner capacities, strengths and resilience that we have. Each person has to develop their own grief strategy.

I learned Elizabeth Kübler-Ross' five stages of grief—denial, anger, bargaining, depression and acceptance—but in life, the process isn't linear (nor did Kübler-Ross intend them to be). Whereas my psychotherapy training followed a more classic disease model (crisis intervention and providing support for a brief period, to reach a specific goal), I've learned to focus on where a person is in this moment and help them develop strategies from that place.

At the Dr. Peter Centre, we consciously create community. Giving and getting support is an important part of people's mental health. Professionals and community members alike build relationships and trust. We meet people where they are and accept where they are. We spend time together on a daily basis. We establish stability and work from there. We aren't about "interventions" in a traditional sense. These shared aspects of daily living *are* our "interventions." In this way, relating to your counsellor is not outside of people's day-to-day experience. I go to them, they don't come to me.

Depression is an aspect of grief, and I believe it is part of people's resilience. Losses are something people have to live with and depression is an integral part of letting go. Although doctors sometimes prescribe medications to people who are grieving, I believe that people have to go through this part of the process to get to the crux of their unique situation. People have to relate to all aspects of their physical, emotional, mental and spiritual parts to be well.

Our clinical team gets together at the beginning and end of each day. We discuss the issues that arise and how we are doing. Many of us have a spiritual practice, such as meditation. I practice yoga and Buddhism (even though I was born Catholic) and try not to get stuck in the material world. I lost my mother 20 years ago. You have to live through these losses. I'm concerned that we don't allow ourselves to go through these times with awareness.

I understand my role is to provide companionship to the person I'm lucky to meet. Through that, I, too, mature as a person. My skills and tools are not just my knowledge but my *presence*, my ability to empathize. As I lend you my strength, I need to keep building my own.

WAYNE FITTON

HIV+: 1988, Consultant and ABRPO (AIDS Bereavement and Resiliency Program of Ontario) facilitator
London, Ontario

Grief was a reality for me even before AIDS hit my community. My younger sister died of throat cancer in 1983. I was her primary caregiver for six months after her tongue and the tumour in her neck were removed. I loved her, so I managed my fear and horror. That's when I saw death for the first time. That experience set me up for the waves of AIDS-related deaths that followed.

In 1985, my best friend John was diagnosed with AIDS. He died nine months later. He was sensitive to the fact that my sister had just died but he needed help. He asked me to set up

Grief has become an active part of my identity, not something to recover from.

a care team for him, which I did. As he was dying, he said, "You're good at this, Wayne, and there's going to be a lot more caretaking to do in the community, so three months after I die, I want you to volunteer for a new group starting up, the AIDS Committee of Toronto." So I did.

A year to the day after John died, my friend Barry took his last breath. And on it went for a decade until anti-retrovirals came in.

How did I go from supporting one dying person to the other? I was not afraid to be with the dying. I stayed in my authentic relationship with people as they changed—it was still Karen, it was still John, it was still Barry... My tribe was dying and I had to step in. I could do this because I didn't stay alone. I found places where I could talk and be real. Once I joined the staff at the Toronto People with AIDS Foundation (PWA) and then the AIDS Committee of Toronto (ACT), we had each other as witnesses, we were people "who got it," who knew what it was like in the trenches.

In 1991 I looked at ACT's AIDS stats. We said goodbye to 147 clients that year—15 of whom were my clients. That same year, I also said goodbye to a lover and to my dad. And there was more loss to come. Richard, who was my coworker and became like a younger brother, died. When I was at his funeral crying, I wasn't even sure my tears were for the guy in the casket. That's when I learned that new loss resurrects old losses.

We took time to say goodbye and to go to memorials. We stopped and recognized the presence of death. We created spaces to tell our stories. We learned about sudden temporary

upsurges of grief [see "STUG," left] and respected the power of a grief hit. I longed for a day when I wouldn't be dealing with grief. But that didn't happen. So I became an expert at this thing called grief. Death and grief are now a part of who I am every day.

I appreciate that I am living with loss. I will never "get over it." Grief has become an active part of my identity, not something to recover from. I claim grief as a link to those I've loved and lost. I am not sick or crazy. I honour my grief because I cared about these people.

What has helped me along the way? Theory and language to locate myself have been crucial. Words and concepts to describe what I'm experiencing in my heart and body validate my experiences. I have found ways to express my fear, sadness and rage so I'm not carrying the emotional pain in my body. If I did not attend to my grief in a sustained way, I would have gotten sick.

