

HOPE

Positive Living

Positive Living

A Resource Guide For Persons Who Are HIV Positive

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Introduction: You're HIV Positive

Learning to deal with an HIV-positive diagnosis is an important first step towards staying healthy. This book was written to help you, your family and your friends:

- Cope with your HIV positive status;
- Stay as healthy as possible;
- Understand the many issues facing HIV positive people; and
- Find help and answers.

HIV-infection is not the quick death sentence it once was. It has now become a chronic, manageable disease. New drugs help people to stay healthy longer while increasing their quality of life. Therefore, you should take an active role in determining your health care needs.

The HIV Positive Health Book was developed by the Virginia Department of Health Division of HIV, STD, and Pharmacy Services with the assistance of people who are living with HIV. It is designed to help you confront many of the issues important in managing your health care.

Fortunately, we know a lot about HIV infection. However, with so much information it is easy to become overwhelmed, especially at first. To help you, we have highlighted the major points on the side of each page. Take your time and if you need help ask for it.

If you want more information or need to find services in your local area, there is a referral listing included in the back of this book. You may also contact the **Virginia HIV/STD/VIRAL HEPATITUS Hotline at 1-800-533-4148**. Trained counselors are available 8 a.m. to 5 p.m., Monday through Friday to answer any questions you may have about HIV and sexually transmitted diseases (STDs).

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Chapter 1

HIV/AIDS Disease Facts

HIV is the virus that causes AIDS. HIV stands for the Human Immunodeficiency Virus. HIV can be passed through blood, semen, vaginal secretions, and breast milk. It usually enters the body through sexual contact or blood (for instance, if you share needles). It attacks and weakens the immune system by seeking out, entering and destroying helper CD4+ cells (also called T-cells). These are the cells that help to keep you healthy.

HIV is the virus that causes AIDS.

AIDS is the last stage of HIV infection. AIDS stands for the Acquired Immune Deficiency Syndrome. Over time, HIV damages the body's immune system by destroying helper CD4+ cells (T-cells). As a result people get infections and cancers which usually are not a threat to healthy individuals. These illnesses are often called opportunistic infections. A diagnosis of AIDS is made when an HIV positive individual becomes sick with one or several of these illnesses or when their immune system becomes weak.

AIDS is the last stage of HIV infection.

What Does a Positive HIV Antibody Test Mean?

A positive test result means your body is producing the HIV antibodies. This means you are infected with HIV. **A positive antibody blood test does not mean you have AIDS.** You don't have AIDS as soon as you're infected with HIV. The disease process takes a while. A person goes from being HIV+ without any symptoms or signs of disease to being HIV+ with symptoms to having AIDS.

A positive test result means you are infected with HIV.

Based on past experience, most people who test positive for HIV will likely fall somewhere in between the two illness extremes. They can expect to have a few symptoms here and there over a number of years before being diagnosed with AIDS. Symptoms won't show up on any set schedule or in any particular order.

Experts now say the average length of time between your infection with the virus and your first serious AIDS-related illness is 10-15 years. Though no one knows exactly why, a large percentage of women, infants, and the elderly seem to become ill sooner.

A positive test DOES NOT mean you have AIDS.

However, keep in mind that these "predictions" apply to the group of HIV-infected people as a whole. You as an individual may have a very different outlook. A lot can depend on your general state of health at the time you got the virus, how long you've had it and how much you decide to fight it now. Only time will tell what your own experience will be.

A positive HIV antibody test also means you can pass the virus to other people, even if you don't have AIDS. The virus can be passed through unprotected sex, sharing drug needles or needles for tattooing or body piercing. It cannot be passed through sweat, saliva, tears, or urine. There is no evidence that HIV can be passed through casual contact such as sharing food or toilet seats.

A positive HIV antibody test means you can pass the virus to other people through sexual contact or sharing needles.

You may have a hard time believing that you are HIV positive-especially if you are not feeling sick. Many people are in good health and have few symptoms when they first find out they are HIV positive. A few men and women won't have any HIV-related symptoms at all. Everyone with HIV will have a different experience. Even if you have no signs of the disease yet, you can still infect others and you should still see a doctor. The sooner you begin treating your disease the better off you will be.

You can have HIV and not feel sick.

Even if you stay well, the HIV virus keeps reproducing and you can pass the virus to others.

The average time between your infection with HIV and your first serious AIDS illness may be 10-15 years or longer.

You will need different treatment at different stages of your illness.

How does HIV progress (turn into) to AIDS?

There are four stages of HIV disease:

1. Shortly after you become infected you may experience flu-like symptoms that last a few days or a few weeks. This period is called Primary Infection - also known as seroconversion.
2. In the second stage of HIV after seroconversion you may or may not experience any health problems. This period is called Asymptomatic meaning that you have no signs of HIV disease. This may last for many years. However, although you remain well, HIV continues to reproduce and you are able to pass the virus to others. Studies show you may be able to pass the virus to others as early as 24 hours after you become infected.
3. As HIV weakens your immune system, you may begin to have health problems such as fatigue, night sweats, diarrhea, or weight loss.
4. Advanced HIV disease or AIDS is the last and most serious stage of your disease. It occurs when your immune system is so weakened that it can no longer fight off infections. At this point, you may develop opportunistic infections (thrush, pneumonia, cytomegalovirus, etc.) or other problems. After you have reached this stage, it is even more important that you receive on-going medical care. Treatments are available to help you fight off these infections and some medications can help prevent opportunistic infections. If your CD4 count falls below a certain level, your doctor may recommend that you start some of these medications. While a diagnosis of AIDS can be frightening, with treatment and regular medical care, people with AIDS can live for many years.

These stages are important because your health must be checked and different treatments considered at each stage.

Chapter 2

Emotional Reactions To Being HIV+

First Reactions

Finding out that you are infected with HIV is usually overwhelming. Everyone will react differently. Often a first reaction is shock and disbelief: "I can't believe this is happening to me!" "The test results must be wrong." You may also be angry with yourself or at someone who may have infected you. You may want someone to blame. Some people also feel guilty about their behavior or about whom they might have infected. Guilty feelings may also arise as you fear burdening loved ones with your care or wonder who will take care of your children if you become ill. You may feel like you have received a death sentence and have strong fears about death or dying.

After the initial shock, some people cope by going through a stage of denial. They try to forget or ignore their diagnosis. While this can sometimes help in handling difficult emotions, it can also be harmful if you continue participating in risky behavior or do not take your medication. Being diagnosed with HIV often makes people feel like they are on a roller coaster of emotions. Your mood may change from day to day or hour to hour. You may be angry one moment and terrified the next. The stress from finding out you have HIV as well as from having to make big changes in your life can lead to physical problems such as headaches, upset stomach, irritability and difficulty concentrating.

If you're a teenager who has just learned that you are HIV positive, you may face some stress that adults and children don't have. You aren't little anymore, but you're not quite an adult yet, either. You may not be very comfortable with your body, your family, your friends or sex. There can be a lot of pressure both from inside yourself and from people around you. The news that you are HIV positive may feel like one big thing too many on your plate. It is very common for young people (and older persons too) to try to make the news that they are infected "go away" by ignoring it. Unfortunately ignoring HIV can leave you lonely, depressed and can be dangerous to your health. You may not have an adult in your life you can talk to. If you are not ready to tell anyone you know personally, try talking anonymously to someone at a hotline or HIV service agency. The Virginia HIV/STD/Viral Hepatitis Hotline number in Virginia is 1-800-533-4148. The most important thing is to find someone who can provide medical care and treatment. Help is available.

Loss

People with HIV experience many losses. These may include changes in body image, loss of employment, insurance, financial security, friends/family and sexual intimacy or spontaneity. Medication schedules can serve as a constant reminder that you have HIV and keep you from feeling carefree. You may also worry about loss of independence and having to rely on others.

Men and women may grieve that having HIV will limit their options for having children. Those who want a family must face the fact that doing so will place both their partner and child at risk for HIV infection. Even people who may have decided not to have children or are already parents may have difficulty dealing with their loss of choices regarding reproduction.

Everyone will react differently when they find out they are infected with HIV.

Anger, guilt, denial, shock, fear, disbelief and grief are common feelings.

Your feelings and emotions will change a lot.

You may not be able to tell your family or friends, but you do not need to handle this alone. Help is available!

People with HIV experience many losses and can feel out of control.

You may also have to deal with loss of privacy about your life. Revealing your HIV status to loved ones may include revealing information about sexual orientation, sexual behavior, drug use, other health concerns or the behavior of a partner.

People with HIV also experience loss in the most basic sense when a partner or friend dies. In addition to losing a person very dear to you and dealing with normal grief reactions, the death may represent loss of your support system and bring up fears about your own death. Some people who are there when a loved one dies wonder who will be there for them when they become ill. Despite the introduction of new treatments, the death of someone who used to be healthy can also take hope away from others living with the virus.

Feeling out of control can lead to depression or alcohol and drug abuse. It can also affect your health.

The loss of control felt by people with HIV makes it very important that you take control of as many areas of your life as possible. Learn as much as you can about the disease and work with your doctor to make decisions about your health care. Ask for help and support when you need it but don't let well-meaning friends do things for you if you're healthy and can do them for yourself.

Depression

A common response to any life changing event or bad news is depression (feeling sad or blue). Most people with and without HIV experience depression at some point in their lives. Depression becomes serious when it lasts longer than a few weeks. Some common symptoms of depression are:

- loss or increase in appetite;
- sleeping all the time or insomnia (being unable to sleep);
- withdrawal from friends, family or activities you used to enjoy;
- uncontrollable crying;
- inability to concentrate;
- loss of sexual interest;
- thoughts of suicide or hurting yourself;
- agitation or mental slowness; and
- feelings of hopelessness.

Do not ignore your feelings. Depression can weaken your immune system and make you sicker.

Your thoughts and emotions have a direct impact on your immune system. Depression and mental stress can weaken your immune system. Depression can also lead to increased use of drugs or alcohol in order to cope with the painful feelings, increased cigarette smoking, not taking your medicines, and risky sexual behavior. All these things can damage your immune system and speed up the growth of HIV disease in your body.

Depression can be treated. You don't have to live with depression.

Sometimes your feelings will be caused by your illness or the drugs you are taking. Some of the medications used to treat HIV or opportunistic infections can cause depression. If you are tired, it may be caused by the virus or depression. Make sure you let your doctor know how you are feeling so that you can determine what is going on.

The most important step in dealing with depression is recognizing that you are depressed. Often it takes friends or loved ones to point this out and suggest that you seek help. Depression can be treated in many ways. Not everyone responds the same way and different methods may help different people. Some things that may help include:

- counseling-either one-on-one with a therapist or in a group;
- support and self help groups-talking with other HIV positive people;
- medication-there are many antidepressants that your doctor can prescribe;
- relaxation or meditation;
- exercise;
- good nutrition; and
- religion or spirituality.

Stress

Everyday we adjust to a variety of changes and stressors. People respond to stress in different ways. You may notice physical changes (muscle tension, increased heart rate, diarrhea, trouble sleeping) or emotional changes (irritability, anger). It will take time to develop ways to cope with the stress you are now facing. Most people over time accept being HIV positive, however this is a difficult process which involves a wide range of feelings. Increasing your awareness and accepting your diagnosis will help you deal with the additional stress.

