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A PRACTICAL GUIDE FOR PEOPLE LIVING WITH HIV DISEASE.

Community AIDS Treatment Information Exchange

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This guide originated as AIDS and HIV Management Goals: A Treatment Primer for People Living with HIV/AIDS, first produced by the Toronto activist group AIDS Action Now! (416- 928-2206) in 1992. AAN! published three editions of its primer, the latest in 1995, and the project has now been passed on to CATIE. AAN! and other treatment activists across the country believe that People living with HIV/AIDS (PHAs) need access to comprehensive information to be able to manage their own health care. Empowerment was the goal of AAN!'s treatment primer and it remains CATIE's goal in producing this guide.

Let us Know what you think.

Let us know what you think of this guide and our other services. We need to know how our services are meeting the needs of PHAs and their caregivers. You are the best ones to tell us how we are doing and help us improve. Call us at 1-800-263-1638 (in Toronto, call 944-1916).

What – More Stuff to Read?

Protease inhibitors, miracle drugs, drug cocktails, undetectable viral loads – people living with HIV/AIDS (PHAs) seem to be bombarded every week by stories and rumours about new treatments, test or results of research trials. More people are feeling a lot better with the new drugs, but many have terrible side effects. And it's getting harder and harder to tell the hype from the real promise; to figure out what might really work for you when there are so many new combinations and so much we don't know about all of them.

So, some real advances in treatment for HIV disease and finally some real hope – but a huge amount of information to make sense of, a lot of uncertainty, a lot of hard decisions for PHAs.

But one thing we do know – PHAs need up-do-date and reliable information to help them make their best treatment decisions. That's what this primer is all about.

This is a basic guide to the latest treatment information for HIV disease – a starting point to help you make your health care decisions and keep up with rapidly changing treatment options. It's a ready reference guide to the kinds of things you could be thinking about at various stages of HIV disease. And it's also a checklist of the quality of care that you have a right to expect from your health care provider. Many PHAs become their own best experts and advocates and we hope this guide can help you negotiate the care you need.

How To Use This Guide

There are four main sections – you can jump ahead to the information relevant to you. There are also a number of sidebar boxes throughout on related issues such as working with your health care provider, how HIV works, finding out which treatments are covered in your province/territory, particular tests like viral load, and advocacy.

- the first section outlines basic things you need to know to be able to manage your treatment – how the virus works, how the various drugs interfere with viral replication and tests to monitor your immune system;
- the second sets out the many promising new antiretroviral drugs that have become available in the past two years;
- drugs to prevent and treat some of the opportunistic infections which people with weakened immune systems can get have also improved – they are discussed in the third section; and
- finally, the last section reviews the importance of good nutrition, exercise, vitamins, and other complementary therapies in maintaining a strong immune system.

Starting Points

The first step in making sense of treatment information is to understand the basic ways HIV disease works.

Stages of HIV Disease

There are four stages of HIV disease:

1. Primary infection - also known as seroconversion - is the time when you first become infected. You may experience transient flu (few days to weeks) -like symptoms;
2. Asymptomatic infection is the period after seroconversion when you remain healthy without any symptoms of HIV disease. This may last for many years. Although you remain well, the HIV virus continues to grow;
3. Symptomatic infection occurs as your immune system is becoming weakened by HIV. You may experience symptoms such as fatigue, night sweats, diarrhea, or weight loss;
4. Advanced HIV disease or AIDS involves severe symptoms such as wasting and opportunistic infections such as CMV retinitis, pneumonia, MAC and other life-threatening conditions.

These stages are important because your health must be monitored and different treatment options considered at each stage. The rest of the guide is set up to help you plan your care stage by stage.

Maintaining your Health Is More Than Medicine

Testing HIV+ can be a tremendous shock that compounds any other problems you may be facing in your life. The mental and emotional impact of dealing with your HIV+ status may affect you for a long time. Take the time to think about your next steps and work through your anxieties. You don't need to make any hasty decisions. There are community resources you can draw on. You might want to get in touch with any of the numerous AIDS Service Organizations (ASOs) or health centres for counselling and emotional and mental support, or just someone you can talk to and confide in. If you can, get to know other HIV+ persons and the different health strategies they are using. There is no one way to cope with being HIV+. You have to find what is comfortable for you and makes you feel good.

When You First Test HIV Positive

Starting Treatment Right Away?

There is debate about how soon to start antiretroviral therapy (drugs that weaken HIV's ability to reproduce and thus delay, minimize or prevent the virus from damaging your immune system). As with so many complicated treatment decisions, it will help to talk to your health care providers and other PHAs who have faced the same dilemmas.

Some providers and PHAs believe that if you initiate combination antiretroviral therapy within 12 weeks of infection, you may be able to eradicate HIV from your body right at the start. This has yet to be proven, and most persons are uncertain as to exactly when they become infected.

There is also some emerging medical opinion that if you have been exposed to HIV through a needle stick injury or other occupational exposure, you should initiate combination antiretroviral therapy within 36 hours of exposure. A number of hospitals have developed protocols on starting treatment after possible occupational exposure.

