

TREATMENT BULLETIN

A comprehensive guide to health and well-being for people living with HIV/AIDS
September 2012



HIV what?!?!

**What you want to know, what you need to know, and
other bits of info to help you out along the way...**

Toronto People With AIDS Foundation

www.pwatoronto.org





I've just tested positive. Where do I go from here?

(we've listed the page numbers below, so only check out what you're ready for. No need to over-whelm yourself with information. It'll be there when you're ready for it!)

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Disclaimer: The Treatment Resources Program at the Toronto People With AIDS Foundation provides information and resources to empower people living with HIV/AIDS to be proactive around their health by working in partnership with their health care providers. We do not recommend or promote any treatment in particular. We strongly urge those interested in any specific treatment to consult a wide range of resources, including a qualified medical and/or complementary therapy practitioner who has experience in working with HIV+ individuals.

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This booklet is going to talk about a lot of stuff. Some of it practical, some of it supportive, and some of it might be a little overwhelming.

We're going to start off by talking about stigma.

Stigma hits us hard. Not only do we feel stigma from other people, but the internalized stigma some of us feel can be the most challenging to overcome.

Please remember: take this all one step at a time, and at your own pace.

Stigma

What is stigma?

UNAIDS (2003) define stigma and discrimination as the following:

HIV/AIDS-related stigma can be described as a “process of devaluation” of people either living with or associated with HIV and AIDS. The stigma often stems from the underlying stigmatization of sex and intravenous drug use – two of the primary routes of HIV infection. Discrimination follows stigma and it’s the unfair and unjust treatment of an individual based on his or her real or perceived HIV status. Discrimination occurs when a distinction is made against a person that results in being treated unfairly and unjustly on the basis of belonging, or being perceived to belong, to a particular group.

What does all of that mean?

There’s a lot of HIV-related fear, shame, and guilt, both within the community and outside of it, which can make developing relationships, participating in social interactions, and loving ourselves, a real bitch sometimes. The relationship between HIV/AIDS and stigma is not straightforward, and it can affect the health and well-being of people living with HIV/AIDS.

HIV Stigma (www.hivstigma.com) is a great website, which discusses stigma in an open and honest way. Their site contains blog entries from people like you, has up-to-date information about HIV-related stigma, and links HIV+ folks to community supports in their area.

What are some ways to combat stigma?

- Find **supports** within the community to support your emotional, psychical, mental, and spiritual help. (Some examples: Join a support group. Take a self-defense class. See a counselor who specializes in HIV-related support. Do some yoga. Find a church of your faith to join.)
- **Get involved** – Volunteering at an agency (i.e. ACT or PWA), or within a political movement in the HIV/AIDS community (i.e. AIDS ACTION NOW!) can be great ways to help combat the stigma and stereotypes that exist out there, or that you may be personally feeling.
- Seek out HIV/AIDS **education** opportunities, both for yourself and for the people in your life! The more knowledge we have, the easier it is to combat the negative stigma that we hear and see around us.

[An ASO] has a unique ability to respond to the complexity of stigma and treat people holistically – lets you move beyond your identity as HIV+

ASO Client

Talking to your friends, family, & acquaintances about your status

Deciding who you will reveal your status to is a very personal issue, which only you can decide for yourself. The decision to disclose may be a quick and easy task, it may take some time to weigh the challenges of disclosure, and there may be some people you never want to discuss your status with, **and that's ok**.

There is no best way to tell someone, and no sure-fire way to know how they will react if and when you choose to tell them. When thinking about disclosure to friends, family, and acquaintances (both personal and professional), here are some things you can consider:

- What is your relationship with the person? What are the pros and cons of telling them?
- Is the individual a part of your direct support network?
 - Contemplate why you'd want to tell them. Will it help them support you better? Will knowing interfere with the support they currently offer you?
 - Determine some of the issues/concerns the individual might have that may affect their ability to support you after your disclosure.
- What is the individual's knowledge about HIV/AIDS? Might their lack of knowledge/education around the facts cause some fear/bias towards your disclosure?
 - Remember – when you tell someone you're HIV+, they themselves might need support to be able to support you. How can you best prepare them for this? What resources can you have ready for them?
 - Information about HIV
 - Counseling services in the community
 - Partners/family members/supports of other HIV+ individuals



What about disclosing to my partner(s)?



