

# One Foot Forward

## A GIPA Training Toolkit

*Designed by and  
for People Living  
with HIV/AIDS*

MODULE

5

## RESOURCES AND RESEARCH

CANADIAN  
AIDS  
SOCIETY



SOCIÉTÉ  
CANADIENNE  
DU SIDA





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*Working together for a healthier world™*

ISBN : 0-921906-57-9

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Printed in Canada



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In this module, we'll look at ways you can conduct research – on the Internet, in the library and in your community. We'll also look at some of the resources available to you through local groups, regional networks and coalitions, national non-governmental organizations (NGOs), as well as the government.

There are many ways to connect with people and information.

At the end of this module, you will find a listing of national NGOs and key government websites.

You can start here to help you find out more in your community and region.

## RESEARCH

When you're thinking about researching a topic, try to think in broad terms about all the various aspects of the topic you want information on. Doing a literature review can provide any number of avenues for information, but if your search is too narrow, you may miss information or find it difficult to track down enough information.

Information more than four years old is too old. Issues, treatments and topics regarding HIV change often, sometimes monthly or even daily. Keep that in mind when you're researching or reading about HIV and all the related issues.

### Online Research

The Internet has a wealth of information from many sources and countries: the government, NGOs, universities and colleges.

But be warned! Not all information or websites are accurate or up-to-date. There are "snake oil" salesmen out there. People advertise a cure for various illnesses, including HIV, with little or no supporting studies, documentation, or medical testing. And not all information on issues will be accurate either. People may be offering their opinion as fact. Be careful. On Wikipedia, an online encyclopaedia, any individual can

"If we knew what it was we were doing, it would not be called research, would it?"

– Albert Einstein

"My sources are unreliable, but their information is fascinating." "

– Ashleigh Brilliant

enter information or change information. Keep your mind open, and your eyes and ears too. Get all the information!

If it sounds too good to be true, it probably is.

There are a number of search engines available online. The most popular these days is Google. Others include Yahoo, AOL, Alta Vista, Sympatico and Lycos.

Searching online means entering a keyword, or a set of keywords, into a search engine. Keywords are words that are related to the topic you are exploring.

Example: If you are looking for general information on HIV/AIDS, you can type "HIV/AIDS" and you'll get every site that has some information on HIV and AIDS. Hundreds of thousands of these websites exist, which is probably too much information. If you are looking for treatment information and HIV, you can type "HIV treatments", "AIDS treatments", "treatments for HIV" and so on. Results will include a list of websites that contain some kind of information with those keywords. The sites will include all treatments for HIV, pharmaceutical companies, HIV non-profit groups, HIV treatment groups, HIV support groups, forums for discussion of HIV treatment and HIV treatment in every country.

This may still be more than you want.

If you are looking for information about a specific treatment, enter the name of the medication. Only information on that medication will be retrieved. Again, there will be many listings and websites and you'll need to sift through the list and visit a few websites to find what you're seeking.

If you are searching for information on the topic "homelessness and HIV in Canada," for example, you are refining your search even more. You'll get fewer returns, but that phrase of keywords will get more specific information – hopefully. It sometimes takes many tries to find what you want in a sea of information.

You'll learn by experimenting with keywords. Try different words to see what comes up. Also consider that search engines look for "tags" on a website. The websites with the highest number of tags matching your keyword are the first to appear in your search results. But, you may find more relevant information if you go down a few pages.



## The Library

Most libraries have many books on HIV and will have a searchable database of their collection. Some of these databases are even available over the Internet, so you can search from home, before you go to the library.

As with the Internet, you can use keywords to find the books that best meet your need. Some books not directly related to HIV, which offer information about health care, fitness, and nutrition, may be of interest to you.

Libraries also have a periodicals section with magazines and newspapers. Periodicals often offer a lot of thoughtful articles, although you may not always find information about HIV. Scientific journals and medical journals will be the most likely periodicals to carry articles and papers about HIV.

Most public libraries use the Dewey decimal system to catalogue their books. It arranges books by series of numbers and the author's last name.