Long-term survivors like me who lived through the '80s and '90s and watched our worlds implode don't do well in isolation. Many of us are in shock about still being alive, and we need to process our stored-up grief; otherwise it gets in the way. To maintain my health, I need to connect with a network of people who are willing to sit down and explore what our grief looks like.

Develop your own healing process. Find people who can listen and validate you. Don't spend time talking with people who try to "fix you." I continue to do my personal work so I can sit well with others. Newly bereaved people need healthy role models and mentors more than they need therapy.

BETTY ANN RUTLEDGE

Volunteer Outreach and Training,
Scarborough Centre for Healthy
Communities, Palliative Care
Toronto

I started doing grief work shortly after Sept 11, 2001—the day much of the world was grieving. And I started doing AIDS work, including facilitating a weekly support group, the year my best friend Ted died of AIDS and my mother died of cancer. Oh, I know

A STUG (sudden temporary upsurge of grief) often occurs at significant times, such as anniversaries, when feelings of grief return with an intensity that surprises people. These upsurges of grief don't usually last as long as the first experience of a "grief hit" and individuals often learn to manage their memories and feelings.

grief. I'm only 48, but I've had as much loss as an 80-year-old.

I know that grief occupies every level of my being: physical, emotional, mental, spiritual, social and sexual. I know that there are times when I am in a "hit of grief" and it seems like I will always feel this way. Even though I feel like I'm going crazy, I'm not. This is normal for me. My grief and how I manage it are uniquely mine.

Grief can feel unbearable. It's like being parachuted into a foreign land with no map, compass, language facility or tools to navigate a relentlessly complex terrain. As bereaved people, we are charged with the monumental task of trying to figure out the "new normal" of our lives. Many of us have felt that we wouldn't survive our losses, but we have.

Fresh grief is so unimaginably painful that we immediately respond by throwing up a blanket of protective denial. That blanket can hang around for days, weeks, months or years. Even when the veil begins to dissipate, it can return when the pain becomes too much to bear.

Early grief may look something like this:

- You wake up in the morning and for those first few fuzzy moments of consciousness, you forget. Then you remember, "*They really are gone.*"
- Moments of intense fear and panic—"*I can't survive this.*"
- Deep lethargy and lack of motivation—simply crawling out of bed and brushing your teeth can seem like a huge, and some days impossible, task.
- Confusion, frustration, anger.
- Sadness and unbearable pain.

How we deal with these thoughts and feelings are as unique as the grief itself. Some people throw themselves into work, a project or an activity. People who, in the immediate aftermath of a loss, create a memorial website, start a foundation, write a book or train for a marathon are sometimes described as *instrumental grievers*. Then there are those of us who tend to experience grief most intensely on a feeling level—sometimes referred to as *intuitive grievers*. In those early

days, many of us feel badly that we are so unable to participate in the world in any kind of "normal" and "acceptable" way (and fear that we will never be able to again), that we may withdraw into ourselves and retreat from a world that is so out of sync with the state we are in. I know how hard it is to resist that tendency to isolate and how vital it is to try to reach out to something, someone, anything that will keep us remotely connected to life.

If you are a multiple loss survivor, the good news is that we know we can survive this, because we have survived it before. (The bad news is that we also know just how bad it can get and how deep that pit of grief is that we must fall into, swim around in and then slowly crawl out of).

Whether this is your first significant loss or not, nothing can prepare you for the swirling mass of chaos that losing someone you love throws you into.

But there is hope. I believe that we all carry within ourselves the capacity to heal. But there is no recipe for healing, no 10 steps to "get over" your grief. (And, by the way, I never want to "get over" losing any of my loved ones! I simply want to find a way to keep honouring the deep love and connection we shared, the gifts given and received, in a way that helps lift the thousand-pound weight from my heart.)

The gift of healing can come in small and often surprising ways: a phone call, an email, someone unexpectedly reaching out to say, "I am here for you"; a song, a quote, a smell, a gentle

reminder that they are still with me, watching over me; the comfort of being able to share my true self with someone who really "gets it" and gets me; the look in someone's eye who has travelled this road and knows the journey is a lifelong one but is willing and able to walk with me for a stretch of time.

I would have chosen to learn these lessons any other way, but there it is and here I am. And amazingly, I feel like a better, stronger person. In my quietest moments, I can hear the sound of my heart slowly and persistently repairing itself around the hole of loss that is now a part of me forever.