Now, disclosing to your intimate partner(s), whether they are people you're in a relationship with, looking to get into a sexual relationship with, friends with benefits, or just a fun hook-up, is an **entirely different ballgame**.

The info we have around disclosure to sexual partners in Canada has been changing a lot lately, so it's always best to get the most up-to-date information around disclosure to sexual partners. While ASOs are knowledgeable on the legal issues surrounding disclosure/non-disclosure, the [HIV/AIDS Legal Network of Ontario](#) (more casually known as [HALCO](#)) or the [Canadian HIV/AIDS Legal Network](#) are your best resources for information around anything to do with your HIV status and the law. Whether you find yourself being discriminated against in an employment setting because of your status, or you want to find out about your legal requirements around disclosure, HALCO are the folks to touch base with. Their services are free for positive folks, and entirely confidential. And even better – they'd *love* to help you with any questions about your rights that you may have! (We just love when our community partners are so enthusiastic about wanting to help people out!)

Talking to my Healthcare professional:

While it is recommended that you tell any healthcare professionals you see about your HIV status, so they can best support your overall health and wellness, this can be done when you feel ready. Only do what you feel comfortable with. You are not obligated to disclose to any healthcare practitioner if you don't feel comfortable.

Find support at your local ASO!

ASOs are a great resource when discussing disclosure. If you are not sure how you want to disclose, or to whom, make an appointment with a counselor at your local ASO. They have experience supporting other HIV+ folks around disclosure issues, and can help you discuss any concerns/fears/nagging questions you may have.

Understanding treatment

Know that treatment is very individual, so it's ok to get lots of opinions on it! Your doctor isn't the be-all and end-all, especially if they're not used to treating patients who are HIV positive. Your doctor might also have had great successes with certain types of medications with their other patients, and those may not necessarily be the best fit for your course of treatment. Seek out someone with an HIV specialty to support you; your local ASO can hook you up with a list of doctors accepting new patients.

Side effects?

These can sometimes be nasty; we're not going to lie. If your medication is causing a reaction or side effect that isn't working for you, make sure you bring it up with your doctor; another combination of treatment might be best for you and your body. Sometimes you may have to put up with some crappy side effects, but make sure you get the facts first. No need to suffer if you really don't have to!

Do I need meds right away?

While treatment can dramatically lower your chances of transmission to potential partners, treatment doesn't have to start right away. Together with your doctor, and your support team (whoever they may be), you can decide what treatment will look like for you.

Poz Peers

Sometimes other positive people can be a great resource, too. While they may not have any letters behind their names, or work for an HIV/AIDS agency, they've gone through some of the stuff you're going through. Lived experience is an invaluable resource to learn from!

Not sure about starting meds? Talk to someone about how their start on meds was for them. You might not have the exact same experience, but you will get some tips. While there are a lot of horror stories that can be told, there are also a lot of people out there who have figured it out, and are doing pretty well. Ask them about it.



Taking care of yourself

What about you? Remember that you need to take care of yourself, too. Everything we've listed here is important, but none of it matters if you're not watching out for you! And we don't just mean your physical self, because being HIV+ is only a small part of who you are. We mean the *rest* of your physical self, along with your emotional and spiritual self. Taking care of all these aspects of who you are can seem really overwhelming when you've got all of this new stuff on the go, but remember that you are still the same person, and you need to continue to feed that person with love and kindness. (And rest assured, you deserve love and kindness from yourself and from the world around you.)

Here are some suggestions of things that have worked for some people, to keep themselves holistically healthy. What do we mean by holistic? The human body is like a puzzle. There are lots of little pieces to it, which make up who we are. We need all of the pieces to live our life to the fullest. *Holistically* emphasizes the importance of the whole person, rather than just parts of you – while we need to place some focus on the HIV, we should also focus on all the other pieces of us that support our health and well-being, and make up the righteous person you are!