Charting Your Health I:

Knowing Where You Are Starting From

It is crucial to monitor changes in your immune system and overall health to be able to effectively assess your treatment options. That is why it is so important to start with good baseline information when first diagnosed.

This list sets out the general physical examinations and laboratory tests your doctor should perform in your initial assessment after first being diagnosed with HIV infection. She or he may add more depending on your health.

Baseline Physical Examination

- weight, temperature, and vital signs
- skin - check for rashes, ulcers and lesions
- lymph nodes
- chest and cardiovascular
- abdominal and gastrointestinal
- genitourinary and rectal
- gynecological (women)
- neurologic
- ophthalmic (eye) exam
- mental/ emotional status
- oral cavity-for thrush, hairy leukoplakia

Baseline Laboratory Test

- chest X-ray
- complete blood count- white & red blood cells, haemoglobin, hematocrit, platelet counts
- $CD4^+$
- HIV viral load
- kidney and liver function tests
- pap smear for women
- rectal smear
- appropriate swabs for STDs (sexually transmitted diseases)- rectal, cervical, vaginal, oral
- TB skin test
- hepatitis B and C antibody test
- toxoplasmosis titre
- CMV antibody test
- VDRL

(1-The above adapted from, "Comprehensive Guide for The Care of Persons With HIV Disease")

Working With Your Physician

It is important that you find a doctor you are comfortable with. Ask ASOs, friends and health centres about recommended general practitioners and HIV specialists. Find a doctor who already deals with HIV+ patients if possible. Usually you have to be referred to a specialist by your general practitioner.

Once you find a doctor, try to establish a comfortable working relationship with him or her. Here are some points to consider to help you take an active role in your health care decision-making:

1. Don't be afraid to ask questions regarding your health or to have your lab results explained;
2. Write down questions you have before your appointment;
3. Book enough time and try not to let doctors rush you through an appointment;
4. Ask for a photocopy of your lab results if you want to keep track of your health;
5. Never leave the doctor's office confused or intimidated;
6. When your doctor advises a certain course of action to take, ask about other options. HIV treatment is constantly changing and there are still many areas of debate and uncertainty. Your doctor should be willing to acknowledge this.

We will be coming back to the importance of other kinds of treatments and health care providers and these same principles apply to working with them. It is best to find health care providers that are comfortable working with practitioners from other disciplines; for example, a doctor who will work with you to incorporate complementary therapies into your medical treatments.

Charting Your Health II:

Knowing Where You're At

There are several powerful tools you can use to follow how your immune system is doing and the amount of HIV in your body.

CD4⁺ count

CD4⁺ cells are a type of white blood cell called a lymphocyte that send signals to other white blood cells to fight off infections in the body. The normal range of CD4⁺ count is between 500 and 1500/mm³.

Viruses cannot replicate by themselves the way other germs, such as bacteria, fungi and protozoa can; they need to get inside and infect cells of the body to be able to reproduce. HIV infects CD4⁺ cells (as well as other cells in the body) in order to replicate; killing these infection-fighting cells is why HIV is so damaging to the immune system.

As the immune system becomes weakened by HIV the CD4⁺ count begins to fall. The level of CD4⁺ cells is one of the most important surrogate 'markers' – indications of how badly the immune system has been damaged or how quickly it is deteriorating. Monitoring CD4⁺ levels carefully helps PHAs and their providers know what opportunistic infections and other conditions to watch for and what treatment options to consider.

People with HIV disease should have their CD4⁺ count measured every 3 months. Other factors such as time of day, laboratory variation, smoking, intercurrent illness can influence the number. It is best to always have your count measured in the same laboratory at the same time of day.

Viral Load

Viral load is a measure of the amount of HIV in your blood, reported as the number of particles or copies of HIV in a millilitre of plasma. The tests currently available commercially to measure viral load are sensitive down to 500 copies per ml. Test results less than that will be described as 'undetectable'. This does not mean there is no HIV in your blood, only that the test was not able to detect it. More sensitive viral load tests that measure as low as 20 copies/ml are being used for research purposes. They will become commercially available in the future.

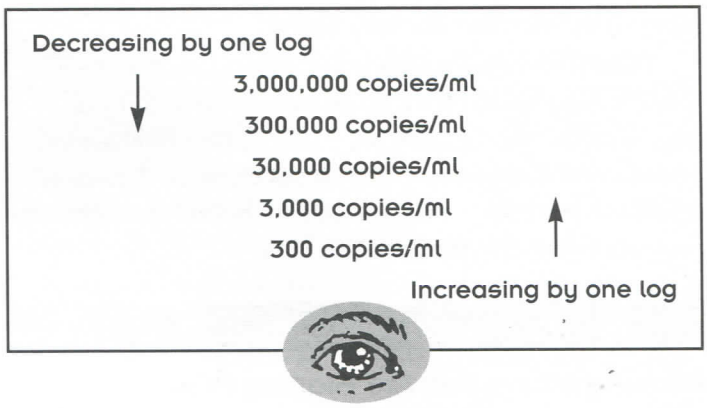
Viral load is very high immediately after infection, but after seroconversion it drops and establishes a 'set point'. Everyone has a different set point and viral load usually remains at this level until the immune system begins to weaken over time. This set point is really important; the lower the set point, the longer it will take for HIV disease to progress and the higher the set point, the more likely to progress faster.