There is no formula that works for everyone. But we do know that some things help us learn to live with grief:

- **Take it one day at a time**—and some days, one moment at a time.
 - **Connect with people** who understand what you're going through.
 - **Get information about grief**, so you know that what is happening to you is a normal, natural response to your loss.
 - **Focus on simple things**—like breathing in and out.
 - **Move**—even a little bit. Walk, stretch, try to stay in your body.
 - **Eat healthfully**—and forgive yourself when all you can do is eat chocolate.
 - **Connect with what gives you hope**—for example, nature, meditating, praying or joining religious services. Or seek the support of a spiritual leader.
 - **Honour the way in which grief moves through you.** If you are a physical person, perhaps dancing or running will soothe you. If you are a creative person, drumming or drawing might comfort you.
- Every day will be different. Every moment will bring a new challenge. But with the right support, information, space and time, you will live into this new reality. You will not be the same as you were before your loved one died, but it won't always feel as awful as it does in this moment. +

Yvette Perreault is director of the AIDS Bereavement and Resiliency Program of Ontario (www.abrpo.org).

It's like being parachuted into a foreign land with no map, compass, language facility or tools to navigate a relentlessly complex terrain.

Free Agent

Visual artist **Joseph Babcock** isn't afraid to speak out, gender-bend and push boundaries.

BY JENNIFER MCPHEE

PHOTOGRAPH BY BRENT GERVAIS

At a recent event where activist and visual artist Joseph Babcock spoke about living with HIV, someone asked about his darkest moment. Babcock, now 44, described a time when he was 27 years old, three weeks after his doctor diagnosed him with HIV and said he could die within three months. That night in Toronto, Babcock was already in a bad mood but when he missed the last streetcar home, he felt nothing but raw anger. He was in such an emotional state that he began to climb the scaffolding next to a building on King Street, intending to jump when he reached the top.

As he made his way up, his mind blocked out all noise. He still remembers climbing in complete silence. But when he reached the roof, he could suddenly hear the sounds of the city again and noticed how the yellow lights of city buildings looked against the black night sky, and how the moon was casting shadows onto those same buildings. "I thought, I want to paint that," he recalls with a laugh. "And then I thought, now how am I going to get down?"

It wasn't the first time nor was it the last that Babcock's artistic nature helped him cope with difficult circumstances. Growing up in the 1980s in a Catholic family in a rural area near Kingston, Ontario, was stifling for the gay teenager, especially since he felt a deep need to express himself in unconventional ways. Once, in the hopes of securing permission to wear a skirt, Babcock tried to educate the principal

of his Catholic high school about the history of kilts. The lesson was not exactly well received, and Babcock wound up changing schools. At his next high school, students threw apple cores at his head and yelled derogatory names at him. But Babcock soon came to realize that the more flamboyantly he dressed, the safer he was. He made his own clothes, styled his black hair into a mohawk and wore tea cups as brooches. "People were frightened of me," he says. "It taught me that how you present yourself can be a powerful thing."

Despite using fashion as armour, Babcock continued to endure a shocking number of assaults over the years. But he refused to let his homophobic attackers silence him: "When they yelled at me, I yelled back."

After high school, Babcock studied fashion design at St. Lawrence College, in Kingston, and eventually began working at Modern Fuel, an artist-run non-profit gallery. By this time, he was estranged from his parents (who had reacted badly to learning he was gay when they saw him on the six o'clock news marching in the 1989 Toronto gay pride parade). It was at Modern Fuel that he finally found acceptance among the "wonderful and kooky" artists working there. Even though most of them were straight, it was a safe place where he was free to express himself and push boundaries.

Babcock began creating elaborate performance/installation exhibits with a youthful in-your-face energy. One installation, called Total Gender Mind F**k, featured men and women dressed

in the clothing of the opposite gender walking down a post-apocalyptic fashion runway, complete with old lumber and overflowing garbage cans. At the end of the performance, the models blew rape whistles while sexist and homophobic slurs flashed across their bodies. "It was about people presenting outside the traditional masculine or feminine norms and the violence that occurs around that," Babcock says.

In 1997, after moving from Kingston to Toronto to pursue a career designing costumes for community theatre, Babcock was diagnosed with HIV. The virus initially left him weighing 70 pounds and covered in Kaposi's sarcoma lesions. He started taking anti-retroviral therapy immediately and made the decision to move back to

"How you present yourself can be a powerful thing."