The system categorizes books by topic, as follows:

- 000 Generalities
- 001 Knowledge
- 002 The book
- 003 Systems
- 004 Data processing. Computer science...

A book on data processing by John Smith might be catalogued as "004.75 Smi."

University libraries use the Library of Congress system, which uses letters and numbers.

RA418-418.5 Medicine and society. Social medicine. Medical sociology.  
RA421-790.95 Public health. Hygiene. Preventive medicine.

A book on HIV prevention might be catalogued as RA421-792.20.

Whatever system your library uses, if you aren't certain how to access what you're looking for, ask a librarian for assistance.

"I have never let my schooling interfere with my education.

– Mark Twain

### Government Resources

If you are looking for information from government departments or ministries, you can sometimes find the information online on the government's website. However, the search engines on those websites rarely provide you with the search results you're looking for.

A separate ministry or department may be easier to search or may have direct links to the information you're seeking.

Try to be as specific as you can about what you're looking for. Choose keywords that fit the topic.

If all else fails, pick up the phone and call the ministry, or pay a visit, to find out where to obtain the information. You can locate government offices in your community through the blue pages in your phone book. You can also seek out information by visiting the constituency office of your provincial and federal elected representatives.

If you are looking for specific information about how the government is responding to a particular issue, make an appointment and provide the questions beforehand, so the assistants can do some homework.

### Health Information

Many provinces now have health authorities with websites that are listed in the blue pages of the phone book.

The services and programs offered through health authorities are also listed in the phone book and online, but it may be a little more difficult to locate the person or people you need to talk to for answers. Sometimes, a community service will have administrative staff in one office and frontline staff in another.

Health authorities provide direct care, hospital care, mental health services, seniors care, outpatient services (including blood work) and medications and pharmacy services. Each department may offer service in several locations in the community, depending on the size of your town or city.

Remember – a health authority is a bureaucracy. There's a lot of red tape, departments and administrators to muddle through. But keep digging – at some point, you'll find the information you seek!

## Treatment Information

The ever-growing, complicated list of treatments and treatment options, including traditional western medicine, Chinese medicine, naturopathic medicine and herbal medicine, can be confusing.

If you're searching for accurate information on treatments, turn to the experts! There are several Canadian NGOs available to guide you in your search. The Canadian AIDS Treatment Information Exchange (CATIE: [www.catie.ca](http://www.catie.ca)), and the Canadian Treatment Action Council (CTAC: [www.ctac.ca](http://www.ctac.ca)) are both reputable groups that are well-informed about current treatments, vaccines, medication trials and more.

Using an NGO as your source will help you find the information you are seeking and will provide fairly objective material to help you make decisions. NGOs will not endorse any particular treatment and will always direct you to your family doctor or specialist for a consultation.

Pharmaceutical companies will list their particular medications and will have their own studies posted online. It is good to know and understand that while pharmas may have very complete information and studies, they are also in the business of marketing and selling their medications and products.

It's more difficult to search for complete information on alternative therapies and medicines. Not all alternative medications are regulated. Vitamins and herbal remedies, for example, may not have been studied sufficiently enough to determine how they interact with HIV medications, whether there are contraindications or how they may affect a person living with HIV.

An example of this is St. John's Wort, a commonly used herbal remedy for anxiety. It was found that St. John's Wort interacted very negatively with some HIV medications, leading to death. As a result, people with HIV now pay a lot more attention to herbal medicines and remedies.

Always remember that medicine – no matter what it's made from – is medicine. Check with your doctor or specialist, research the medications thoroughly and make informed decisions before starting any regimen.

Some agencies provide treatment literacy workshops to assist people living with HIV in understanding the complexities of treatments and how they work. Ask if your agency offers such treatment literacy workshops. If not, perhaps you might want to start one.