Certain other factors, such as immunizations or infections like the flu, a cold, or a herpes outbreak, will increase HIV replication temporarily and, therefore, viral load, so it is best to avoid taking a viral load test for about a month after an infection or immunization. Recently infected persons should wait for six months before getting a viral load test. By this time their set point will be established.

Your first viral load test will give you a baseline value to compare to future test results. You should have your viral load measured at least twice a year, and more often if you are beginning or switching antiretroviral drugs.

Interpreting Your Viral Load Results

The increase or decrease in viral load is often referred to in 'log' terms. A log, or logarithm, is a factor of 10: an increase in viral load of one log equals the previous number of copies x 10; a one log decrease equals the previous number of copies divided by 10. So, if you have one thousand copies of HIV particles per millilitre of blood and the viral load increases by a log, then you will have ten thousand copies. The chart below illustrates how log changes work.



Antiretroviral Therapy:

Protecting the Immune System

The chart (opposing page) shows how the virus works and how the various drugs stop or slow down its ability to replicate.

HIV is a specific type of virus called a retrovirus. Two enzymes called reverse transcriptase and protease play an essential role in its replication cycle. There are now a number of antiretroviral drugs which inhibit or block these two enzymes' functions in the virus' replication.

Reverse transcriptase inhibitors

These drugs block the reverse transcriptase enzyme in the replication cycle of HIV. This is an enzyme unique to the virus and not contained within your own body's cell.

There are two classes of reverse transcriptase inhibitors: the distinction is important because they work in different ways and are used in different combinations.

- Nucleoside analogues (NRTIs or nukes) include AZT (zidovudine or Retrovir), ddI (didanosine or Videx), ddC (zalcitabine or Hivid), d4T (stavudine or Zerit) and 3TC (lamivudine or Epivir).
- Non-nucleoside reverse transcriptase inhibitors (NNRTIs or non-nukes) include delavirdine (Rescriptor), nevirapine (Viramune) and loviride.

Appendix 1 *describes the dosages, side effects and drug interactions associated with the nukes.*
Appendix 2 *describes the dosages, side effects and drug interactions associated with the non-nukes.*