Signs of Stress

It is important that you recognize signs of stress. These include:

- Increased muscle tension
- Headache
- Loss of appetite
- Use of sex for escape or relief
- Decreased productivity
- Irritability
- Anxiety
- Blaming others
- Sense of helplessness
- Upset stomach
- High blood pressure
- Increased use of drugs
- Spacing out
- Increased illness
- Depression
- Withdrawal
- Emotional outbursts

Ways to Cope with Stress

Learning to cope with your stress is also important. Ways to deal with stress include:

- Mindfulness
- Yoga
- Silence, solitude
- Pets
- Group support
- Humor
- Crying
- Meditation
- Prayer
- Slowing down
- Affirmations
- Helping others
- Self acceptance
- Being assertive
- Relaxation
- Breath awareness
- Exercise, sports
- Counseling
- Information
- Sharing feelings
- Developing a hobby

Talk to your healthcare providers about any problems you may be having coping with stress in your life. It may help to talk about your feelings with a counselor or mental health professional.

Learning that you are HIV positive will also add stress to your life.

Some of the stress comes from feeling like you have lost a lot or fear of the future.

Like depression, stress can weaken your immune system and can make you sicker.

To fight feelings of loss, sadness and stress try to take control of your life. Get help if you need it.

Family And Friends

Your family and friends will have many of the same feelings you have if they know you have HIV. Give them time to work out their feelings.

Your family and friends may experience similar emotions to yours in finding out that you are HIV positive. Shock, anger, denial, and depression may affect them just as deeply. They may feel guilty that they are HIV negative and healthy. They may feel panic about not knowing what to do if you become ill. They may not know a lot about HIV and be worried that they could become infected. They also need support and people to talk to. Many organizations have support groups for partners, family and friends of those with HIV.

Finding The Positive Aspects Of Being HIV Positive

Your life does not have to be all doom and gloom. People who are not HIV infected and those who are newly diagnosed might laugh at the idea that HIV can bring positive changes to your life. However, people living with HIV have found it provides them with personal challenges that have allowed them to discover strength within that they never knew they had. It gives other people the opportunity to learn to accept assistance and love. You may also find out that there are true friends and family members who will stand by you with laughter, support and love. Many people with HIV begin living a healthier lifestyle than they ever have before and feel better than they did before their diagnosis. An HIV diagnosis also gives some the motivation they need to stop using drugs or alcohol. Humor, in the face of difficulties and challenges, can often be our best weapon in returning joy to our life.

HIV positive or negative, we will all die someday and none of us knows what day that will be. People living with HIV have the opportunity to recognize the uncertainty of life and the importance of not wasting time, doing things they have put off in the past and healing relationships.

Even though you are HIV+, your life does not have to be all doom and gloom.

Learning they have HIV inspires many people to make positive changes in their lives.

Chapter 3

Telling Others You Are HIV Positive

Review the people in your life to determine who needs to know your HIV status. It is your choice who to tell, however, there are several people you must inform.

Who You Must Tell

The people who should know about your illness are:

1. Past and current spouses

If you are currently married or have ever been married in the past ten years, you will need to inform your current and former spouse(s) that they may have been exposed to HIV. If you do not want to contact a former or estranged spouse, the Virginia Department of Health offers partner counseling and referral services. The health department will contact your spouse(s). This is done safely and confidentially. Your name will not be given. If you are afraid of your spouse's reaction, contact a local AIDS Service Organization and ask for the services of a Case Manager. (See Chapter 13 for a list of organizations that can assist you.)

2. Past and current sexual partners or needle sharing partners

These individuals also need to be told that they may have been exposed to HIV. Encourage them to seek HIV testing and counseling. If you don't want to tell your partners, the Virginia Department of Health partner counseling and referral services can assist you by contacting previous partners. Again, this is done safely and confidentially. Your name is never given. Information on your status will also not be given to your employer or your insurance company. If you need help, contact your local health department or ask your health care provider to contact them for you.

3. Future sexual or needle-sharing partners

Before having sex or sharing needles with anyone, tell them you have tested positive for HIV. This protects you from legal problems and prevents the spread of HIV. While you may fear being rejected, it is important that your partners be able to make an informed choice about their health care.

4. Doctor & Dentist

It is best to reveal your status to all your health care providers in order to receive the best possible medical and dental care. Speak with your doctor about what could happen if your test results are placed on your medical and dental records. This is important because it could be given out to other parties, such as insurance companies. Doctors and dentists may have negative reactions when they find out you are HIV positive. If you feel your doctor or dentist can no longer provide you with the kind of care you want or need, find a new health care provider. (See Chapter 6 for help in choosing a doctor.)

You do not have to tell everyone that you are HIV+. In most cases, it is your choice.

You do need to tell your current and former spouses and past, current and future sexual or needle sharing partners.

The Virginia Department of Health offers Partner Counseling and Referral Services to help you contact former partners.

You should also tell your doctor and dentist that you are HIV positive.

Telling Friends and Family

Other than those who should know, think carefully before you tell others.

Sharing with others that you are HIV-positive is very difficult. While having HIV is nothing to be ashamed about, you should still be careful who you tell. Other than your health care providers and sex or needle-sharing partners, think carefully about others who may need to know. If you decide to tell your friends or family, you may want to ask them to keep the matter to themselves. Friends and relatives may also ask about personal issues regarding your lifestyle and contacts. They may want to know exactly how you became infected with HIV. You do not have to answer all their questions. You have the right to privacy.

Telling people about your HIV status can be very hard and some people may not react positively.

Telling someone you are HIV positive can be a very emotional experience. Remember, not all reactions may be supportive. Choose to tell your friends where you feel safe and comfortable expressing your feelings. Have realistic expectations. Try to remember how you felt when you were first told that you were HIV-positive. The person you are telling may have the same feelings you had at that time. Try not to be hurt by someone's desire to be left alone. They may simply need time to adjust to your news.

Knowing your HIV status may affect a friend or loved one's desire to be with you. The reason for someone's negative reaction may not make sense. For example, some people may fear they will "catch" HIV from you. Explain how HIV is transmitted. Some of your friends and family members may fear losing you to this disease. Explain that HIV has become a more manageable disease. If your family and friends have questions you cannot answer or feel uncomfortable answering, give them a brochure about HIV and AIDS or refer them to the Virginia HIV/STD/Viral Hepatitis Hotline at 1-800-533-4148.

Telling Your Boss

You do not need to tell your boss unless your illness is affecting your work.

Should you tell your boss you're HIV-positive? It depends. Employers cannot discriminate against people with disabilities and this includes people infected with HIV. However, just because you have some protection, it does not mean that letting your boss know that you are HIV positive is a good idea. Knowing about your HIV status may affect other things such as how your boss feels about you. Also, although information in your medical and personnel records is private, casual conversations with your boss aren't. Once you share your HIV status with him or her, you have no clear legal protection if your boss shares your story with others. If you haven't had any HIV-related symptoms or illnesses and are not on medicine that is affecting your work, there's probably no need to tell anyone at your job.

You cannot be fired for having HIV.

However, there are reasons why you may want to tell your boss. If your illness is making it hard for you to do your job or you need to take a lot of time off work due to illness, you should let your boss know you have HIV. You cannot be fired for having HIV, but you can be fired for not doing your job well. If your health is affecting your work and only you know why, you can't blame your boss. However, before you talk with him or her, you should know that you do have certain legal rights in the workplace.

You do have some protections under the Virginians with Disabilities Act (VDA) and the Americans with Disabilities Act. (ADA). For instance, your company cannot lay you off just because you have HIV. Your employer must also make “reasonable accommodations” to help you keep working. This means letting you work a different schedule or giving you a break when you need to take medicine. Another law called the Family Medical Leave Act (FMLA) lets you take off work for up to 12 weeks a year for medical reasons. During this time your job and your benefits are protected. However, your company does not have to pay you during this time, if you have used up all your sick or annual leave. (See Chapter 12 for information on other workplace issues.)

If you decide to tell your boss, ask your doctor to write a letter explaining the current state of your illness and how it might affect how you do your job. Keep a copy for yourself. Let your boss know you want to continue to do your job as best you can, but that because of your illness or medication, there are times when your schedule or workload may have to be changed. Your employer must make reasonable changes to help you.

Sharing With Others Who Are HIV Positive

There is no need to handle your HIV status all by yourself, and it is probably a mistake to even try to do it. It is much more difficult to get on with your life and live happily if you are trying to do it alone. You are not the only person facing this. Sharing with others who are HIV positive can be very helpful. Just hearing how they are living with the virus can help you find ways to cope with your illness.

Having support from others not only can help you cope emotionally, it can also provide positive physical benefits. Studies have shown that people with lots of social support stay healthier longer.

Support groups are a powerful way of learning to cope with this change in your life. There are many support groups offered by HIV/AIDS organizations. (For information on how to find a support group in your area, see Chapter 13.)

By taking an active role in monitoring your health care as well as acquiring a healthy outlook, you will be working toward maintaining your health. Choosing to share this information is difficult and takes a great deal of courage. Remember that you are not responsible for other people’s reactions. You need to take care of yourself.

If you are having trouble doing your work because of your HIV, your boss must make Reasonable Accommodations meaning he/she must try to meet your needs.

Talking with others who are HIV+ can help you cope with your illness.

Support groups are a good way to talk about your feelings.

Remember, you are not responsible for other people’s reactions!

Chapter 4

How Your Body Fights HIV

Your immune system defends your body against disease. For example, when a cold virus invades your body, your immune system sends special cells to fight it. You may sneeze, sniffle and feel miserable for a few days, but finally your immune system works to kill or control the virus and you feel fine again.

Your immune system protects your body from disease.

Viruses, like those that cause the common cold, cannot grow 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 is different from a cold virus because it directly attacks the infection-fighting cells called CD4+ cells in your immune system. HIV infects CD4+ cells (as well as other cells in the body) in order to grow, killing these infection-fighting cells. This is why HIV is so damaging to the immune system.

People who have HIV and a weakened immune system can't fight infections as well as a healthy person's immune system can. They often suffer from illnesses that healthy people don't have to worry about.

HIV attacks and weakens the immune system.

Keeping Track of Your Immune System

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

CD4+ Count

CD4+ cells are your cellular immune system's fighter cells. Therefore, when HIV weakens the immune system, the number of CD4+ cells begins to fall. The level of CD4+ cells is one of the most important ways that your doctor can tell how badly the immune system has been damaged or how quickly it is failing. Carefully keeping track of CD4+ levels helps you and your doctor know what illnesses to watch for and what treatment options to consider.

When your immune system is weak, you get sick.

People with HIV disease should have their CD4+ count measured every three months. Normal CD4+ counts in healthy people are generally above 500. Since, CD4+ cells are the major targets of the HIV infection, CD4+ counts can vary by time of day, from day to day, and from lab to lab. Therefore, it is important to take the test about the same time of day and at the same lab. Other viral infections, smoking and stress may also affect CD4+ counts. Cell values tracked over time are valuable in determining how your immune system is working.

Your doctor will carefully watch your immune system. You should talk to your doctor about changes in your immune system, especially your CD4+ cells, as this will help you make important decisions about if or when you should start certain treatments.

Two tests tell you how well your immune system is doing.

Viral Load

The viral load test is another way to find out how your immune system is working. Viral load measures the amount of HIV in your blood. Testing viral load is a simple process- just a little blood is drawn- but it has become very important in the management of HIV infection. The test counts HIV in your blood, the higher the number the more HIV. This test is important because it may tell you how well your drugs are working, if you are going to get sick soon, and possibly how long before you get AIDS.

They are called CD4+ COUNT and VIRAL LOAD.

You need to take a test to fix a starting point from which to measure your CD4+ count and viral load.

Because viral load testing is so important now that you are HIV positive, you should learn what this test is and how it is used. Trying to understand viral load measurements is not easy. Ask your doctor to help you understand this process.

Different types of viral load tests are used. Because the tests do not give exactly the same results, it is important to have the same type of viral load test done each time. This will give your doctor a measurement against which all other changes can be compared.

Your first viral load test will give you a baseline (starting) value to compare to future tests. You should take two different tests two to three weeks apart to find out your baseline value. After that, you should repeat the test every three to six months or after starting or changing drug therapy.