Kingston to be closer to his friends and family. (Following his mother's death in 1996, he had reconnected with his father.)

Once again, Babcock turned to art to process difficult emotions. He began painting and nailing angry text onto blank canvases only to paint over those words again and again with primer (see "Conversation #6," opposite). "It was cathartic," he says. "It was a way of getting those things out of my body so they were no longer part of me."

As he began to feel better, both physically and emotionally, his focus became the side effects of HIV medications. In one painting, Babcock placed Andy Warhol-esque images of his own face over his childhood photos and painted words like "ugly" and "dead" over each image. "It was a reaction to my doctor coming in and saying, 'So,



Joseph Babcock with "Conversation #6"

does the facial wasting bother you?" he explains. "I wasn't actually aware of the facial wasting until he pointed it out." Another piece is meant to resemble Leonardo da Vinci's "The Last Supper," but the 12 disciples are different images of Babcock and the table is a pill dosette. "It was about having to take medication forever," Babcock says. "But people really related to it because we are so medicated in our society today."

Six years ago, Babcock joined a discussion group for men living with HIV at Kingston's AIDS service organization HARS (HIV/AIDS Regional Services). He was immediately struck by the power of peer groups. "That was the first time I was in a room where I felt comfortable saying I was positive because

I knew that everyone in that room was positive, including the facilitators," he recalls. He not only became a facilitator of that group but he also joined the HARS board of directors, which he now chairs, and began representing the interests of people living with HIV in eastern Ontario at the provincial level. Today, Babcock is still heavily immersed in volunteer work at HARS, doing everything from staffing the front desk of the drop-in centre to educating teenagers about safer sex at workshops where the participants create art using condoms. Last year, the United Way recognized his activism by selecting him as a winner of its annual "Volunteers Grow Community" award.

Babcock now helps others with HIV become effective leaders. "We teach people how to sit on a board and know what they're getting into. And

we teach them public-speaking skills and self-care." But whenever Babcock is badly in need of self-care himself, he retreats into his studio. "When I am worn out and exhausted, I produce more art," he says. "It allows me to regroup, refocus and participate fully in community work again." These days, a key part of that work is passing on, in a non-identifying way, the stories of people who can't speak out themselves. "I have the luxury to be open about my status," he says. "But a lot of people can't speak out for fear that their kids or their parents will find out. A lot of people still live with constant fear." +

Jennifer McPhee is a freelance writer who contributes regularly to *The Positive Side*. Her work has also appeared in *Chatelaine*, *The Globe and Mail*, *Childview* and numerous other publications.



This is Not a Cocktail Party

Living with HIV for over 25 years, I've met a lot of pills. In fact, I've consumed 2,000 bottles of them! Mostly antiretrovirals but other meds and supplements too.

With the help of friends and family, I constructed this seven-foot cocktail glass using more than 2,000 empty bottles.

When people ask me what the sculpture represents, I might say any one of the following (depending on the day and my mood):

- "It's about the pill burden of living with HIV."
- "I wanted to point out how the medical profession names things inappropriately. Calling the pills I have to take each day a 'cocktail' always struck me as strange."
- "Look, trash is beautiful!"
- "We are destroying the environment when we throw these plastics in the landfill."
- "The gorgeous, beaded red ribbons made the sculpture! Ironically, they come from Africa, where there is little access to medication and the world's largest percentage of HIV-positive people."
- "This sculpture represents the difference between life and death. Wanna drink to it?"

Last summer my friend Cathy and I drove the sculpture from my studio in Victoria, BC, to the beautiful Kingsbrae Garden (pictured here) in St. Andrews, New Brunswick, where it was a finalist in a national sculpture competition. In my blue pickup truck, Babe, we covered 8,792 km in 29 days, making 20 stops along the way.

From west to east coast, we engaged people in conversation and invited them to put messages in the bottles. The messages that peers living with HIV and the community that supports us popped into the bottles were both uplifting and inspiring. Here's a toast to getting HIV out into the art world! +

—Peggy Frank

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IMPORTANT: 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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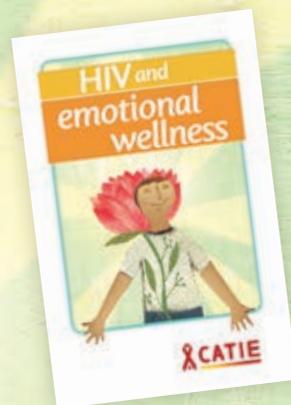


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