Viral Replication Cycle

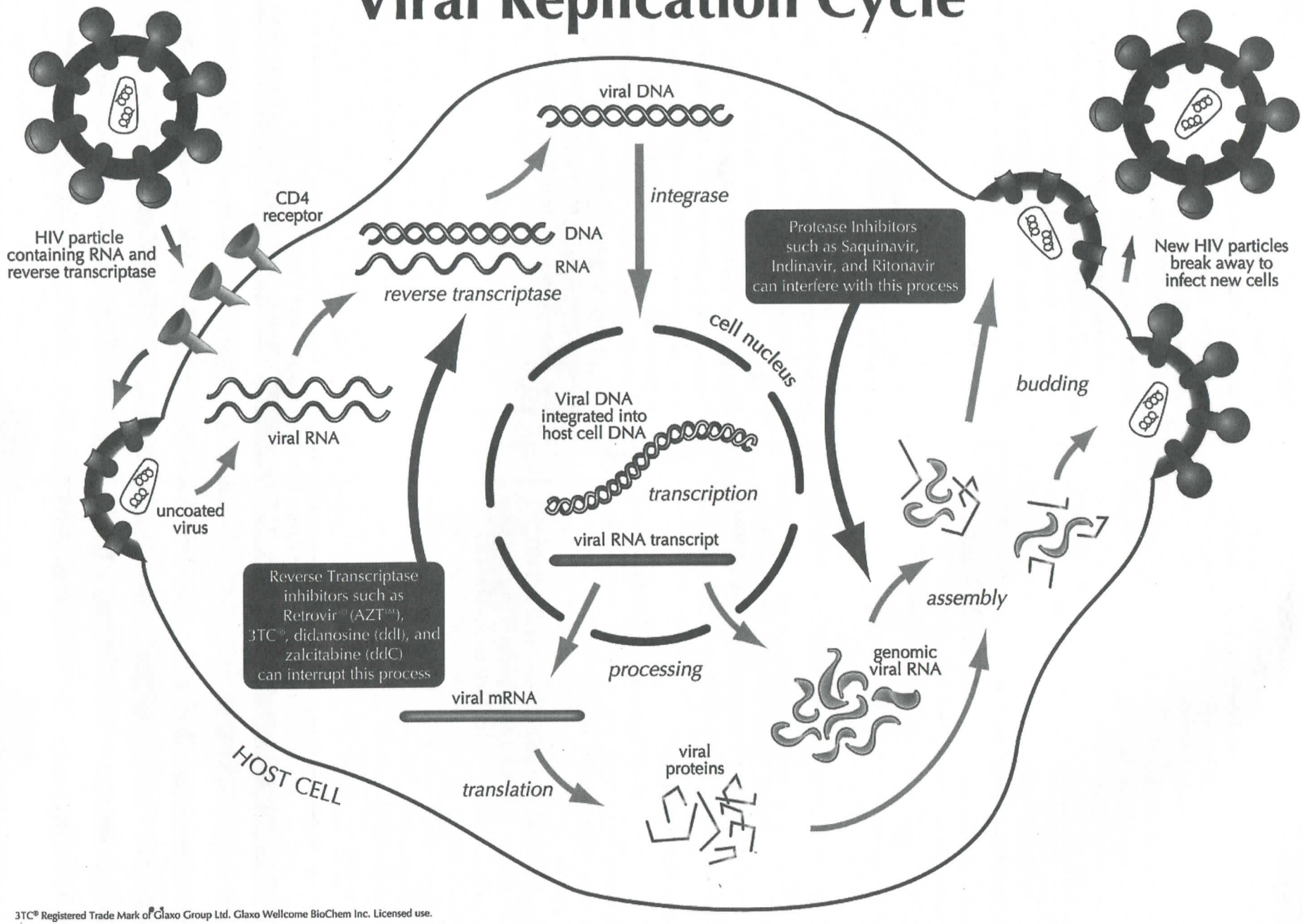


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Image courtesy of GlaxoWellcone Inc.

Protease Inhibitors

Protease inhibitors are a new class of antiretrovirals that interfere with the last stage of HIV replication. They prevent newly-formed viruses from being assembled properly by blocking the protease enzyme, resulting in defective copies of HIV which cannot infect other cells.

There are currently four protease inhibitors being used for HIV treatment: saquinavir (Invirase), ritonavir (Norvir), indinavir (Crixivan) and nelfinavir (Viracept).

***Appendix 3** describes the dosages, side effects and drug interactions associated with the protease inhibitors.*

Antiretrovirals in the pipeline

There are many other antiretrovirals currently being studied. Those furthest along in development include:

- 1592U89 - a nuke developed by GlaxoWellcome;
- DMP-266- a non-nuke which acts like a nuke, developed by DuPont-Pharma (Dupont Merck in the US)
- 141W94- a protease inhibitor developed by GlaxoWellcome and Vertex

See CATIE's regular "What's New" bulletins or call us for updates on clinical trials and approvals of new drugs, or keep in touch with your health care provider or local ASO.

Combination therapy

As well as the new drugs that have been developed, the crucial recent advance has been combination therapy. Taking various combinations of antiretroviral drugs together has become the standard of care.

Monotherapy is no longer recommended as anti-HIV treatment because of the rapid development of drug 'resistance'. (The virus mutates within the body and becomes resistant to the particular drug so that it can no longer prevent HIV from replicating.) It is much more difficult for HIV to become resistant to a combination of drugs than to just one. So combining different antiretrovirals works for a longer time and is more effective at slowing down the replication of HIV.

Antiretroviral Treatment Guidelines

Guidelines for antiretroviral therapy are continually evolving and a lot of research is exploring which combinations work best for longer. You will want to keep in touch with these developments to know your options. The information below reflects the best consensus at the moment and is taken from the Ontario Guidelines for Antiretroviral Therapy and from the United States National Institute for Health Guidelines for the use of Antiretroviral Agents.

Currently, the goal of antiretroviral therapy is to bring viral load down as much as possible, ideally below detectable levels (currently < 500 copies/ml). However, in patients with a high viral load or extensive prior antiretroviral treatment, a viral load reduction below 5,000 copies/ml or a one log drop may be the best that can be achieved. A decrease of 1 log with treatment has been associated with improved survival. A viral load test should be done a month after starting therapy. The expected viral load decreases in antiretroviral naive patients (people who have never taken antiretrovirals before) are:

- 1 to 1.5 log with a combination of 2 nukes;
- 2 to 2.5 log with a combination of 2 nukes plus a protease inhibitor or 2 nukes plus a non-nuke.

Deciding which of the specific drugs to take will depend upon your particular condition, the side effects and benefits of the particular combinations, other treatments you may require, what you are able and willing to tolerate, and whether and what antiretrovirals you have taken before. You will need to have regular blood work done to monitor changes in your viral load and your immune system. Whether the treatment is considered successful depends on changes in your viral load, $CD4^+$ count and how you are feeling. Talk to your health care provider or call CATIE – we have fact sheets and other information on many of the specific antiretrovirals.

HIV Treatment Guide for $CD4^+$ Count and Viral Load

$CD4^+$ cell count/mm	Viral Load (RNA copies/ml)	Anti - HIV treatment
less than 200	any level	triple or quadruple combination
less than 500	more than 5,000 - 10,000	triple or quadruple combination
less than 500	less than 5,000 - 10,000	double, triple or quadruple combinations
greater than 500	more than 100,000	triple or quadruple combinations
greater than 500	more than 5,000 - 10,000	discuss with your doctor

The following combinations should be avoided. For various reasons, they are known to work less well when taken together than on their own:

1. non-nuke + non-nuke. **2.**AZT + d4T. **3.** ddC + ddI.
4. ddC + 3TC. **5.** saquinavir + indinavir. **6.** indinavir + ritonavir.