"I came to [an ASO] to get a jar of vitamins and shop at the Essentials Market – and this touched off waves of engagement that enabled me to start taking care of myself, get treatment for substance abuse and ultimately, find a new sense of purpose."

ASO Client

Some spaces in Toronto where you can seek out this holistic support

AIDS Committee of Toronto

- Free counseling support
- Free job search assistance & training support
- Free harm reduction support groups & harm reduction supplies

Toronto People With AIDS Foundation

- Free yoga classes; Therapeutic treatments (i.e. acupuncture, massage therapy, reiki)
- Free Groceries
- Free health and wellness workshops

Sherbourne Health Centre

- Free Naturopathic Clinic supporting folks who are living with HIV/AIDS
- Chiropractic Clinic – fees are on a sliding scale

The 519 Community Centre

- Free counselling
- Free & low-cost community arts programs; free yoga classes; AA/NA meetings
- Free community support groups
- Wen-Do self-defense classes – reduced fees are available on a sliding scale

David Kelly Support Services at Family Services Toronto

- HIV-related counselling and support



Contacting your local ASO... Asking for help is healthy! (We promise!)

For some, the idea of contacting an AIDS Service Organization (ASO) makes their diagnosis real. And *real* can be a very scary thing.

Another scary thing about ASOs is they're called **AIDS** service organizations, and this name really isn't relevant so much anymore. Historically, this term unfortunately made a lot of sense. ASOs were helping support a community who were at that point in their illness – they had AIDS. Today, most of the poz-people ASOs see are generally healthy, and just looking for some help managing their lives as HIV positive individuals. Many agencies have been mindful of this and are changing their names, and a lot of us are discussing it. Please don't let the term scare you – ASOs provide most of their support to people living with HIV, helping them to manage their HIV so they aren't living with AIDS.

Taking that first step and talking about your positive status with someone can be terrifying, but honestly, your local ASOs are an **amazing** resource. They want you to contact them because they've got a whole whack of resources that they want to share with you. Some offer counseling, some offer free massages and therapeutic care (Massages! I know, right?!), and some can offer you the practical supports that you may need, whether it be around finding a doctor, getting legal advice, snagging some free groceries, or just figuring out how to manage this new part in your life.

Pay them a visit, give them a call, or shoot them an email. And know that however you choose to contact them, it's going to be absolutely **confidential**. And remember, getting to know your ASO doesn't have to be walking through the door. Call them just to chat. Send them an email about being nervous about coming in. Don't want to meet them at the office? Ask if you can meet someone from your local ASO at a nearby coffee shop, or on the bench at a park by the office. One of the wonderful things about ASOs is they don't just exist within the four walls of the agency. They're out in the community, supporting and advocating for their clients.

People think we're dealing with poverty and food – it's true in some cases, and we're also about capacity building and dreaming, engaging clients in the way we provide services – we look for the questions/support/lens that helps the person dream in such a way that they move from "I need food" to "this training program sounds really interesting."

ASO Staff

Coming into an ASO can be *#!%ing scary because a lot of what we think ASOs look like might not be reality. One of the biggest fears we hear from people about coming into an ASO is that they're going to run into someone they know. But, you know what, if you do, that's ok. Why? Because chances are if they're in an ASO, they're going to be "on your side". Whether it's that they're going through similar experiences as you and are a client, or they're helping support the community through volunteerism, chances are they're in that space for a positive reason. (See what we did there? The double meaning of positive? ASO staff can be charming and funny, too!)

We've also heard that folks are scared they're going to come into a place filled with sick people. Just ask yourself, do you look & feel "sick"? Chances are, the majority of people you meet in an ASO aren't going to look "sick" either. (And if you do feel sick, let us help you feel a heck-of-a-lot better!)



Before coming to [an ASO], I felt very medicalized. [An ASO] gave me back the missing pieces of overall health and well-being. As a volunteer, I'm reconnecting with the world, have validation, engagement times 50, got me out of my own HIV. It reminded me that there's still room to grow – still things to learn and contribute. And for me, it's a stepping stone back into a workplace setting."

ASO Client and Volunteer

What the #!@% is HIV?