You will then need to check both your CD4+ count and your viral load regularly.

When you are first infected, the viral load is very high, but then it usually drops and levels out - that level is called the “set point.” Everyone has a different set point and their 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 cause AIDS and the higher the set point, the more likely it is you will get AIDS sooner.

Certain other factors, such as immunizations or infections like the flu, a cold or a herpes outbreak, will increase HIV growth for a short time and therefore viral load, so it is best to not take a viral load test for about a month after an infection or immunization. Viral load tests are expensive so it is important to have them taken at the right times.

If you are not taking anti-HIV drugs, your viral load may provide clues to the likely course of the HIV infection if left untreated. Among a group of people who have the same CD4+ count, those with higher viral load tend to get sick faster than those with lower viral load.

Your CD4+ count and your viral load will tell you if HIV is growing in your body and how well your anti-HIV drugs are working.

If you are thinking about taking anti-HIV drugs, it is also useful to have a viral load test. The result, along with other things such as your CD4+ count and symptoms, may help you decide whether or not to start treatment. Some doctors advise people who have very high viral load to take more powerful treatments. (See Chapter 5 for information on the treatment of HIV.)

After treatment, many individuals have an undetectable level of virus in their blood. Undetectable levels mean that HIV has fallen to very low levels in your blood. **Even if your HIV level is undetectable, it DOES NOT mean that you are “cured” or cannot spread the disease to others.** You may still have small amounts of HIV in your blood. Also, viral load only measures HIV in the blood. You still have HIV in other parts of your body.

To stay healthy, your CD4+ count should stay high and your viral load should stay low.

People with HIV should have both their CD4+ and viral load tested regularly. Together these two tests can help your doctor determine how to treat your disease.

Watching For Symptoms

Checking for changes in your immune system is one way to figure out how your HIV disease is progressing. You can also help your doctor by watching for symptoms or changes in your body that you do not think are normal. It's important that you keep a close watch on your body but try not to go overboard. When you are nervous or upset, it's easy to mistake normal conditions (like acne or mosquito bites) for something more serious.

New symptoms or illness can be frightening, particularly when you first find out that you are HIV positive. If you notice something that is out of the ordinary, make a note of it. You may want to use the Event Tracker at the back of this notebook for this. Take your tracker to the health care provider each time you go so you can find out if it is something to worry about. Don't be embarrassed if it turns out to be nothing.

If you are in pain, do not question whether or not your new symptom is a problem: call your doctor.

After treatment, many people have a level of HIV in their blood that is Undetectable meaning HIV in the body is at a very low level.

Even if your HIV level is undetectable, you are NOT CURED. You still have HIV and you can still give the virus to others.

Don't count on your test results alone to know how you are doing. Watch for other changes in your body and tell your doctor about them.

Chapter 5

Treatment Of HIV

Although there is still much to discover about HIV/AIDS, medical research has learned a lot about treating people who have it. New drugs and treatments are being developed all the time. While it may be hard to understand all of the medical and scientific terms, these treatments are your best chance for living a healthy life with HIV disease. Thus it is important that you:

- Try to understand the various types of treatment;
- Talk to your health care provider about treatment options; and
- Carefully follow the instructions on how to take any drugs you are given.

In addition to medical treatment, many people see improving their general state of health as a very good way of fighting HIV. By becoming healthier, you will help keep your immune system strong. Giving up smoking or other drugs, exercising, eating right, and reducing stress through relaxation are all steps you can take to improve your health and thus fight HIV. Suggestions on how to live a healthier life are provided throughout this book.

Types of Drugs

HIV belongs to a group of viruses called retroviruses. So any drug used to attack HIV is called an anti-retroviral. But it is simpler just to think of them as anti-HIV drugs. There are a number of anti-HIV drugs that are available for use in the United States and several others that are still going through testing. New drugs are often being introduced. Ask your doctor about new drugs or treatments. If you want to learn more about treating HIV, you can also get information that explains new treatments in terms that most people can understand. (See Chapter 13 to learn where to go for more information.)

Anti-HIV drugs fall into four groups:

- Nucleoside/Nucleotide analog reverse transcriptase inhibitors (sometimes called simply nucleosides/nucleotides);
- Non-nucleoside reverse transcriptase inhibitors;
- Protease inhibitors.
- Fusion inhibitors

Each type of medication works at different steps in the process that HIV goes through when it makes new copies of itself inside cells.

Reverse Transcriptase Inhibitors (RTIs)

The nucleosides/nucleotide, and non-nucleosides both have the same “target.” They slow down the action of the HIV enzyme that scientists call reverse transcriptase. Reverse transcriptase is important because it changes HIV in a way that lets it become part of the infected cell inside the cell’s command center, its nucleus. If reverse transcriptase isn’t able to do its job right, HIV can’t take over the infected cell from inside the nucleus and can’t start making new copies of itself. Because they inhibit (slow the growth of) reverse transcriptase enzymes, these two types of drugs are both called reverse transcriptase inhibitors (RTIs).

New ways to treat HIV & AIDS are being discovered all the time.

Talk with your doctor about your medical treatment. Ask questions if you aren’t sure about what you are told.

Taking good care of yourself, eating right, exercising, avoiding street drugs and alcohol can help you fight HIV.

Different drugs fight HIV in different ways.

The difference between nucleosides/nucleotide, and non-nucleosides has to do with how their molecules are linked. It is not important to understand the difference between these two kinds of drugs. The important thing is that both of these drugs stop the way the HIV enzyme (reverse transcriptase) works even though they do it in a different way.

RTIs are the oldest and most widely used HIV/AIDS treatments. They include drugs such as AZT, ddI, ddC, Sustiva, Viramune and others.

One problem with RTIs is that they can be toxic to people who use them—that is, they may have very harmful effects. AZT, for example, slows the creation of bone marrow, which the body needs to manufacture new blood cells. Pancreatitis, which causes severe stomach pain, can be caused by ddI.

All of these drugs may have other side effects as well, ranging from nausea to pain in the hands or feet. Although many of these side effects do not appear to be dangerous, and often go away with continued use, they can still make it very difficult for people with HIV/AIDS to use RTIs easily.

Another problem with RTIs is that their benefits may not last very long. Just as HIV tries to escape the body's natural efforts to fight it off, over time it may also be able to fight off these drugs so they will no longer help you. **This is called drug resistance.** Knowing when and how to use RTIs so that they work the best is among the most important unanswered questions in HIV/AIDS care today.

None of this means that RTIs are not important or useful parts of HIV/AIDS treatment. They have been proven in at least one large study to increase the life span of people with HIV/AIDS and their use by pregnant women greatly lowers the risk of giving HIV to a child at birth.

RTIs and Protease Inhibitors are groups of drugs that fight HIV. There are many different drugs you could take in these groups.

Using different types of drugs helps prevent Drug Resistance. This means it makes it harder for HIV to fight back and stop the drugs from working.

Protease Inhibitors

The third group of anti-HIV drugs is called protease inhibitors. They get their name because they slow down the action of another HIV enzyme, protease. Protease goes to work inside infected cells after proteins made by HIV come out of the nucleus. It works like "chemical scissors," cutting up these long chains of HIV proteins and enzymes into smaller pieces. HIV needs these smaller pieces to make active new copies of itself. Protease inhibitors gum up the protease "scissors." The result is that new copies of HIV aren't made the right way and they can't go on to infect new cells.

Protease inhibitors include the drugs Crixivan, Viracept, Norvir and Invirase. Studies have shown that protease inhibitors are more powerful than RTIs. Certain protease inhibitors can reduce the amount of virus in a person infected with HIV by as much as 99 percent. But a protease inhibitor alone is not a cure for HIV infection or AIDS.

Drug resistance is a serious problem in HIV treatment.

Fusion Inhibitors

The newest type of anti-HIV medication is called fusion inhibitors. Fusion inhibitors work by blocking how HIV gets into immune system cells. Currently there is one drug available in this class called Fuzeon (enfuvirtide). Fuzeon is not available in pill form, it is administered by injection. The most common side effect from this medication is injection site reactions, swelling, redness where the shot is given. Patients are required to inject themselves, which can be problematic for patients who are former IV drugs users, or have a fear of needles. Fuzeon is only prescribed when all other anti-HIV medications are no longer effective.

Drugs that boost your immune system

Some researchers think that HIV can be treated by using drugs that strengthen the immune system, helping it recover from the effects of HIV or fight opportunistic infections. These drugs are called Immunomodulators. Alpha interferon (Roferin), a drug made from a chemical manufactured by the body itself, is one example. It has helped treat Kaposi's Sarcoma or KS, a kind of cancer that can occur in people infected with HIV.

These drugs can be very toxic and more study is needed before we will know just how well they work.

Drug Combinations

As well as the new drugs that have been developed, an important recent advance has been combination therapy- taking various anti-HIV drugs together. Combination therapy has now become the standard of care.

Monotherapy, taking only one drug, is no longer recommended as anti-HIV treatment because HIV can quickly find ways to fight the drug. The virus mutates (changes) within the body and becomes resistant to a particular drug. This means it will no longer work to stop HIV from progressing. Drug resistance is a major concern in fighting HIV. It is much more difficult for HIV to become resistant when you take several drugs at the same time.

Another reason that drugs are taken together (in combination) is that it takes a lot to stop HIV. HIV makes new copies of itself inside infected cells at a very fast rate. Every day, billions of new copies of HIV are made. Every day, millions of infected cells die. One drug, by itself, can slow down this fast rate of infection. Two drugs can slow it down more. Three drugs are needed to slow it down enough to prevent resistance. Your drug combination should include 3 or more drugs.

Yet another benefit of taking more than one drug is that different anti-HIV drugs attack HIV at different steps in the infection process. RTIs stop HIV just after it enters a cell, protease inhibitors stop HIV just before it leaves the cell. Together these drugs just work better. Different drugs also attack the virus in different parts of the body. Since it is important to go after HIV wherever it is hiding, it makes sense to try different drugs. For instance some RTI drugs get inside cells in the brain and spinal cord better than other drugs.

Finally, when anti-HIV drugs are taken the right way, their side effects will not be increased. When doctors plan combination therapy, they try to give drugs that have different side effects so that no one side effect will be so bad that a person has to stop taking the drug or drugs. Your doctor will help you find the strongest combination of drugs with the lowest level of side effects.

Goal of Treatment

The goal of any treatment or drug therapy should be to control the spread of HIV in your body and to stop or delay your getting AIDS. Because all three types of anti-HIV drugs stop HIV from progressing, the best way to see how well the drugs are working is to measure the amount of the virus in your blood by testing your viral load.

Many people with HIV take a number of different drugs. This is called Combination Therapy.

Anti-HIV drugs affect every person differently.

Many anti-HIV drugs have side effects.

Your doctor should help you find the right mix of drugs that fight HIV without making you feel bad from side effects.

If the medicines are working, HIV should stop spreading in your body.

We have already talked about the tests to measure viral load and CD4+ counts. These tests will tell you how well the drugs you are taking are working and will let you know when or if they stop working. The best way to use these tests is for your doctor to measure your viral load and CD4+ count before you start or change any therapy and then test you again every three or four months, or even more often depending on your situation.

For some people, the anti-HIV drugs taken in combination will get rid of so much HIV in the blood that the virus is undetectable, meaning it can no longer be measured by the tests. For others the virus will still be detectable in their blood. The time it takes the virus to reach such low levels is different for each person. A lot depends on when you start taking the drugs. If you have more virus in your blood when you start, it can take longer to reduce the amount of HIV in your blood. Your viral load can also change. Once it goes down, it can, from time to time, go back up. If that happens don't panic. You should talk to your doctor about the best way to deal with this change.

Two tests, Viral Load and CD4+ Count will tell if HIV is spreading in your body.