In Canada, AZT, ddI, ddC, 3TC, d4T, saquinavir, ritonavir, and indinavir are the only antiretroviral drugs currently approved for treatment. Nelfinavir, delavirdine and nevirapine are available through expanded access programs, pending approval by the Health Protection Branch.

What about Women?

HIV clinical research is flawed - much of it has been done on men only. We just don't know for certain if the same combinations, at the same dosages, will work as well for women or what their side effects will be. It's a scandal, but under pressure from HIV+ women and activists, standards of care for women are finally being developed.

The goal of therapy when pregnant is to both protect the woman's immune system and prevent transmission to the fetus. Pregnant women should have a viral load test. If the level is low, AZT monotherapy is considered appropriate after the first trimester of pregnancy. If viral load is high or doesn't decline with monotherapy, then combination therapy is recommended. However, possible harmful effects of many of the drugs on an unborn child is unknown.

Women with HIV disease who choose to have children deserve the best care for their own health as well as that of their fetuses. Pregnant women must be told all the risks and benefits of any treatment; for example, there is currently some concern that combination therapy may have a higher risk of birth defects. However, antiretrovirals have only been in use for a short period of time and definitive information will not be available for many years. At any rate, women should never be denied access to combination antiretroviral therapy out of medical fear of birth defects – women have the right to weigh the risks and benefits for themselves.

Getting Started on Antiretroviral Treatments

When you are considering beginning antiretroviral therapy, there are other things to think about besides your $CD4^+$ count and viral load.

- In order to get the maximum benefit from therapy, and avoid developing drug resistance, it is extremely important to take each dose of your drugs as prescribed. This is called compliance or adherence by doctors. It might be better to think of it as making the treatments work for you, but it can be really hard to keep up. Some of the drugs have very bad side effects and some are a lot of trouble – you have to take them at particular times, on a full or empty stomach, with specific kinds of food, and so on. This gets even more complicated with combination therapy, with large numbers of pills and a very rigorous schedule or regimen. It can be very difficult for some people to adhere to these regimens over a long period of time.
- So you'll be thinking of all these kinds of things in addition to the purely medical benefits of the particular drugs. Choose a combination which you feel best suits your lifestyle. You need to ask yourself if you are mentally and emotionally ready to commit to the therapy. It is better to wait until you are ready than to take them irregularly as your virus will become resistant.
- Are you taking any other medications or recreational drugs which may have interactions with the antiretrovirals? Find out about potential drug interactions before you start.
- The other problem is that the antiretroviral drugs can be very expensive. Can you afford the drugs or are they covered by your provincial health plan or private health insurance policy?
- When choosing a particular combination, try to include at least one drug that crosses the blood-brain barrier in order to prevent HIV from replicating in the nervous system. AZT, d4T, 3TC and nevirapine are the drugs currently available which cross the blood-brain barrier.

Advocacy

People with HIV disease have a right to the best possible health care. But many PHAs face terrible problems – from inadequate home care to discrimination, from welfare or disability cuts to homelessness. Access to high-quality treatment is also highly inequitable: what health care resources are available varies greatly depending upon where you live; access is much worse for some PHAs – for prisoners, poor people, IV drug users and Aboriginal people; many physicians and other providers are not aware of the latest treatment strategies; many treatments are hugely expensive; and many are not covered by private or public insurance. Getting access to the treatment, care and support you need often requires direct action by PHAs and their supporters. This includes putting pressure on pharmaceutical companies, governments, insurance companies and AIDS service organizations. Without continued pressure, the fight against HIV disease will not be fought as hard or won as fast as is needed. And whatever the major advances in HIV treatment, there is still no cure. We need to keep fighting for the intensive research effort that will find that cure in the very near future.

Access to HIV Drugs

The provinces and territories have very different policies and programs covering drug costs and tests.

Due to the rapidly changing nature of HIV/AIDS treatment and the current climate of health care restructuring and cutbacks, information on drug coverage is constantly changing. Please contact your regional AIDS Organizations, provincial /territorial health ministries, or CATIE for up-to-date information on what is covered where.

Changing or Stopping Antiretroviral Therapy

There are three main reasons for considering a change in antiretroviral therapy. The first is if the treatment isn't working. Treatment failure can be reflected by an increase in a viral load of 0.5 log or moving back towards your baseline result; no change or a decrease in CD4⁺ count; or clinical progression of HIV disease, including the development of a new opportunistic infection. The second reason is toxicity and intolerance that outweigh the benefits of the treatment. Finally, compliance – you may not be able to adhere to the prescribed combination.

There are no defined guidelines around stopping treatment. It is a big decision because it could be very dangerous; it could mean that the virus will go back to replicating quickly and your immune system could be damaged as a result.

