

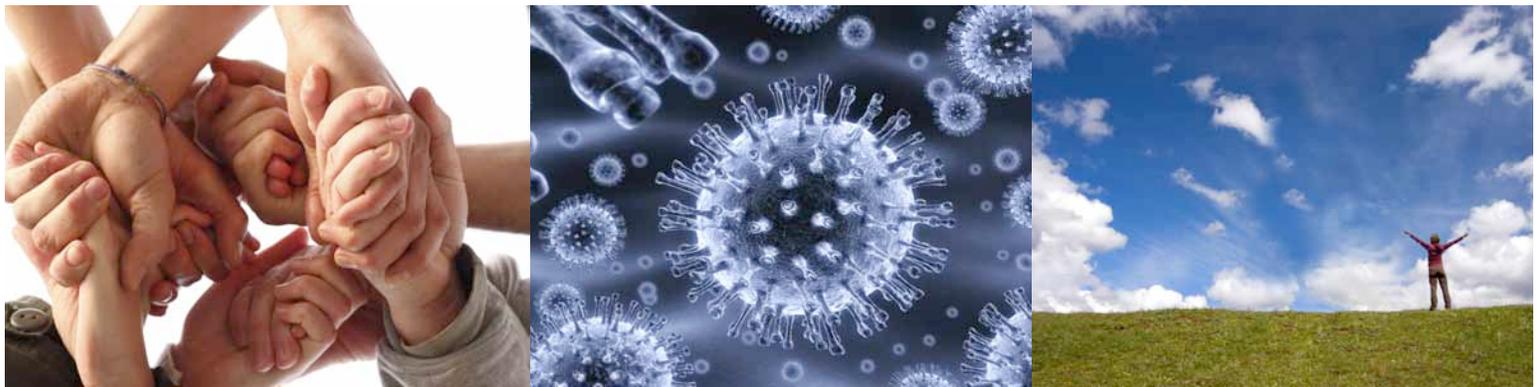


Toronto People With AIDS Foundation

Treatment Bulletin

Newly diagnosed? A guide to living well with HIV

March 2010 No. 2



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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Receiving an HIV positive diagnosis is life changing. It can be overwhelming and scary. You will likely have a lot of questions and there will be a lot of information that you all of a sudden have to process. Stop. Take deep breath. You will be okay. HIV is not the terminal diagnosis it used to be. You can live well and be healthy with HIV.

This guide is intended to help dispel some common myths and be a starting point to get you on your way to living well with HIV.

Support

Whether you are newly diagnosed or have lived with HIV for years, having a good support network will never stop being important. A support network is a group of friends or family that you feel close enough with, to comfortably turn to whenever you need a supportive conversation or a friendly smile. Surround yourself with people that will make you feel better, not bring you down.

You don't need to tell everyone about your HIV status right away, or at all. Start with even just one or two people that you know will be supportive and help you while you make sense of everything. If you know others who are also HIV+ you may even want to talk to them. They've been where you are and may understand what you're feeling.

If a support network isn't available to you or you feel like you might need extra support, another option is talking to a counselor/therapist or social worker. These are trained support workers who can work with you through whichever issues you feel you need help with. Try to find a therapist or social worker trained in working with people who have received a positive diagnosis. There is a list of resources you may find helpful at the end of this bulletin.

Acceptance/Community

Finding acceptance and a sense of community is an important step in living well with HIV. You don't have to accept and come to terms with your diagnosis overnight – it may take you years to accept it and that's okay. The important part is to work toward acceptance – it will make living well with HIV a lot easier.

Feeling a sense of community and getting involved can be empowering. Being around other individuals who are also positive may not only be a support network, but also remind you that you are not alone. There are many people out there living with HIV. In fact, close to 70,000 others in Canada have been diagnosed with HIV. There are many places you can meet others who are also HIV+. There are support groups that exist where you can talk about HIV in a group of others who are also positive. Not all community interaction has to be about HIV. Many AIDS Service Organizations (ASO's) offer social events where you can go and just be in a group of your peers without having to think or talk about HIV. You may also choose to volunteer for an ASO or get involved in fundraising, or anything that gets you involved.

Education

Educating yourself on HIV will be very important. There is so much information out there that it can become easy to become overwhelmed. Start with the basics first. There are some basic terms and concepts that you should become familiar with since you will often hear your doctor talking about them. Here is some basic terminology to get you started:

Viral Load: The amount of HIV virus in your blood. This is measured as the number of copies of virus per millimeter of blood. A viral load test can help to give your doctor an indication of how well your body is controlling the infection, and if you are on medication can help them to determine how well the treatment is working. The best value you can have is a viral load that is undetectable. This doesn't mean you have been cured of HIV, but it does mean that the levels of virus in your blood are below what the test can detect. A high viral load is considered over 100,000 copies/ml, whereas a value of less than 10,000 is considered low.

CD4 Count: A measure of the number of a particular type of immune cell in your blood. This immune cell is a white blood cell and has a specific name called CD4+ T cell. Think of CD4 as a flag that is attached to a white blood cell that identifies it. HIV identifies and specifically targets these CD4 containing cells and by monitoring their number we can monitor HIV disease progression. Normal CD4 counts are roughly between 800-1500. When they fall below 200, you are at risk for developing opportunistic infections that are characteristic of a

diagnosis of AIDS. The infections are called opportunistic because they take the opportunity when your immune system is running on low to surface and cause disease. Ideally treatment is started before you reach a CD4 count of 350 and will help to restore your CD4 cells to a more normal level.

HAART: Highly Active Anti-Retroviral Therapy. This is the name of the HIV medication regimens that many living with HIV/AIDS take. It is composed of a combination of medications that target HIV at various points along its life, or replication, cycle. It is very important to take your medication exactly as prescribed and miss as few doses as possible, otherwise the virus can become resistant to the medication and you may have to change your medications.