Taking a strong combination of anti-HIV drugs should make HIV become undetectable and stay undetectable. This is the goal that you and your doctor should strive for. But for some people, this may not be possible. However, people can still do well even if they cannot reach the goal of having such low levels of HIV in their system.

Remember, if your tests do not find any HIV in your blood, this does not mean that you are cured, or that you can no longer infect other persons. You should still continue your drug therapy and avoid exposing others to the virus.

Medical Considerations

Doctors don't know yet what the best combination of anti-HIV drugs may be. Combination anti-HIV treatment should be carefully chosen based on several things. You and your doctor need to think about the following:

- Which anti-HIV treatments have you already taken?
- Which combination has the best chance of reducing the amount of HIV in your body for the longest time?
- What are your choices if this combination stops working?
- What are the possible side effects of the drug combination?
- How many pills will you need to take?
- What symptoms do you have now?
- Are you taking any other medications or using drugs that may interfere with the anti-HIV drugs? If you are, find out about how these drugs will affect any drugs you take to fight HIV.

Your doctor may also want to take a blood test that measures how your HIV responds to different medications. This is called a resistance test (also called a genotype or phenotype test). It can help your doctor decide which medications will work best for you.

You should also think about whether you can pay for the drugs or if they are covered by your health insurance policy. Anti-HIV drugs can be very expensive. If you cannot afford these drugs there are programs that can help you pay for them.

If the tests do not find HIV in your blood, you still ARE NOT CURED! You can still give HIV to others.

Personal Considerations

When you are thinking about taking anti-HIV drugs, there are other things to think about besides your CD4+ count and viral load.

In order to get the biggest benefit from therapy and not have drug resistance, it is very important to take each dose of your drugs as your doctor tells you to.

Doctors call this compliance or adherence. 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 harder with combination therapy, with large numbers of pills and a very demanding schedule or regimen. It can be very difficult for some people to stick to these rules over a long period of time.

You need to be thinking of all these things in addition to the purely medical benefits of the particular drugs. Choose a combination that you feel best suits your lifestyle. You need to ask yourself if you are mentally and emotionally ready to commit to the therapy. If you are not ready or do not think you can take the medicines as directed, it is better to wait. Taking the medicines incorrectly or taking them for short periods of time will cause the virus to become resistant and the medicines won't work for you.

Once you begin taking drugs, it is very, very important that you follow your doctor's directions. If you have trouble understanding or remembering the directions, ask for help.

When to Start, When to Stop

AIDS researchers are not certain when it is best to start treatment for people with HIV, using the anti-HIV therapy. This type of treatment is called HAART (Highly Active Anti-Retroviral Therapy). There are several things for you and your doctor to consider before deciding to start treatment.

First, studies have shown that even though most people with HIV feel perfectly healthy and have no symptoms, HIV is actively reproducing itself in the body soon after infection.

Secondly, it makes sense to try to keep your immune system from being damaged, rather than waiting until it has already been badly compromised. Early treatment might stop or at least slow down the loss of CD4+ cells, keeping them at a level where they can continue to fight off infections.

Thirdly, some researchers feel that it is better to start treatment before the viral load is too high (above 50,000 - 100,000 copies). This will make it easier for the drugs to fight HIV and to reach the goal of lowering levels until they can no longer be detected. They will also be able to reach this goal in less time, making it more difficult for HIV to develop resistance to the drugs.

Although there are many reasons to start drug therapy early on, researchers still have some concerns that you should think about. Some researchers say that it is simply a matter of time before people taking many different drugs develop resistant strains of HIV. Since these drugs would no longer work, people taking these drugs could have fewer choices for treatment in the future when even better treatments may be available. The threat of resistance means that some people prefer not to start treatment, waiting until more research data are

To fight HIV you might need to take many, many pills.

You will need to take these pills at different times and in different ways.

It can be hard to stick to a drug schedule and take your pills in the right way at the right time.

If you do not take your drugs in the right way it could make it harder to treat your HIV in the future.

If it is too hard for you to take the drugs, tell your doctor.

Talk with your doctor about what is best for you.

available or until after they have developed symptoms, when they feel they will most need the drugs. Others prefer to start treatment early, and hope that more or better drugs will be available should they develop symptoms in the future.

It is also possible that the drugs may cause side effects that outweigh any advantage. People who use anti-HIV drugs early in the disease before they have symptoms, may end up taking them for longer periods.

Sometimes, it may be necessary to change the type or amount of drugs you are taking. There are three main reasons for considering a change in anti-HIV therapy. The first is if it isn't working. You can tell if your drugs aren't working if:

- Your viral load increases by certain amounts (0.5 log or moving back towards your baseline result);
- There is no change or a decrease in CD4+ count; or
- Your disease gets worse, including the development of a new opportunistic infection.

Once you start taking medicine DON'T STOP unless you have talked it over with your doctor.

The second reason is that the side effects from taking the drugs outweigh the benefits of the treatment. Some people may think about stopping therapy when they have been unable to tolerate any combinations of anti-HIV drugs.

A third reason is adherence - you may not be able to follow the rules for taking the drugs that your doctor gave you.

There are no defined guidelines around stopping treatment. **Never stop taking your drugs on your own. Talk with doctor before you stop or change any drug schedule.**

It is a big decision because it could be very dangerous. It could mean that the virus will go back to quickly growing and your immune system could be damaged as a result.

When Drugs Don't Work

Anti-HIV drugs work for some people and not for others.

HIV is not one single virus. Rather, the virus comes in many different forms. Some are stronger than others are. Some react better to drug treatment than others do. In some cases, in spite of new drugs and advances in how the drugs are used, drug therapy does not work.

Doctors differ on what to do when drugs stop working. Some doctors are recycling drugs to their patients (using a drug that the patient had already used early on in the course of disease.) In some cases recycling these drugs has proven useful for a while but not usually for any significant length of time. Remember HIV has seen these drugs before and could have developed some type of resistance to them.

There are two types of laboratory tests called resistance tests which may help HIV positive people for whom drug therapy is no longer working. A genotype test can detect the pattern of HIV genes in a person's blood and detect those that have been associated with the virus's resistance to certain drugs. By knowing what drugs won't work with the type of HIV you may have in your body, your doctor can tell what drugs he or she should try. You and your doctor won't have to waste time and effort with drugs that won't work.

Genotype tests are relatively expensive. If you reach a point where your drugs aren't working, however, you should talk with your doctor about genotype testing to see if you might benefit from such a test.

The second type of resistance test is called phenotype. It measures how your virus grows in the presence of different drugs. It is easier for your doctor to interpret than genotype testing but it is very expensive.

To get the most accurate results from resistance tests, you need to follow your doctor's instructions about your anti-HIV medications. Whether or not you are taking your medications has a big impact on the test results.

The development of anti-HIV drugs and HIV tests is an ongoing process. We cannot know what the best method for fighting the disease will turn out to be. You should discuss any concerns you may have with your doctor. Information about new treatments is available if you want to keep up with the latest treatment choices. (See Chapter 13 to find resources about new treatments.)

Alternative Treatments

A health treatment that does not fit the standard medical treatments (such as those we have talked about in this chapter) is often called alternative treatment. This includes many different types of care including:

- Healing practices such as acupuncture and Native American healing;
- Physical therapies such as chiropractic, massage and yoga;
- Homeopathy or herbal treatments;
- Relaxation, meditation and visualization; and
- Other techniques including Reiki or polarity therapy.

Alternative therapies are very popular and many HIV positive people use them regularly. However, it is difficult to find good information about how well they work. You also need to be careful because some treatments might be harmful and in some cases you might be dealing with health care fraud. Before starting any therapy, ask the following questions.

- When and how was the therapy developed?
- How does it work?
- Have any studies been done?
- Are the therapists trained, certified or licensed?
- Are there any known side effects or other risks?
- How much do the treatments cost?

If you do decide to use an alternative therapy, let your regular medical doctor know. Some doctors don't like alternative therapies. Others think they can reduce stress, relieve pain and stomach upsets caused by many antiviral drugs or have other benefits. Check your doctor's attitude and knowledge of alternative therapies. Ideally, your doctor can keep an open mind and help you decide what therapies might help you the most. (See Chapter 6 for help choosing both conventional and alternative doctors.)

There are tests that can help your doctor tell which drugs may work for you. One test is called GART.

There is no one way to fight HIV.

New ways are being developed all the time.

Talk to your doctor about what treatment is right for you.

In addition to regular treatment, some people with HIV try other ways of treating the disease such as Alternative Treatments.

Examples of alternative treatments are yoga, massage acupuncture, and meditation.

Some alternative treatments may help you, others could harm you.

If you use alternative treatments, make sure to tell your doctor.

Combining Conventional and Alternative Treatment

There are advantages and disadvantages to combining alternative and conventional (standard) treatments. On the positive side, combining treatments gives you more options and allows you to get information from a number of different viewpoints. This can give you a sense of control over your condition. Alternative treatments are usually harmless, and may be beneficial in reducing toxicity or providing relief from side effects of conventional drugs.

However, it may be difficult to judge the value of various treatments, particularly when they are used at the same time. Harmful side effects may occur when alternative treatments are used with conventional medical therapies. You may also feel bombarded by conflicting information from your various providers. If you are taking anti-HIV drugs, adding more pills to your schedule can make it even more confusing and difficult to follow your medication schedule. Combining treatments and seeing multiple health care providers can become time consuming and expensive, especially since most alternative medicine is not covered by health insurance or welfare. (Check your own policy for limitations.)

Some common herbal medications including St. John's Wort, Milk Thistle and Garlic, can interfere with the effectiveness of your HIV medications. Make sure that you discuss all medicines that you are taking, including herbal therapies and vitamins with the doctor who prescribes you anti-HIV medications.

Chapter 6

Choosing Your Doctors

One of the most important things you can do is find a doctor or other health care provider you can trust, understand and talk to easily. Because a team of health care providers (doctor, gynecologist, nurse practitioner, physician assistant, etc.) usually works better in treating HIV and AIDS, you will probably be working with a number of people. You should be comfortable with all of your providers. This level of comfort includes being able to talk openly about your fears and concerns. You should also feel comfortable asking questions when you don't understand. If you have a conflict with a provider, think about finding someone else to treat you.

In addition to your primary health care providers, your team should include a dentist and ophthalmologist (eye doctor). Eye and dental care are important, as these providers are sometimes the first to notice certain early symptoms.

When choosing a health care provider(s), make a list of providers to contact in order to discuss your health care needs. Talk to others in your health situation and see if they have found health care providers who are HIV and AIDS knowledgeable.

When you are interviewing a potential provider, you may want to include some of the following questions:

- Are there others in your practice who have treated people with HIV and/or AIDS?
- How many HIV patients have you treated?
- How do you keep my medical records private?
- Are you willing to work with my other provider(s) and will you refer me to specialists when necessary?
- Will I be able to get an appointment quickly, if I need to?
- How do you keep up with new methods of treatment for HIV?
- Are backup calls referred to another physician if you are on vacation? If so, who?
- Do you work with a hospital? If so, which one?
- Can you be reached after office hours?

Write down your questions along with the person's answers. This will allow you to make an informed decision. You might want to bring a trusted friend with you for support and for a second opinion.

Treatments for HIV/AIDS are constantly changing and your doctor or other health care provider may be cautious about new or less used treatments. However if you hear of a new treatment, talk it over with your provider. He or she should take the time to find out if the treatment you asked about is right for you. If you feel your health care providers aren't taking your treatment questions seriously, tell them. Do not keep information from your doctor or any of your health care providers. If you do it will make it harder for them to help you.