People may think about stopping antiretroviral therapy when they have been unable to keep on or tolerate any combinations of antiretroviral drugs. Or they have tried all the available antiretroviral drugs and not benefited from them – this could mean feeling worse, your CD4⁺ count continues to decline, or your viral load increases or doesn't decrease.

Preventing Opportunistic Infections

As the immune system is weakened and CD4⁺ counts drop, people with HIV disease become more susceptible to opportunistic infections, commonly called OIs. It is important to consider preventive medication (prophylaxis) when the state of your immune system leaves you at risk of developing OIs.

The chart (bottom page) describes prophylaxis that is available for some of the OIs and when it is recommended to start the medications.

There have been some real advances lately in treating OIs if you do get them. These treatments are too extensive to summarize here: talk to your health care provider, look at CATIE's specific fact sheets or call us for detailed information on any OI and its treatment and on what drugs are covered in your region.

Complementary Therapies

Much of Western medicine has been based on allopathic (pharmaceutical) drugs. PHAs have also been using many other kinds of treatments, lumped together under the general term of alternative or complementary therapies.

Unfortunately, there has been little systematic research to investigate the effectiveness of these various alternative therapies in fighting AIDS. But many PHAs believe they have made an important difference to their health and quality of life. Many PHAs and health care providers have come to see that they can be an important complement or supplement to mainstream Western medicine.

CD4⁺ count	Opportunistic infection	Available/approved prophylaxis
Any count	Herpes simplex I and II (if you have a history of recurrent outbreaks of herpes)	acyclovir (Zovirax)
Any count	Candidiasis/thrush	nystatin, ketoconazole, fluconazole, itraconazole
less than 200	Toxoplasmosis	pyrimethamine + sulfadoxine, pyrimethamine + clindamycin, azithromycin, Mepron
less than 200 (or other evidence of immune suppression)	Pneumocystis carinii pneumonia (PCP)	TMP/SMX (Septra/Bactrim), dapsone (Avlosulfon), aerosolized pentamidine, atovaquone (Mepron)
less than 100	Mycobacterium avium complex or avium intracellular (MAC/MAI)	rifabutin, azithromycin, clarithromycin
less than 100	Cytomegalovirus (CMV)	ganciclovir, foscarnet (can be taken orally, IV or intravitreal)

Nutrition and Vitamins

In HIV disease the body's immune system is constantly fighting off the virus and more nutrients are needed to fuel the immune system than for uninfected people. Nutrients can also become depleted in the course of the disease, leading to malnutrition and weight loss, and some HIV drugs themselves reduce nutrients in the body.

All of this means that good nutrition and diet are crucial components of maintaining your health. Different foods play different roles. A balanced diet of macronutrients (proteins, carbohydrates and fats) and micronutrients (vitamins and minerals) is important for maintaining a healthy immune system. Supplementing a balanced diet with extra vitamins and minerals can help avoid nutrient deficiencies caused by HIV disease and HIV-related medications.

Free radicals are unstable oxygen atoms produced naturally through cellular processes in the body which can lead to increased risk for cancer and other health problems. Antioxidants are micronutrients that help eliminate free radicals. Supplementing a balanced diet with antioxidants, such as vitamin A, vitamin C, vitamin E and selenium, can also help maintain a healthy immune system.

The chart below is a basic regimen for people living with HIV who want to supplement a balanced diet with additional micronutrients:

vitamin B-complex	vitamin E
zinc	NAC (n-acetyl cysteine)
vitamin C	evening primrose oil/flax oil
selenium	calcium/magnesium

(9. Reprinted from HIV& Nutrition, A Start)

There are many other supplements which some PHAs take in addition to this basic regimen. If possible, try to consult with a nutritionist or naturopath who is knowledgeable about HIV disease. They can help you determine which supplements are appropriate for you at a cost you can afford.

Other Complementary Therapies

Complementary therapies are non-medical treatments that can be used besides the medications you are taking. Some of the wide range of complementary therapies PHAs have been using can be seen as different forms of medicine or treatment: Acupuncture; Aromatherapy; Ayurvedic Medicine; Chiropractic; Herbalogy; Homeopathy; Energy Balancing; Iridology; Traditional Chinese Medicine; and Naturopathy. Some involve more psychological or emotional facets of health: Pranic Healing, Psychotherapy, and Counselling. Some are more physical practices or exercises such as Massage, Reiki, Reflexology, Shiatsu, Tai Chi and Yoga. People use these treatments or practices for various reasons: boosting the immune system; counteracting drug toxicities; relieving symptoms; side effects and overall stress; and improving general emotional, mental, spiritual and physical well-being.

Access to Complementary Therapies

Unfortunately, complementary therapies are not available in all parts of the country and can be expensive. As with so many other areas of HIV treatment, care and support, this means that access to these therapies is inequitable.

Some complementary therapies are covered in a few provinces and territories and by private insurance plans. Some ASOs provide free vitamins or nutritional supplements. In addition, some ASOs provide financial assistance for complementary therapies and can negotiate a reduced fee for a complementary service. Check around to see what the situation is for the therapies you need.