Self-care

Self-care is one of the best things you can do for yourself. This means exactly what it sounds like: taking care of yourself and your needs. When you are stressed or overwhelmed it is important to take a step back. Stress can affect your immune system and the body's ability to cope with HIV infection. Taking time to enjoy life, time with friends and family, and even time to yourself can be vital in helping you to live well with HIV. Try to get out and do activities you enjoy as often as possible.

Self-care also means taking care of your body. Eating well and exercising are an important part of self-care. Try to focus on eating healthy meals that provide your body with lots of vitamins, minerals, and other nutrients. If you are not sure about the types of foods you should be eating there are plenty of guides and resources available or you can connect with a nutritionist or registered dietician to help.

Consider reducing frequency or combination of substance use such as alcohol, tobacco, and/or recreational drugs. Besides having negative effects on the body, some of these can also exacerbate anxiety and depression, and potentially lead to risky behaviors.

Make sure that you keep your appointments as best as possible. Whether this means doctor's appointments, counseling appointments, dentist, or massage therapy appointments, keeping up with scheduled appointments will help you to stay on track to being well. Even something as simple as a haircut may seem trivial, but can help keep your self esteem up.

Treatment

One of the concerns many living with HIV/AIDS have is going on medication. Just because you have been diagnosed as being HIV+, it does not mean that you have to start medications right away. Even when you do start medications there are many more options available now that make the treatment regimens simpler and easier to take.

Your doctor will make the decision whether or not to start you on medication based on how your body is responding to infection by looking at your CD4 counts and viral load. If you and your doctor decide that it is time to start medication, find out which medications your doctor is considering for you and learn about them. Many people fear the side effects of medications but being prepared for what to expect can make starting treatment much smoother.

Consider using complementary and alternative therapies such as vitamins, minerals, herbal therapies, homeopathy, and acupuncture. Many of these have been shown to be helpful in keeping people living with HIV healthy and combating side effects of medications. A word of caution, however, that some natural therapies can interact with certain medications or even be harmful if not taken correctly. You should consult someone trained in the use of natural therapies such as a naturopathic doctor, herbalist, or traditional Chinese medicine doctor, who is also familiar with HIV.

The Do's and Don'ts of HIV infection

DO ask questions about HIV and any other health or wellness concern you might have. The more you understand the better position you will be in to make decisions about your health that are right for you.

DO practice safe sex to avoid transmitting HIV to your partner(s) and to protect yourself from contracting a sexually transmitted infection or another strain of HIV. Barrier methods such as condoms are the only known way of preventing transmission.

DON'T panic. HIV is not a death sentence any more and stress can make things worse. Take a deep breath and come up with a plan of action. Know that you are not alone and that there are many people out there also living with HIV, and living long productive lives.

DO give yourself permission to be upset or angry. It's a natural reaction to a life-changing situation. As you work through coming to terms with your diagnosis and toward acceptance, the negative feelings will fade.

DO build and make use of your support network. Consider disclosing your HIV status to a few select friends or family who you trust and who can support you through the initial stages of a positive diagnosis.

DON'T be afraid to ask for help. Whether it be your doctor, your local ASO, your friends, or your family, there are people who can help you or connect you with someone who can.

DO take charge of your health. Learn what you can without being overwhelmed and integrate it into your life. Just because you are living with HIV it does not mean you can't be healthy. Many ASO's offer workshops, and there is plenty of reading material out there that can give you some great tips and strategies for living healthy.

DON'T ignore other health conditions or any feelings that something might not be right with your health. You are the best judge of what is going on in your body and you should consult a doctor if you think something might be going on.

DO keep up with all of your doctor's appointments. It is important to be monitored regularly so that you can get the best treatment possible. It is also important that you find a doctor that you connect with and feel comfortable asking questions to, and who will hear your concerns. DON'T be afraid to switch doctors if you don't feel supported by your health care team.

DO go out and have fun. Be social. Do activities you enjoy and make time for relaxation. A balanced lifestyle is an important factor in keeping you feeling well.

Community Resources

The following are some local community groups and resources in Toronto that you may find helpful as you start on your well to living well with HIV.

Poz Social

What it is: A website listing social events across Canada for the heterosexual HIV+ community.

Website: www.pozsocial.ca

OutNPoz Toronto

What it is: A group for HIV positive individuals that are interested in a social gathering with others in a safe friendly environment. This website will give you ideas of where a social event is happening in Toronto for HIV positive individuals and poz friendly that wish to attend.

Website: www.outnpoztoronto.bravehost.com

AIDS Committee of Toronto (ACT)

What it is: An AIDS Service Organization that helps prevent HIV infections through education, outreach, and community. They provide free, confidential help to men, women, and youth living with HIV/AIDS. A list of their services can be found on their website

Website: www.actontario.org

Toronto People with AIDS Foundation (PWA)

What it is: An AIDS Service Organization that exists to promote the health and well-being of all people living with HIV/AIDS by providing accessible, direct, and practical support services. A list of their services and additional treatment bulletins are available on their website.

Website: www.pwatoronto.org

Canadian AIDS Treatment Information Exchange (CATIE)

What it is: CATIE provides free HIV information services and support to people living with HIV and their caregivers, to health care providers, to AIDS service organizations and to related front-line organizations.

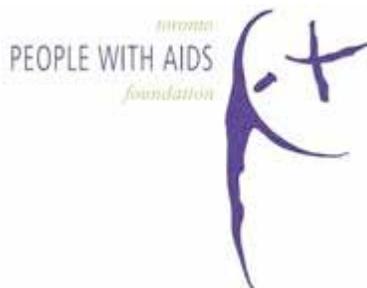
Website: www.catie.ca

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Mission

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