Managed Care

Managed care is a general term used to describe certain types of health care plans. Health maintenance organizations (HMOs), preferred provider organizations (PPOs) and managed care organizations (MCOs) all fall into the category of managed care. Although managed care is a relatively new form of health care, it is rapidly becoming the most common form of health care plan. In Virginia, if you are being treated under Medicaid, the publicly financed health

Most people with HIV are treated by a team of doctors.

It is very important that you trust, understand and feel comfortable with all your doctors.

If you have a choice of doctors, make sure each one knows how to treat people with HIV.

Treatments for HIV change all the time. You should be able to talk with your doctor about new options.

Many people receive health coverage through a Managed Care Plan.

Under managed care your doctor is your Primary Care Provider (PCP) and will coordinate your care. You still have the right to choose your PCP.

In addition to traditional doctors, some HIV+ people use alternative health care providers.

Make sure your doctors and any alternative health care providers work together as a team.

care for low-income persons, you will be covered by a managed care plan. Under a managed care plan, your doctor will be called a primary care provider (PCP). Your PCP will take care of most of your health care needs. Your PCP will also decide when you need to see other doctors or specialists. You will only be able to choose a doctor from a list provided by your managed care plan. Even though you may have a more limited choice of doctors, you should still use the same considerations when choosing a PCP as you would if you were choosing a doctor from any other type of health care plan.

Because people who have HIV have complicated health problems and need a lot of care, they are sometimes worried that they may not get all the health care services they need in managed care. To be sure you get the care you need, you need to understand how managed care works, what to do when it doesn't work and how to pick a doctor. If you have trouble understanding the rules and guidelines, ask for help.

If You Have No Health Insurance

Even if you have no health insurance, you will still need medical care. There are programs available to assist you with your health care costs such as Social Security, Medicare and Medicaid. (See Chapter 12 for more information about your insurance options.) You can also receive services through clinics and hospitals who treat uninsured patients. Your local AIDS Service Organization (ASO) can help you find medical assistance in your community. (Local Resources are listed in Chapter 13.)

Without insurance you will have less options in choosing your doctors. However, you should still take an active part in your medical care. You should feel comfortable with your doctor and able to ask questions about your care. If you have trouble with any of your health care providers, ask your case manager or local ASO for help.

Alternative Health Care Providers

If you choose to have an alternative provider (naturopath, homeopath, Eastern physician) as well as a conventional medical provider (MD, nurse practitioner, physician assistant), it is important your alternative provider be licensed, knowledgeable, and experienced with HIV and AIDS. Check with your local board of health for further information.

All your health care providers must be comfortable working as a team and communicating openly with each other. Here are some questions to ask when seeking an alternative health care provider.

- What are you legally licensed to do in this state?
- Do you support combining conventional and alternative treatments?
- Are you willing to work with my other provider(s)?
- What types of alternative treatments do you recommend? Is there evidence that they work?
- Do you have any referral sources in the conventional medical community?
- Do you communicate openly with them?
- Do you believe there is a cure for HIV infection or AIDS? Be wary of any provider who claims to know of a "cure," as comforting as it may seem.

Help Your Health Care Provider Help You

Once you select a health care provider(s), you must be able to talk easily about your treatments. The following are guidelines that may help you keep your relationship working at its best.

1. Talking with your doctor

Write down things that you think your health care provider should know. You can use the Event Tracker at the back of this book to note any symptoms you are having. Don't withhold information out of fear or embarrassment, and don't try to diagnose your own symptoms. Your health care provider(s) should always be up-to-date on any and all medication you are taking. This includes birth control pills, vitamins, herbal remedies, anti-depressants and any other medicines prescribed or purchased over-the-counter. Also, inform your doctor of any health problems not related to HIV. Your doctor should also know if you smoke or use alcohol or street drugs.

2. Asking questions

Write your questions down before you visit your doctor. Use the question log in the back of this book so you can remember everything. The better prepared you are for your visit, the more you will get out of it.

If your provider isn't answering your questions, or if you don't understand the answers you have been given, speak up! Don't pretend to understand something you don't. The only person that gets hurt in that situation is you.

3. Working with your doctor

Do not stop taking a prescription without telling your health care providers. Carefully follow all instructions about your medications, if you have any questions about taking your medication make sure to discuss them with your doctor.

When calling your health care providers, keep your message brief or leave a message with the nurse. Use the emergency room only when necessary.

Remember, if your health care provider recommends a treatment or surgery about which you are uncertain, get a second or third opinion. Educate yourself by finding out about your medical condition and sharing this information with your health care providers. Also, be skeptical of miracles and cures or drastic treatments you may read about in magazines. People who promote cures or drastic treatments may be more interested in your money than your health.

If your doctor is not meeting your needs, you need to consider finding a new health care provider. If you are part of a managed care plan and have problems getting the care you need, call your health plan's Member Services.

Going to your health care provider(s) doesn't have to be an unpleasant chore. When you are taking an active role in your health care, office visits can be productive and rewarding. Keep the communication with your health care provider open and honest. Remember you are part of a team. Trust your health care provider(s) and yourself.

Write down your questions and your problems before your visit so you won't forget to talk with your doctor about your concerns.

If you do forget or don't understand, ASK QUESTIONS!

Write down what your doctor says. Always follow your doctor's instructions, especially when taking anti-HIV medicine.

If your doctor is not meeting your needs, consider finding a new health care provider.

To stay healthy longer, take an active role in your health care.

You may need additional help from people other than your doctor.

Support Groups can offer emotional support.

You may want a Case Manager. Case Managers are people who can help you find the services you need.

Finding Help For Needs Other Than Health Care

Your health care provider(s) should be sensitive to your needs, but he/she cannot meet all of them. You may have other needs that your doctor cannot and even should not have to meet. It isn't possible for one person to provide all of the services you need, especially if your need is outside his/her field.

If you need emotional support, try a support group or mental health counselor. If you are having trouble managing all the different aspects of being HIV+, you may also want to use the services of a Case Manager. Case management is help provided by HIV knowledgeable people who may assist you in getting services. Case Managers can be social workers, nurses, outreach workers or other social service providers. This individual is often an important source of information and support. Check with the local health department or an AIDS Service Organization for information. (Local resources are listed in Chapter 13.)

Chapter 7

Drugs and Alcohol

Learning that you are HIV positive can bring feelings of helplessness and despair. Often people use drugs or alcohol to forget about their feelings. However, using alcohol and other drugs can cause you to make poor choices. As a result, these choices may make you take more risks such as catching new infections from others as well as passing HIV to them. Drugs and alcohol may offer temporary relief, but they will only increase depression and weaken the body's ability to fight infection.

Reducing or quitting drugs and alcohol may help your body stay healthy longer. Rapid advances in the treatment of HIV are allowing people to live longer as well as maintain a higher quality of life than before. As opportunistic infections become more preventable and treatable, relatively good health is easier to maintain and quitting drugs and alcohol will only make your body stronger.

If you do continue to use drugs or alcohol, make sure your health care provider(s) are aware of your use. It is important to talk openly with them about your behaviors. Mixing street drugs with your anti-HIV drugs could affect how the drugs act. This is called a drug interaction and some of them can be dangerous even deadly. **We don't know a lot about how street drugs react with anti-HIV medicines so your best bet is to not take any street drugs if you are using anti-HIV medicines.** (For more information, see the chart on page 31).

If you use any type of drug, whether heroin, methamphetamine, cocaine, steroids, insulin, erythropoietin, epinephrine, or vitamins, it is important that you **do not share your syringes or works.** They could become infected and spread HIV. Use your needle once and dispose of it in a plastic jar or bottle. If you do reuse syringes be sure they have not been used by anyone else. Clean your syringes thoroughly each time you use them even if you are not sharing.

You Can Stop Using Drugs

Quitting the use of alcohol and/or drugs is the best way to stay healthy. If you are unable or not ready to stop, then consider decreasing the amount and frequency of your drug and alcohol consumption.

There are several successful techniques that are used to stop or reduce the use of drugs and alcohol. It is important to set your own goals to change your drug or alcohol use. While there is not one specific treatment, belief system, or trick that works for everyone, there are certain strategies that may help. These include guided imagery, internal pep talks, behavioral changes, support groups and treatment programs. (See Chapter 13 for information on groups that can help you stop or reduce your drug and or alcohol use.)

Remember, relapse or "slipping" happens to many people who try to change addictive behaviors. People often relapse in response to social pressures, anxiety, fear, depression, frustration, anger, etc. If you relapse from your goal, do not view it as a failure. It can be used to examine certain thoughts, situations, and cues, which may have lead to the behavior. Take this chance to learn about yourself, renew your desire to change, and seek more help if needed.

Reducing or quitting drugs or alcohol can help you stay healthy longer.

If you use drugs or alcohol make sure your doctors know.

Mixing street drugs with HIV drugs is very dangerous.

If you want to quit drugs or alcohol, help is available.

If you are trying to quit don't be discouraged if you relapse or slip. Try again and ask for help if you need it.

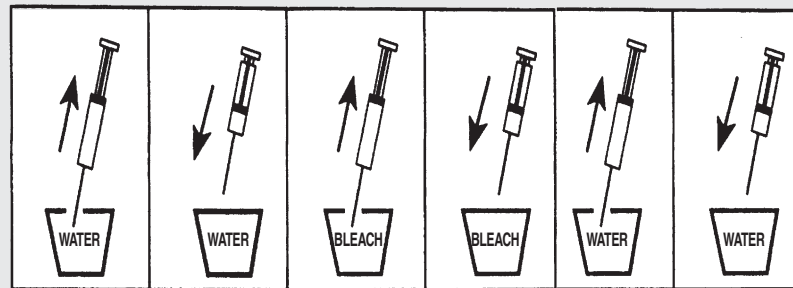
If You Don't Stop

If you use any type of drug, DO NOT share your works with others. They can become infected with HIV!

If you continue to use drugs, cleaning needles and syringes with water and bleach can reduce the risk of giving HIV to someone else. **It is important to clean your works, but remember you should never share needles.**

Don't Share Your Works

Always use your own needles, syringes, cookers, cotton and filters. If you must share with anyone, clean your works with household bleach, before and after using. Always use full strength household liquid bleach. Bleach kills HIV. You must leave the bleach in your works for 30 seconds. It will not damage your works.



If you must share, make sure you clean your works. (See box at right which shows you how to clean your works.)

Always clean your works right after you use them - before the blood dries or clots.

1. Fill the syringe completely with water.
2. Shake and tap the needle to loosen all of the blood.
3. Shoot the water out on the ground or in the sink. Do these steps several times, until you can't see any blood or pink color.
4. Then, fill the syringe completely with bleach and wait for 30 seconds.
5. Allow the bleach time to break down any blood or virus remains that may be in the needle.
6. Shoot the bleach out on the ground or in the sink.
7. Fill the syringe again with NEW water to rinse out the bleach. Do not use the same water you used in Step #1. The water could still contain the virus.
8. Shoot the water out on the ground or in the sink. This process needs to be done 2 or 3 times to make sure all of the bleach is out of the works.

Dangers from Commonly Used Street Drugs

Drug	General Effects	Effect When Mixed With HIV Drugs
Alcohol	Impairs decision making ability Damages liver (the liver gets rid of toxic substances & medications) Decreases white blood cells Impairs immune system	Risk of pancreatitis (intense stomach pain) Makes it easier to overdose Increases side effects
Nicotine	Damages lungs	May cause your HIV drugs not to work as well
Marijuana	May suppress immune system May increase chance of infections	Affects the way Marijuana reacts with your body
Heroin (smack, brown, junk, China) & Morphine	Increases chance of infections and cancers Interferes with hormone system Speeds the growth of HIV	Depending on the HIV drug you take, it could make it easier to overdose
Cocaine (coke, blow)	Increases chance of infections and cancers Interferes with hormone system Speeds the growth of HIV	No known interactions but may speed up how fast you get sick from HIV infection
Amyl and Butyl Nitrates (Poppers)	Increases the likelihood of injury during sex	Can interact with liver and speed up how fast you get sick
Amphetamines Crystal-Meth, Tina etc.	Weight loss; Sleep disturbance Weakened immune system, Paranoia	Makes overdoses more likely
Barbiturates	Liver Damage	Makes overdoses more likely
Ecstasy	Liver Damage	Can cause death by making it easier to overdose
Sedatives (Valium, Halcion, Ambien,	Liver and lung damage	Could stop you from breathing

Methods

Smoking

- Weakens lungs
- Can lead to cancer
- Can lead to pneumonia

Snorting

- Weakens nasal passages

Shooting

- Risk of bacterial infections of heart, lungs, joints, blood
- Can lead to skin abscesses
- Sharing works (syringes, needles, cookers, cotton, water) can transmit hepatitis or expose you to new strains of HIV

Chapter 8

What About Sex?