Choosing complementary therapies and therapists

It may be helpful to consider the following questions when you look into a specific complementary therapy or provider:

1. What are you hoping to get out of it?
2. Is there any research or other information on the therapy?
3. Have other PHAs used the therapy or the therapist providing it?
4. Are you able to talk to any of them about their experience?
5. Are there any side effects from the therapy?
6. Does the therapy combine well or badly with any medication you are taking?
7. Are home or hospital visits possible if needed?
8. How often do you need to have treatments?
9. How much does it cost?
10. Is there a sliding scale of fees depending on income?
11. How much experience/knowledge/training does the therapist have in HIV?
12. Is the therapist affiliated with an association?
13. What are his or her qualifications?

We sketched out some signposts for dealing with your doctors earlier. The same considerations apply to complementary therapists as well.

So, Who's Got All the Answers?

No one. HIV treatment and clinical science are changing all the time. Even the most dedicated health care provider or PHA has trouble keeping up and there is still a lot we don't know. The best health care providers are going to recognize this uncertainty and complexity. They are going to be comfortable sharing all available information (even when it is contradictory and incomplete), discussing all the pros and cons of your treatment options (even when they believe strongly one option is preferred) and helping you decide what is best for you (best in terms of your quality of life, not just your $CD4^+$ count). You would be right to be really sceptical of any provider who tells you they know all there is to know about HIV treatment or that there is only one way to treat your particular situation.

The best way to manage your treatment is in partnership with your doctor and other providers. But ultimately, you make the decisions – it's your body and your life. Being comfortable with that may be the best test of all of how good your health care provider is.

Conclusion: Managing Your Treatment

There have been some real advances in the range and effectiveness of HIV treatments and there is finally hope of major improvements for PHAs' health. At the same time, basic scientists are gaining a clearer insight into the complex workings of the immune system. Their discoveries may pave the way in the near future for therapies that could help restore and rebuild damaged immune systems.

But this progress doesn't mean it is getting any easier to manage your treatment. The sheer volume of research reports, medical literature, clinical guidelines and other treatment information can be mind-boggling. Sorting out the hype from the hope and trying to make your best decisions among so many options is getting harder and harder.

We started this guide by saying that amongst all the uncertainty and the sometimes overwhelming amount of new information, there is one thing we know for sure - access to easy-to-use, understandable and reliable treatment information is more important than ever. That's what this guide has been all about - a good starting point for the information you need to manage your treatment. And that is what CATIE is all about - providing PHAs and their caregivers with all the treatment information they need. So get in touch with us when you need more detailed or specific information on any facet of HIV treatment.

Further Resources

This guide contains basic information on treatments, but it is really only a starting point. You can discuss anything in this guide, get more detailed information on particular treatments or conditions, and get help with decision-making by calling the bilingual, confidential and free national HIV/AIDS Treatment Information Network at CATIE at 1-800-263-1638 (in Toronto, call 944-1916). CATIE also publishes a variety of factsheets and other material on HIV treatment which we can send you or you can visit our website.

CATIE's HIV/AIDS Treatment Information Network

1-800-263-1638, in Toronto call (416) 944-1916
Free and confidential access to treatment information, in both French and English.

Treatment Information Consultants are available:
Monday, Friday, Saturday - 10 a.m. to 6 p.m. (EST)
Tuesday to Thursday - 10 a.m. to 10 p.m. (EST)

Internet: http://www.catie.ca **e-mail: info@catie.ca**

Disclaimer

The Community AIDS Treatment Information Exchange (CATIE) provides information resources to help people living with HIV/AIDS who wish to manage their own health care in partnership with their care providers. We do not recommend or advocate particular treatments and we urge users to consult as broad a range of sources as possible. While we update our material regularly, users should be aware that information changes rapidly. Additional or updated information can be obtained by calling CATIE at 1-800-263-1638 or at our website at www.catie.ca. Users relying on the information do so entirely at their own risk. Neither CATIE, Health Canada nor the Ontario Ministry of Health accept responsibility for any damage that may result from the use or misuse of this information. Decisions about particular treatments should be made in consultation with a health care professional knowledgeable about HIV-related illnesses and the treatments in question.

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Appendix 1 : Nucleoside analogue reverse transcriptase inhibitors

DRUG: AZT (Zidovudine, Retrovir)

Dose: 200 mg three/day or 300 mg twice/day

Side effect: anaemia, neutropenia, myopathy (muscle weakness), nausea, insomnia, headaches, fatty liver, lactic acidosis

Drug interactions: probenecid, myelosuppressive agents - ganciclovir and chemotherapy

DRUG: ddI (didanosine, Videx)

Dose: >60 kg-200 mg twice/day. <60 kg- 125 mg twice/day taken on empty stomach

Side effect: pancreatitis (nausea, vomiting and abdominal pain), peripheral neuropathy, diarrhea

Drug interactions: interference with absorption(ketoconazole, dapsone, tetracyclines, quinolones, antacids, d4T, ddC, pentamidine, oral ganciclovir and drugs associated with peripheral neuropathy and pancreatitis)

DRUG: ddC (zalcitabine, Hivid)