There are a lot of scary things flying around out there about HIV. Before some of these things get you too concerned, keep in mind that HIV/AIDS today looks a lot different than it did 20 years ago. Heck, it looks a lot different than it did 2 years ago! Thanks to advancements in medications, folks who are poz (HIV positive, that is) are living long, fulfilling lives. And you're no different. Trust us!

But let's go through the basics, because knowledge is power:

Human (only humans can get it)

Immunodeficiency (it creates a flaw in your immune system)

Virus (it's a virus – not a bacteria)



Acquired (it's not hereditary. you have to "get it" – even babies born HIV positive have gotten it from their mothers)

Immune (again, it affects your immune system)

Deficiency (again, it creates a flaw in your immune system)

Syndrome (A syndrome is a collection of symptoms and signs of disease. AIDS is a syndrome, rather than a single disease, because it is a complex illness with a wide range of complications and symptoms)

What's the difference?

The difference is simply medical terminology. (And we're sure that without some understanding of it, it can be really confusing!)

Because HIV affects your immune system, an HIV positive individual is considered to have AIDS when their body gets sick from various infections (**see below**: we'll give you some examples), and their CD4 count (which is what lets doctors know how strong your immune system is) drops below a certain marker. When a person's CD4 count drops to below 200 (a normal range is 500-1,400), their immune system has a hard time fighting off infections. The syndrome part of AIDS is the group of infections that can attack the body when your CD4 count is extremely low. Now, getting ones of these "AIDS defining infections" use to represent the "end of days" (if you will), but now with the huge leaps that have been made in treatment and medications that are available, people can "bounce back" from having AIDS to being HIV+. There's much controversy around where HIV ends and AIDS begins, but there's really not need for you to be worrying yourself with that right now. It's important to be knowledgeable about what can cause your HIV status to develop into AIDS, but really only so you can keep yourself healthy, and continue to be the fabulous person that you are right now!

Stigma and AIDS

As much as there's all this medical jargon that tells us the difference between HIV and AIDS, there's also a lot of stigma around the two. AIDS really used to have this hashtag of being #death, which create a lot of stigma around developing AIDS. The lack of education around the differences between the two, and ignorance of the current methods of treatment that can bounce someone back from having AIDS to being HIV+, can contribute to this stigma. Comments like someone having "full blown AIDS" or "dying of AIDS", while incorrect, create negative (and scary!) language around HIV/AIDS, and crappy language can be difficult to get rid of.



How did I get HIV?

While we can't tell you how you specifically got the HIV virus, there are three things that need to be in place for someone to become HIV positive:

- Contact with someone who is HIV positive. (if the virus isn't around, you're not getting it)
- Bodily fluid from that HIV positive person (**note**: there are only 6 fluids that carry enough of the virus to transmit it – blood, vaginal secretions, semen, pre-ejaculate, anal secretions, and breast milk)
- There must be a barrier-free path for the HIV infected fluid to get into the bloodstream of another person. The virus is most often transmitted by: unprotected vaginal and anal sex; sharing insertive sex toys; sharing needles and related equipment; and from an HIV+ mother to her baby through breast milk.

** without these conditions, HIV can **NOT** be transmitted!

Common misconceptions?

The following fluids can NOT transmit the HIV virus:

- saliva, snot, tears,
- Sweat, vomit
- Urine, feces

HIV can **NOT** be transmitted through every day activities: shaking hands, sharing utensils/drinks/food, kissing, hugging, sneezing on another person – none of these will transmit the HIV virus.

Do you live with people who are HIV negative? An important thing to remember is that while the HIV virus is resilient inside the body, outside the body the virus is quite delicate, and it will not survive outside of the body for very long. If you have HIV- (HIV negative) roommates, friends, or family members you live with, your chances of passing the virus to them are almost none, unless you engage in the activities listed above with them (just a reminder: unprotected vaginal and anal sex; sharing insertive sex toys; sharing needles and related equipment). You can still share utensils, drink out of the same glassware, share a toothbrush holder, use the same bedding, share towels, and do all the same daily activities with them that you did before. The HIV virus is not jumping from your toothbrush to theirs – promise.

(Again, just to be sure, maybe refer back to the heading we called "How Did I Get HIV". If all of those three things are in place with one of your friends or roommates that you live with, remember that HIV can be transmitted.)