When people were first struggling to make changes in behavior to stop the spread of HIV, the most commonly heard piece of advice was: “Assume that any sex partner could be infected with HIV and practice safer sex accordingly.” This remains good advice considering that there are thousands of people who have HIV and don’t know it because they have not been tested. If you have been following this advice, the good news is that things don’t really change much now that you know that you’re HIV positive. If you haven’t been following “safer sex” guidelines faithfully in the past, you need to begin doing so now. **Safer sex means not sharing semen, blood, and vaginal secretions.**

Most safer sex guidelines were written to stop the spread of HIV. But those who are already HIV positive have additional reasons to practice safer sex.

Sexually transmitted diseases (STDs) (e.g., cytomegalovirus or CMV, other herpes viruses and Hepatitis B) pose an even greater threat to your health now, because for individuals who are HIV positive, these diseases can be life threatening. STDs are carried in semen and vaginal fluids and unprotected sex will expose you to these infections.

If your partner is also HIV positive, you still need to practice safer sex. Your partner may be carrying other diseases, which could cause serious health problems.

You should always reveal your HIV status to all potential sex partners. It is important each partner has an equal opportunity to participate in reaching decisions about sexual intercourse. It isn’t always easy to discuss safer sex options with your partners. However you decide to tell your partner, plan it out before you talk to him/her. Whenever possible, discuss sexual safety in a neutral setting before you become aroused - the earlier the better.

Some people, after finding out they are HIV positive feel like they are damaged in some way. They think that no one will want to touch them or love them and that they are less desirable. They think that because they are HIV positive, no one will ever want to have sex with them again. The medicines you take for the disease, or any illness you may have, may also cause you to lose your sex drive.

While you might not feel like having sex now, you may change your mind in the future. When and if that time comes, you need to be prepared so you can protect yourself and your partner.

Not having sex is the only sure way of not getting sexually transmitted diseases (STDs) or spreading HIV. Therefore being abstinent is one choice some HIV+ people make. If you plan to have sex, it is very important to practice safer sex. You will probably need to change your behavior to protect your health and the health of others. Some common questions about sex risks are provided below. If you have more questions, speak with your health care provider(s) or others who can help you.

Now that you are HIV+ you need to practice safer sex or not have sex.

Safer Sex means not exchanging semen, blood and vaginal secretions.

If your partner is HIV positive, you still need to practice safer sex.

You should ALWAYS tell your sex partners that you are HIV+.

Safer sex practices can also help protect you from Sexually Transmitted Diseases (STDs).

STDs are very harmful to persons who are HIV+ and make it easier for them to infect others.

ALL unprotected sex (oral, anal or vaginal) is risky.

HIV from semen, blood or vaginal secretions can pass through very small cuts in the skin that you may not know you have.

Not having sex is the only way to be absolutely sure that you will not get pregnant, an STD or infect others. However, using condoms (rubbers) can greatly lower your risks.

Common Questions

Q. Why isn't it safe for me to put my penis in someone's anus, vagina or mouth without a condom (rubber)?

A. The urethra (the opening at the end of the penis where urine and semen come out) may be a place where HIV can enter or exit the body. Therefore, if the opening of the urethra comes in contact with the vaginal secretions, semen, feces or blood of someone who is HIV positive, the virus could be transmitted. Also, other dangerous sexually transmitted diseases could enter the body through the urethra or small sores or tears on the penis.

Q. Is unprotected oral sex risky?

A. Yes. Many people mistakenly believe that oral sex is safe. Although, it may be less risky than vaginal or anal sex, getting infected vaginal secretions, menstrual blood or semen in your mouth can still transmit the virus and still places you and your partner at risk. When performing oral sex on a woman, one way to reduce the risk is the proper use of a barrier such as a latex dental dam, a sheet of plastic wrap or a cut condom. Use a nonlubricated condom, cut the tip off and cut it down the side to get a square latex sheet. Place the barrier between the mouth and the genital area. Make sure to cover the whole area. Using a small amount of a water-based lubricant on the side touching the genitals will increase the sensation. When performing oral sex on a man, use a condom for the best protection.

Q. What if I am allergic to latex?

A. The female condom is made of polyurethane and can be used by people with latex allergies. Male polyurethane condoms have also been approved for use and can protect against HIV infection.

Q. Can I pass HIV by putting my fingers or hand in my partner's rectum or vagina?

A. HIV cannot pass through skin unless there is a cut or sore. However, you may not be aware of cuts or sores. We recommend you use a latex glove with lots of lubricant. That will eliminate scratching the inside of the vagina or anal canal during stimulation by the hand or fingers, which could create a route of entry for the virus.

Q. Is mutual masturbation risky?

A. Mutual masturbation (people watching each other masturbate, people masturbating themselves together, or people masturbating each other) which does not involve penetration or contact with sexual fluids is a safe way to enjoy sex. When masturbating a woman it is very important there aren't any cuts on the hand, or latex gloves are used. Also, bleeding can occur as a result of mutual masturbation on a man or woman without your knowledge. Therefore, unprotected sex after masturbation is a very risky activity.

Q. Can I get or pass HIV from sharing sex toys?

A. Yes. Blood, feces or vaginal fluids that contain HIV could transmit the virus if they are on shared sex toys. The best advice is not to share. However, if you do, always cover the toy with a condom. After each use, wash the toy with soap and hot water and rinse with bleach or any disinfecting solution.

Q. Why is anal or vaginal sex with a condom still risky?

A. Although condoms greatly reduce the risk of disease transmission, they are not 100% effective. When condoms do fail it is most often due to improper use. Following these guidelines will further reduce the chance of condom failure.

How To Use a Condom (Rubber)

1. Always use latex (or polyurethane) condoms. Do not use “natural skin” condoms which have tiny holes that can allow virus to pass through. Using condoms correctly decreases the chance of getting sexually transmitted diseases; however, condoms can fail.
2. Hold the tip of the condom to squeeze out the air. This leaves some room for the semen when you cum (ejaculate). Put the condom on the end of your penis.
3. Keep holding the tip of the condom. Unroll it onto your erect penis all the way down to the hair.
4. Put the condom on before you enter your partner.
5. You can use a water-based lubricant like “K-Y,” “Foreplay,” or contraceptive gel. Oil based lubricants like Vaseline, hand cream, baby oil or Crisco should not be used with latex condoms as they can break down the latex.
6. After you cum (ejaculate), hold onto the condom and pull out while your penis is still hard.
7. For the best protection, use a new condom every time you have sex. Only use a condom once and then throw it away.
8. Used the right way, latex (or polyurethane) condoms protect you very well against pregnancy and sexually transmitted diseases. To further help prevent disease, use them for oral and anal sex as well.
9. Always check the expiration date to make sure your condom is still usable. Don’t store them near heat.

To protect yourself and others, always use a latex (or polyurethane) condom.

Make sure you know the right way to use a condom.

Store condoms correctly and don’t reuse them.

Using alcohol and drugs makes it harder to practice safer sex.

Be aware of things that get in the way of sticking to your safer sex commitments. These vary from person to person, but a big one for many people is alcohol and other drug use. If you or your partner drink or take drugs, it may make it harder to practice safer sex. You should take steps to avoid alcohol and drugs before it becomes a problem.

Fear of upsetting your partner or losing the spontaneity or romance in your relationship may also present barriers to safer sex. Talk to your partner and decide your limits before you have sex. Make sure your partner agrees on these limits that way you will be able to support each other’s commitment to safer sex.

Your partner should help you practice safer sex.

Talk with your partner about safer sex before you start.

Chapter 9

Good Nutrition-You Are What You Eat

Good nutrition means eating foods each day that will give you the vitamins, minerals and other things you need to keep your body strong. It means eating foods that give you enough calories to have a healthy body weight. It means getting enough protein to keep your body built up and repair any damage it may have from HIV.

Good nutrition means different things at different points in your HIV disease. If you are infected with HIV but have no signs of disease, you will want to eat a wide variety of healthy foods each day. There is no one type of food that has everything our bodies need. Try to choose all of your foods from the basic food groups that we talk about later in this chapter.

If your HIV infection is causing minor health problems, eating may be more difficult and your appetite may be poor, but it is also important to eat well. You may need to avoid certain foods or change the time you eat.

If your HIV infection is causing serious health problems, you may even need help shopping, cooking or eating. Talk with your doctor or a nutritionist (a health care provider who specializes in healthy eating). They can help you figure out what you need to be eating.

Eating Well And Taking HIV Medications

In the early day of AIDS treatment, “AIDS wasting” was the big dietary problem. People were losing too much weight. Today the drugs that are now an important part of treating HIV are creating new problems when it comes to eating by making it difficult to know when and what to eat. The drug companies are working hard to combine drugs and decrease the number of pills you need to take each day. Until that happens, deciding what and when to eat is a complex puzzle. Side effects from the medications add to the confusion.

Having to take medicines and watch when and how you eat reminds you several times each day that you have HIV. Nausea, vomiting, diarrhea, weight loss, weight gain or a bad taste in your mouth from HIV or your medicines make it tempting to give up. Hang in there. Ask for help. Read everything available on HIV and nutrition. Figure out what works best for you. Do not allow your medicine to cause you to lose weight.

Keep talking to your health care providers. Many HIV/AIDS health care teams will include a nutritionist to help fit your eating into your medication schedule and lifestyle. Call an AIDS Service Organization in your community. They can help answer nutrition questions. (A list of organizations is provided in Chapter 13.) Ask the reference librarian at your local library to help you get the most recent information from the Internet. Librarians have an ethical code of confidentiality. Talk with your peers at support groups. Ask your case manager for a referral. They may have information on local resources and know about things that will help decrease side effects. Every hospital has a nutritionist on staff. Most hospitals have a medical library that will help consumers. Health departments employ nutritionists.

Now that you are HIV+, it is more important than ever to eat the right types of foods.

The drugs you may take or the illnesses you may have, can make it difficult to eat right.

You may have to eat different things at different stages of your disease.

Eating right can help you stay healthy longer so ask your doctors or others for help when you need it.

Choose a diet that is healthy and has foods you like to eat.

In rural areas, the Extension Agent will be able to help you with general information from the Internet and nutritional advice. If you know someone who has been through cancer treatment with drugs and radiation, ask them what worked to keep their appetite and weight up during the treatments. Cancer treatments cause similar eating problems.

Like every other part of HIV/AIDS, keeping track of your nutrition and your medicines is an adventure. If you feel too tired to keep track of your medicines, ask for help. Keep asking until you get the help you need to feel better.

Be flexible. You can eat pizza in the morning or cereal at night.

HIV treatment is challenging, but AIDS is worse. By being an informed HIV consumer, you can do many things to make yourself feel better. Be honest with yourself and your health care team. If you feel lousy, say so. If you are not taking or cannot take your medicines, say so. Let your health care provider know if you have any side effects. Letting people know how your medication is affecting you is yet another way you can take control of your situation.