Dose: 0.75 mg three/day

Side effect: ulcers, pancreatitis, peripheral neuropathy, rash

Drug interactions: other drugs associated with peripheral neuropathy and pancreatitis such as: pentamidine, ddI, disulfiram, ethionamide, ganciclovir, isoniazid, phenytoin, vincristine, hydrazaline, metronidazole

DRUG: d4T (stavudine, Zerit)

Dose: >60 kg- 20 or 40 mg twice/day, <60 kg - 15 or 30 mg twice/day

Side effect: peripheral neuropathy, pancreatitis

Drug interactions: ddI, ddC, foscarnet, amphotericin, dapsone, ganciclovir

DRUG: 3TC (lamivudine, Epivir)

Dose: 150 mg twice/day

Side effect: neutropenia, gastro-intestinal intolerance

(2. Reprinted from Therapeutic Guidelines Committee, Ontario)

Appendix 2 : Non-nucleoside analogue reverse trancriptase inhibitors

DRUG: Delavirdine

Dose: 400 mg three/day

Side effect: rash, increase in liver enzymes

Drug interactions: rifampin, rifabutin, terfenadine, astemizole, cisapride, triazolam, alprazolam, midazolam, saquinavir, indinavir

DRUG: Nevirapine

Dose: 200 mg twice/day (200 mg escalated for two weeks, then 200 mg twice/day)

Side effect: rash, increase in liver enzymes

Drug interactions: terfenadine, astemizole, warfarin, cimetidine, ranitidine, dilantin, ketoconazole, itraconazole, corticosteroids, erythromycin, saquinavir, indinavir

DRUG: Loviride

Dose: 100 mg three/day

Side effect: rash

(3. Reprinted from Therapeutic Guidelines Committee, Ontario)

Appendix 3 : Protease Inhibitors

DRUG: Saquinavir (Invirase)

Dose: 600 mg three/day close to every 8 hours as possible, not to be taken on an empty stomach.

Side effect: rash, fatigue, nausea, diarrhea, stomach discomfort

Drug interactions: rifampin, rifabutin, terfenadine, astemizole, cisapride, delavirdine, triazolam.
increase saquinavir levels: clarithromycin, ketoconazole, itraconazole, rantidine, erythromycin
decrease saquinavir levels: dexamethasone, nevirapine, dilantin, rifabutin

Additional Information: only 4% of saquinavir is absorbed, it should be taken within two hours of a high fat meal (cheese, peanut butter, pizza), ketoconazole and grapefruit juice helps increase absorption of saquinavir

(4. Reprinted from Therapeutic Guidelines Committee, Ontario)

DRUG: Ritonavir (Norvir)

Dose: 600 mg twice/day every 12 hours, with a light meal or on an empty stomach, manufacturer recommends taking ritonavir with food

Side effect: nausea, weakness, vomiting, diarrhea, tingling sensation of lips, altered taste, elevation in liver enzymes and lipids, low glucose

Drug interactions: rifampin, rifabutin, ethinyl estradiol, theophylline, anticonvulsants, astemizole, terfenadine, meperidine, propoxyphene, piroxicam, amiodarone, quinidine, encainide, flecainide, propafenone, bepedril, desipramine, cisapride, bupropion, clozapine, alprazolam, diazepam, midazolam, flurazepam, triazolam, disulfiram, metronidazole

Additional Information: must be refrigerated, single capsules can be kept at room temperature for up to 12 hours, to minimize adverse side effect it is recommended to follow dose escalation, due to the numerous drug interactions it is important to let your pharmacist and the doctor know of all prescriptions you are taking

(5. Reprinted from Therapeutic Guidelines Committee, Ontario)

DRUG: Indinavir (Crixivan)

Dose: 800 mg every 8 hrs, to be taken on an empty stomach or with a light snack

Side effect: insomnia, kidney stones, elevation in indirect bilirubin

Drug interactions: rifabutin, rifampin, ketoconazole, itraconazole, terfenadine, astemizole, cisapride, triazolam, midazolam

Additional Information: to be taken two hours after a meal or one hour before a meal, a light snack consists of corn flakes and skim milk, toast with jam, juice, or coffee/tea, recommended to drink six-8 oz glasses of water or 1.5 litres /day

(6. Reprinted from Therapeutic Guidelines Committee, Ontario)

DRUG: Nelfinavir (Viracept)

Dose: 750 mg three/day to be taken with food

Side effect: mild to moderate diarrhea, abdominal pain,elevation in liver enzymes

Drug interactions: rifampin, rifabutin, terfenadine, astemizole, cisapride, triazolam, midazolam

Additional Information: works well with AZT, ddI, ddC, d4T, or 3TC, may be beneficial for persons who have developed resistance to other protease inhibitors

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1-800-263-1638, in Toronto call (416) 944-1916
Free and confidential access to treatment information, in both French and English.

Treatment Information Consultants are available: Monday, Friday, Saturday - 10 a.m. to 6 p.m. (EST). Tuesday to Thursday - 10 a.m. to 10 p.m. (EST)

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