Other stuff to check out:

Not ready to venture into an ASO yet? No problem! We get it. Sometimes it can take a while. If you want to learn more without leaving the house, check out some of these sites.

(They're great, validated, resources about HIV/AIDS, and will also connect you with other folks from around the world who are HIV+. Sometimes, just knowing there's a lot of other people out there going through the same thing as you can be a breath of fresh air. But again, take it at your own pace. Too much info can be really over-whelming sometimes!)

Positive Lite

positivelite.com

A Canadian Online HIV/AIDS Magazine based out of Toronto. Positive Lite is a great resource for persons living with HIV/AIDS in Toronto, as it makes reference to many political, social, and cultural happenings in and around the Greater Toronto Area. Positive Lite provides a broad spectrum of information, including current affairs, legal issues, activism, and arts & culture.

Smart + Strong

smartandstrong.com

Smart + Strong is a collection of health-focused magazines and online social networking tools (including: AIDS meds; Poz Magazine; Real Health; Tu Salad; Sane; and hep). Their 'AIDS meds' publication provides information in both English and Spanish about prevention, treatment and medication, and new research.

POZ magazine

poz.com

POZ magazine, affiliated with Smart + Strong, is a lifestyle magazine, connecting persons living with HIV/AIDS with the HIV community. The magazine provides information about hot topics, pop culture, media stories, and connects readers with bloggers and online community members.

Positively Aware

positivelyaware.com

Positively Aware houses The HIV Drug Guide, which provides an at-a-glance reference of the 34 HIV medications available in the United States, and gives perspectives on the medications from both a physician's point-of-view as well as an HIV+ activist's. The guide also contains easy to read information about new research in HIV medications, as well as a chart outlining potential interactions with other medications.

The Body – The Complete HIV/AIDS Resource

thebody.com

The Body's mission is to use the internet as a resource to improve the quality of life for all people living with HIV/AIDS. It seeks to foster community through human connections online. The site contains a mix of new research and medical information, as well as blogs and stories from HIV+ individuals. It provides information on treatment, prevention, living with HIV, HIV medications, side effects, and connects folks with bloggers and community members who share their personal experiences around HIV/AIDS.

AIDS Map

aidsmap.com

AIDS Map, originally the National AIDS Manual, provides HIV/AIDS resources in a number of different languages: Arabic, Dutch, English, French, Italian, Hebrew, German, Norwegian, Polish, Portuguese, Romanian, Russian, Somali, Spanish, Swedish, Thai, and Turkish. Their treatment resource information guides in these languages are easily available for printing from any personal computer. They include topics such as resistance, viral load and CD4 counts, HIV & children, HIV & hepatitis, HIV & sex (and many more!)

CATIE

catie.ca

The CATIE website is available in both English and French. CATIE is Canada's source for up-to-date, unbiased information about HIV and hepatitis C. They connect people living with HIV or hepatitis C, at-risk communities, healthcare providers and community organizations with the knowledge, resources, and expertise to reduce transmission and improve quality of life. Information resources can be ordered free of charge from CATIE's ordering centre (<http://orders.catie.ca>).

We've listed off a bunch of great, Toronto-based resources throughout this booklet. Here's the contact information for them – Check out their websites, give them a call, or pay them a visit!



Toronto People With AIDS Foundation
200 Gerrard Street East, 2nd Floor
phone: 416.506.1400
email: info@pwatoronto.org



AIDS Committee of Toronto

AIDS Committee of Toronto
399 Church Street, 4th Floor
phone: 416.340.8484
Email: ask@actoronto.org



Sherbourne Health Centre
333 Sherbourne Street
phone: 416.324.4180
email: info@sherbourne.on.ca



The 519 Community Centre
519 Church Street
phone: 416.392.6874
email: info@the519.org



HIV & AIDS Legal Clinic of Ontario
65 Wellesley Street East, Suite 400
phone: 416.340.7790
email: talklaw@halco.org

The Toronto People With AIDS Foundation exists to promote the health and well-being of all people living with HIV/AIDS by providing accessible, direct, and practical support services.

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