Each drug therapy requires a slightly different approach to meals and nutrition. Like drug treatment, your diet will need to fit your personal needs.

Eat what you like, what you can afford and what meets your medical needs.

Basic Steps To Eating Right

Only you know what and how you like to eat. Some people like to have three meals a day. Others prefer to eat smaller amounts more often. Either way is just as healthy. Just as it doesn't matter when you eat, it also doesn't matter what you eat, as long as you get the right amounts from each of the basic food groups. For instance, everyone thinks that eggs and bacon are "breakfast" foods and turkey and gravy are "dinner" foods. This is only true if you like them that way. There are many people who eat pizza for breakfast and cereal and milk for supper. There is nothing wrong with this.

Eat foods from each of the four basic food groups.

When selecting what foods you might eat from the basic food groups consider such things as:

- What you like to eat;
- What you have on hand;
- What you can afford; and
- What helps you meet your medical needs.

The five basic food groups

There are five basic food groups in a healthy diet. You should eat a variety of foods in each of these groups everyday. These groups are:

- Grains (Cereals, Breads, Crackers, Rice, Pasta)
- Vegetables
- Fruits
- Milk (Milk, Yogurt, Milk Products, Other Calcium Sources)
- Meat & Beans (Meats, Beans, Nuts, Seeds)

Eat more of some foods than others. For example eat more fruits and vegetables than meat.

In addition to eating the right foods, you need to eat them in the right amounts. MyPyramid, from the U.S. Department of Agriculture gives you a picture of how you should eat.

For a detailed assessment of your food intake and physical activity, go to the U.S. Department of agriculture website at mypyramid.gov.

While the food pyramids may be helpful, each person has their own specific nutritional needs. Talk this over with your doctor. You may also need to consult with a nutritionist.

Grains

Grains and cereals supply a variety of vitamins and minerals, as well as protein (for strength) and carbohydrates (for energy). Try to eat at least four servings per day. One serving could be any of the following:

- One slice of bread (preferably whole grain)
- One bowl of breakfast cereal
- One half cup of noodles, macaroni, rice or grits. This would be the size of a scoop of ice cream. A typical plate of spaghetti would be two or more servings.
- One pancake, waffle, tortilla, biscuit or slice of cornbread
- Five crackers

Pluses: Besides being nutritious, grains are tasty and filling.

Minuses: Due to heavy processing, a lot of grains lose their nutritious value. It's best to choose brown rice instead of white rice because it has more fiber, protein and minerals. If you are trying to gain weight, grains are not rich in calories, but you still need to eat them.

Vegetables

Many people do not eat enough vegetables. You should try to eat three to five servings of vegetables each day. You can eat them cooked, in juice, or in a natural state- as long as you make sure to clean them. A serving could be one of the following:

- One carrot or other raw vegetable
- One-half cup of cooked vegetables
- One glass of vegetable juice (tomato, carrot, etc)

Pluses: Vegetables are rich in vitamins, minerals, and fiber and serve as good cleansers for your intestines. They are full of water, which can help quench your thirst. Researchers have suggested that eating fresh vegetables may help protect against stroke and some forms of cancer.

Minuses: Because some vegetables are high in fiber, they can cause diarrhea. If you are already suffering from this, temporarily reducing the amounts or types of vegetables you eat may help.

Fruit

Many people do not eat enough fruit. You should try to eat three to five servings of fruit each day. You can eat them cooked, in juice, or in a natural state- as long as you make sure to clean them. A serving could be one of the following:

- One orange or banana or other raw fruit
- One half cup of cooked fruit
- One glass of fruit juice

Pluses: Fruit are rich in vitamins, minerals, and fiber and serve as good cleansers for your intestines. They are full of water, which can help quench your thirst. Researchers have suggested that eating fresh fruit may help protect against stroke and some forms of cancer.

Minuses: Because some fruit are high in fiber, they can cause diarrhea. If you are already suffering from this, temporarily reducing the amounts or types of fruit you eat may help. For instance, bananas and peeled apples may help prevent diarrhea. Cooked fruits are less likely to cause diarrhea than raw fruits, however, cooking also destroys some of the vitamins in fruit.

The food pyramid will help you decide how much to eat from each food group.

Foods at the top of the pyramid, you should eat in small amounts. At the bottom are foods you should eat more often.

Insert Food Pyramid here

Insert Food Pyramid here

Grains include bread, cereal, noodles, pancakes, crackers, pasta rice and grits.

You can eat whole fruits and vegetables or drink fruit and vegetable juices.

Meat, fish, poultry, eggs, nuts and beans provide vital protein which is important to your immune system.

Dairy foods include milk, yogurt, cheese ice cream, pudding and custard. They provide calcium in your diet.

Many people have trouble eating dairy foods. If you have trouble, learn about ways you can eat dairy foods and not get sick.

Dairy

Milk, cheese and yogurt are in this group. They give you protein, vitamins and calcium. Eat at least two servings each day. One serving can be:

- An 8 ounce glass of milk (about the size of a coffee cup)
- Eight ounces of yogurt (about the size of a store container)
- Two slices of cheese, or two one inch cubes
- One bowl of pudding or custard
- One and one half cups of ice cream (three scoops or three ice cream bars)

Pluses: Dairy products are an excellent source of calcium and protein.

Minuses: Some people are lactose intolerant, meaning that they have gas pain, diarrhea or cramps when they eat dairy foods. If you think that dairy products may be the source of some problems, juggle your diet around a bit, don't eat as many dairy foods, and try smaller portions to see if this helps. You can also buy milk with reduced lactose in many grocery stores. Check with your healthcare provider to see about medicine that may also help. If you cannot eat dairy products at all, leafy green vegetables and fortified soymilk can provide the protein and calcium your body needs.

Proteins (Meat, Fish, Eggs and Beans)

Protein is an important building block in the body. Proteins are especially important for persons with HIV because your immune system is made up of protein. Some people feel that HIV positive individuals need more protein than people do in general, especially if they are recovering from an AIDS related illness. Three servings per day of extra-lean beef, fish, chicken, cheese or beans provides your body with a lot of protein as well as vitamins and minerals. One serving is as follows:

- Two ounces of meat, fish, chicken or turkey. An ounce is the size of a slice of bologna or other cold cut. A typical chicken leg has about two ounces of meat on it. A normal hamburger patty is three ounces.
- Two eggs
- One cup of cooked beans or peas. This would be about the size of two scoops of ice cream.
- Two handfuls of nuts
- A thick coating of peanut butter on a typical slice of bread

Pluses: Meats, beans and other foods in the group provide your body with the protein (or energy) that it needs to work well. Red meats, fish, and poultry are excellent sources of iron which may prevent some forms of anemia (a blood condition that can make you weak or tired and is most common in women.)

Minuses: Some forms of meat are high in fat and have been linked to high cholesterol which may be a problem for some people. If you are concerned, ask your healthcare provider or nutritionist.

Other Concerns For Your Diet

Fat

Fats are the most concentrated in calories among all types of food and nutrients. High fat diets may increase the risk of heart disease and colon cancer. Therefore, you need to be careful about the amount of fat you are eating. Some HIV medications may increase cholesterol and other fat levels in your blood, making eating a diet low in fats very important. Be sure to discuss your cholesterol level with your doctor to determine if changes in diet or medication is necessary.

Vegetarian Nutrition

Vegetarian diets can provide complete nutrition if careful planning is used. For further information on creating a healthy and complete vegetarian diet, consult your health care provider. There are also many good books you may find in the library, which will give you information and ideas.

Vitamins

Many people choose to take extra vitamin pills (supplements). There are very positive benefits from taking an all-purpose vitamin tablet daily, particularly if you are missing certain foods from your diet. Vitamin supplements can help fill these gaps.

In spite of the benefits, vitamin supplements may add to the number of pills you need to take each day, which may be confusing. It can also be expensive. You may also be able to get the nutrition you need by simply eating a balanced diet. Talk with your doctor or a nutritionist about whether you should add vitamins to your daily medicine schedule and what type would be best.

Food Fads

Be cautious of the many special dietary treatments that claim to be “cure-alls,” as they often do not have important nutrients. If a diet makes claims that seem too good to be true, it may be because the claims are not true.

Special Health Concerns

Persons with HIV have special health problems that can be made better or worse depending on what you eat.

Diarrhea (loose bowels)

Diarrhea is often a problem for people with HIV disease. To help control diarrhea drink lots of fluids such as Gatorade, fruit juices mixed with water, herbal teas and salty soups and broth. Do not drink coffee or soda pop or tea with caffeine. Do not eat dairy products or products with lactose. Avoid dietary supplements such as Ensure or Sustacal. Even though they do not have lactose they are rich in fat and sugar, two things that increase diarrhea. You should also not eat fat, fried food, chips, cheese snacks or nuts (although peanut butter is OK). Some foods will help stop diarrhea such as white bread, crackers, white rice, bananas, applesauce and cooked fruits, starchy vegetables like peeled potatoes and cooked carrots or squash. There are a number of anti-diarrhea medicines available over the counter which can also help.

Nausea and Vomiting

Don't eat food with strong smells, usually this means food that is fatty or greasy. Eat cold foods rather than hot because they do not smell. Sandwiches are usually easy to eat. Don't eat your favorite foods when your stomach is upset. You may link them to your illness and begin to dislike them as a result. You should also eat dry and salty foods (saltine crackers, baked pretzels, plain salted popcorn, and plain cereal without sugar). Don't eat sweets. Drink cool liquids, but don't drink them with solid foods. Eat a lot of small meals so your stomach is never empty. Don't eat a lot, eat slowly and chew well.

Constipation (no bowel movements)

Eat foods that are high in fiber such as nuts, fresh fruits with peel and fresh vegetables. Whole grains like bran cereal and brown rice are also good. Processed grains such as pasta, white rice or white bread can make constipation worse. Prunes and prune juice help. Drink lots of warm liquids particularly in the morning. Exercise helps too.

In addition to the four basic food groups, there are other things in your diet you need to think about.

There are some foods you should eat in small amounts such as fats.

Fats are found in sweets, fried foods, some meats and dairy products.

If you don't eat meat, talk to your doctors about how to plan a healthy diet.

Vitamins can be an important addition to your diet.

Be careful of food fads or other foods that claim they can cure your HIV.

People who are HIV+ may have health problems that will affect what they eat.

Try to remember that although your diet is important, it's not a cure. Be alert to your body's reactions to new patterns of eating. Talk to your health care provider. If you are thinking of trying to lose or gain weight, or if at any point you begin to experience an unexplained weight loss of 10 pounds or more, you should also see your doctor. As we said before, no two people are alike. Find a diet that works for you. Talk with your doctor, trust your body's cues and make changes when you have to.

Eating And Cooking Defensively

Even if you feel sick, you still need to eat right. Ask for help if you need it.

It is not only important to eat the right kinds of food, you need to know how to eat foods safely. People with HIV are more likely to get sick from food-borne infections because their immune systems are damaged. Most people can get food poisoning; however, people with HIV can be at greater risk of serious illness. In addition, once they get sick, these illnesses can be difficult to treat and may happen over and over.

It's important that you know how to protect yourself from food-borne infections (salmonella, botulism, or infectious hepatitis) as they can cause serious illness or even death. You can get most of these illnesses from the foods you eat. Here are some tips for safe eating.

People who are HIV+ can be at serious risk from food poisoning.