*"Never face facts; if you do you'll never get up in the morning."*

*– Marlo Thomas*

### Non-Western Medicine

Medicine is cultural. Different cultures often approach medicine differently. Within European culture, medicine has also evolved: in the middle ages, physicians used leeches to clean wounds. Curiously, this practice is being revived today. It was once believed that a lack of balance in the “humors” – our blood, mucous and bile – caused illness. Herbal remedies were widely used and are now making a comeback. Even the chicken soup of old wives’ tales has proven beneficial.

Chinese medicine uses herbs and teas, as well as other ingredients, to treat specific illnesses. In Chinese medicine, if the remedies provided by the doctor are not keeping you healthy and you become ill, the doctor will work to reformulate the herbal remedies to successfully treat the illness. Chinese medicine is based on the concept of “Chi,” the life force that runs through our bodies. When Chi is not in balance, we get sick. The doctor works to ensure that your Chi is always in balance.

In traditional First Nations medicine, herbal remedies are also used. Cedar is considered a healing tree, Salal, a healing plant. There are also many other plants, berries and trees that provide healing. First Nations medicine people work with the person who is sick to develop the most effective remedies for prevention and treatment of the illness. There is a sacred nature to First Nations medicine, which, similar to Chinese and other eastern medicines, recognizes the connection between the body, mind, spirit and earth. They all stress that balance fosters good health.

All medicines focus on the imbalances that can cause “dis-ease”. Western medicine is starting to adopt the same ancient ideas.

### Social Networks

There are a number of social networks on the Internet. Two of the main ones are Facebook and MySpace. Each of these allows people to place their personal information and interests online with photographs, blogs and email connections.

While these sites are great ways to connect with others and even find other people living with HIV, be careful. These sites are not privacy-protected and the personal information you post on them is available for anyone on the planet to read.

Check out various social network sites and, if you think they're worthwhile, take the leap and try getting involved in them. Before you decide what information you wish to post, examine the content of other sites.

Here are some useful websites for other organizations:

- Canadian AIDS Society: [www.cdn aids.ca](http://www.cdn aids.ca)
- Canadian Aboriginal Aids Network: [www.caan.ca](http://www.caan.ca)
- Canadian AIDS Treatment Information Exchange: [www.catie.ca](http://www.catie.ca)
- Canadian HIV/AIDS Legal Network: [www.aidslaw.ca](http://www.aidslaw.ca)
- Canadian Treatment Action Council: [www.ctac.ca](http://www.ctac.ca)
- Interagency Coalition on AIDS and Development: [www.icad-cisd.com](http://www.icad-cisd.com)
- Canadian Working Group on HIV and Rehabilitation: [www.hivandrehab.ca](http://www.hivandrehab.ca)
- Global Network of People Living With HIV/AIDS North America: [www.gnpna.org](http://www.gnpna.org)
- Volunteer Canada: [www.volunteer.ca](http://www.volunteer.ca)
- Public Health Agency of Canada: [www.phac-aspc.gc.ca](http://www.phac-aspc.gc.ca)

## TERMS IN THIS MODULE

**NGO:** Non-governmental organization. Any community-based group that is not directly connected to government is an NGO.

**Literature Review:** Also called a "lit review," it is any research of available literature, papers and studies that covers a particular topic.

**Blogs:** A web log – pages on the internet where people can express their personal views and ideas online.

**Pharma:** Pharmaceutical company.

**Contraindications:** When you take a medication, it may interact badly with another medication or may not be appropriate if you have another existing condition. That alerts the pharmacist that it is "contraindicated." That is, the medication should NOT be taken with the other medication or with the other existing condition.

**Regimen:** A course of medications.

## SELF ASSESSMENT

After completing this module, I learned:

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I still need more information about:

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My strongest areas right now are:

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My weakest areas right now are:

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My next steps will be:

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I can complete my next steps by: \_\_\_\_\_

**Rate the statements below by circling the number that you think fits.**

	Very confident			Need to work on this	
I spent enough time on this module.	1	2	3	4	5
I'm using my energy wisely.	1	2	3	4	5
I know where to find more information.	1	2	3	4	5
I can find a person to help me out.	1	2	3	4	5
I know how to apply what I learned.	1	2	3	4	5