1. Wash your hands before and after you touch food.
2. Wash all of your fresh fruits and vegetables to remove chemicals and harmful pesticides. Organic produce may be a good option. Organic produce should also be washed. Never buy fruits and vegetables with a broken skin.
3. Keep juices of uncooked meats and fish away from other food. Never cut raw meats or poultry on the same surface that you are using to cut vegetables and fruit. This is very dangerous. Avoid using wooden cutting boards.
4. Use only pasteurized milk, milk products and juice. Never eat cheese with mold on it.
5. Never defrost food at room temperature. Thaw food in your refrigerator. Put leftovers in the refrigerator as soon as you are finished eating (never leave out more than two hours).
6. Whether you're using a microwave or a conventional oven, follow your directions carefully. Use a meat thermometer rather than guessing to see if it's done. Taking shortcuts can make you sick.
7. Make sure you cook meat, fish and eggs well. The center of meat must be gray (not red) and the juices should run clear (not red).
8. Serve food hot. Chill leftovers quickly and keep them cold.
9. When cleaning cooking utensils, cookware, dishes and silverware, use paper towels, dishcloths or rags that are frequently laundered and used specifically for that task. Place sponges in the dishwasher or micro-wave frequently to keep them fresh. Don't use what you clean your dishes with to clean counters and stovetops.

Learn how to handle and cook foods safely.

Always wash your hands before and after you touch food.

Wash all vegetables and fruits.

10. Buy only refrigerated uncracked Grade A eggs. Store them in the back of the refrigerator, not the door. The door is never cold enough.
11. Never buy dented cans.
12. Wash the tops of cans before opening to avoid getting any germs in your food.
13. Most importantly, use common sense. If a piece of food doesn't look or smell right, or if you are just not sure - don't risk it. Choose something else.

Getting sick from food can be especially risky when you eat out. You have no idea who is handling your food, or in what way. Don't take any chances when eating out. Persons with HIV need to avoid the same foods in restaurants that they would at home. Always order food well done; if it is served medium to rare, send it back. A good way to determine doneness is to cut into the center of a steak, hamburger, or other piece of meat. If it is the least bit pink or bloody, it needs more cooking. Fish should be flaky, not rubbery, when cut.

Order fried eggs cooked on both sides instead of sunny side up, and avoid scrambled eggs that look runny. If you are unsure about the ingredients in a particular dish, ask before ordering.

Raw seafood poses a serious risk of food poisoning for persons with HIV. Raw shellfish, like raw meat and poultry, should be assumed to harbor harmful bacteria. Oysters on the half shell, raw clams, sushi and sashimi should not be eaten. Steamed, boiled or broiled shellfish is fine, as long as it is cooked thoroughly.

Do not be shy. Ask your waiter or waitress to send your food back if it is not cooked in a way that is safe for you.

It is very dangerous to cut vegetables and fruits on the same surface on which you cut raw meats.

Don't eat your meat rare. Cook food well, serve it hot, and chill leftovers quickly.

Thaw foods in the refrigerator.

Use common sense, if it doesn't look, smell or taste right, don't eat it!

Be careful when you eat out as well.

Don't eat raw or lightly steamed seafood, runny eggs or undercooked meat.

Chapter 10

Women, Pregnancy, and HIV

HIV, as with many other things, affects men and women differently. Plus, women often are dealing with different issues than men such as pregnancy and reproductive health. This section addresses some of the issues facing HIV positive women.

You may not have had a doctor before you became infected with HIV. It is important that you have one now. Some women feel strongly about having either a female or male provider. Whatever, your preference, it is important that you have a health care provider with whom you are comfortable. (See Chapter 6 for more information on how to choose a doctor.)

You may also be eligible for case management services. As we mentioned in Chapter 6, case management is help provided by HIV knowledgeable people who may assist you in getting services. This individual can also help you deal with your children's needs. Check with your local health department for more information. (Local health departments are listed in Chapter 13.)

Women's Illnesses (Gynecology)

There is still much to learn about how HIV infection specifically affects women. The following gives some information about women's illnesses and HIV. Keep in mind that many of the HIV-related symptoms you may have will be like those found in men. As a woman, there is just more you need to know.

Although it is important for all women to get a yearly gynecological exam it is even more important for women with HIV.

1. **Yeast Infections:**

Many HIV positive women have repeated vaginal yeast infections. Sometimes this is your first HIV-related symptom. If the immune system is still fairly strong, these infections can usually be treated quite successfully. HIV positive women with weaker immune systems may have chronic or less treatable vaginal yeast infections. Women who are HIV negative may also have frequent yeast infections, so it does not need to be a cause for immediate alarm. If you do have yeast infections, they should be watched along with your CD4+ cells and treated. Any antibiotics you take may bring on a yeast infection or worsen one you already have. Ask your health care provider how to avoid this and discuss treatment before taking any medicines by yourself.

2. **Cervical Cancer/Dysplasia:**

Abnormal pap smears, cervical dysplasia and cervical cancer occur more commonly in HIV positive women. It is important to have a pap smear at least once a year. If your CD4+cell count is less than 500, it is best to have a pap smear every six months. Research has shown that cervical cancer progresses faster in HIV positive women than in negative women, so it is crucial to detect early forms of cancer as soon as possible.

3. **Recurrent Pelvic Inflammatory Disease (PID):**

Although infection and inflammation of the pelvic organs occurs occasionally in HIV negative women, in HIV positive women this condition may happen more often, last longer, and be difficult to treat. Infected women, when their immune system becomes severely damaged, may require repeated or continuous treatment.

HIV affects men and women differently.

It is very important that you get a Gynecological Exam each year.

You may be eligible for Case Management Services that can help you find the services you need.

HIV+ women are more at risk for yeast infections, cervical cancer, pelvic inflammatory disease (PID) and sexually transmitted diseases (STDs).

You have many choices of birth control.

No matter what form of birth control you use, you should also use a condom.

Condoms (rubbers) are better at preventing the spread of HIV and other diseases than any other birth control method.

Even if your partner is HIV+, you should still use a condom to avoid STDs.

4. Sexually Transmitted Diseases (STDs):

Women infected with HIV may have unique symptoms of some sexually transmitted diseases that produce sores, such as syphilis, gonorrhea, chancroid, and herpes. If you notice sores in your genital area, it is important to get prompt treatment. Remember, using latex or polyurethane condoms is the best way to prevent all STDs.

Birth Control Options

Many forms of birth control are available for HIV positive women. However, it is crucial you use latex or polyurethane condoms regardless of other forms of birth control you may already use. A latex or polyurethane condom is the only barrier that will prevent you and your partner from sharing sexually transmitted diseases, including HIV, gonorrhea, chlamydia, and syphilis. This is especially important for your current health, since these diseases could damage your immune system and your partner could get HIV. Even if your partner is HIV positive, you should still use a latex or polyurethane condom to prevent reinfection of yourself. The following are various birth control options.

Birth Control Devices (Contraceptives)

Male Condom (Latex or Polyurethane)

- A sheath or cover that fits over the penis
- Important to use every time you have sex including vaginal, anal, and/or oral intercourse
- Offers better protection against STDs than any other method

Female Condom (Polyurethane)

- A sheath that has a flexible ring at each end. The closed end inserts into the vagina, fitting over the cervix, the sheath fits loosely inside the vagina extending to the opening. The open end remains on the outside of the vagina during intercourse.
- Can be inserted prior to sexual intercourse, and offers an alternative to the male condom.
- Offers better protection against STDs than any other method(except male condoms)

Birth Control Pill

- Oral contraceptive
- May not work as well if taken with some medications including anti-HIV medications.
- Does not prevent the transmission of STDs and/or HIV/AIDS

Diaphragm

- Barrier method that blocks the opening to the uterus and prevents sperm from entering
- Must be used every time you have vaginal intercourse
- Does not prevent the transmission of STDs and/or HIV/AIDS

Norplant

- Tiny rods implanted under the arm which release hormones that prevent ovulation
- Lasts five years
- Does not protect against STDs and/or HIV/AIDS

Depo-Provera

- A hormone injection taken every three months that prevents ovulation
- Could interact with other HIV medications
- Does not protect against STDs and/or HIV/AIDS

Tubal Ligation (tubes tied)

- An operation to tie your Fallopian Tubes
- Permanent form of birth control
- Does not protect against STDs and/or HIV/AIDS

IUD

- An unsafe method for HIV positive women because of the risk of infection
- Does not protect against STDs and/or HIV/AIDS

Having unprotected sex could infect your partner and you could become pregnant.

HIV+ women can have healthy babies, however, they can also give HIV to their baby.

If you are HIV+, being pregnant could affect your health and weaken your immune system.

If you get sick from HIV you may not be able to care for your infant.

Pregnancy

You need to think about who will take care of your children if you are very sick or if you die.

You may have already been planning on having a baby when you discovered you were HIV positive. It is common for HIV positive women to experience many different thoughts and feelings about having children. Decisions about pregnancy can be difficult for infected women. Although many HIV positive women can have healthy babies, there are some HIV-related issues to consider.

- You can give your baby HIV, if you do not receive anti-HIV medications during your pregnancy.
- If you are sick with HIV illnesses, you may not be able to take care of your baby.
- It is possible that pregnancy may affect your health and immune system.
- If you get pregnant through unprotected sex, your partner will be exposed to HIV.
- Who will take care of your children if you become very ill or if you should die?

Only you can make the decision to end or continue your pregnancy.

Talking with your doctor or health care professional about pregnancy and HIV+ women should help you make an informed decision about having a baby.

Your Decisions, Your Health

If you are pregnant or thinking about getting pregnant, here is some important information you should know.

There are drugs (AZT) you can take during pregnancy that can lower the chances of your giving your baby HIV.

1. **Health care is important and available.** It is important for you to find an obstetrician, a doctor who works specifically with pregnant women, or other health care provider(s) who have specific knowledge about HIV and pregnancy. Your provider(s) can offer you early medical tests, nutrition counseling, referrals for drug and alcohol treatment, and early identification of any problems surrounding your pregnancy. If you are on anti-HIV medications they can make sure that the medicines you are taking won't adversely affect your baby. If you are not taking anti-HIV medications, your doctor can prescribe a three-part ZDV(zidovudine, AZT or retrovir) regimen to prevent transmission of HIV to your baby during pregnancy, delivery and for the first six weeks after birth. Good prenatal care is essential to having a healthy pregnancy. Pre-natal care is available for all women, even if your income is low and you have no insurance or Medicaid. Check with your local health department. You may also be eligible for the Women, Infants, and Children (WIC) nutritional support programs.
2. **Pregnancy may affect your health.** Researchers don't know if pregnancy causes HIV to progress faster. However, pregnancy does stress the body and lower CD4+ cell counts. Studies are underway to determine if an infected woman's CD4+ cells return to "normal" after pregnancy as quickly as do those of an uninfected woman. Problems with pregnancy are no more common for HIV positive women than those who are not infected with HIV.
3. **Case management is available.** An HIV positive woman who is pregnant or has given birth can obtain the services of a case manager for help with everything from finances to housing.
4. **The decision to continue your pregnancy after learning you are HIV positive is yours to make.** Planned Parenthood can provide information on your options on continuing or ending your pregnancy.

Giving birth by Cesarean Section can lower chances of giving your baby HIV.

Your Infant's Health

1. **You can give the virus to your baby.** A baby may become infected with HIV at any point during the pregnancy or throughout labor and delivery if anti-HIV medication is not prescribed. All babies share parts of their mother's blood and therefore, it is possible for a woman to give her baby HIV. A high viral load, a low CD4+ count and advanced stages of the disease appear to increase the risk of HIV infection in the baby.

As is the case with all pregnancies, good prenatal care and good nutrition will increase the likelihood of having a healthy baby. There are other things you can do, however, which will specifically decrease the chance that you could pass HIV to your baby. There are anti-HIV drugs, such as AZT, which can greatly reduce the chance that you will infect your baby with HIV. You will need to discuss your options for using anti-HIV medications during pregnancy with your doctor. Recent research also suggests that even if a woman is not able to take anti-HIV medications during pregnancy, taking the anti-HIV medications during delivery or within 48 hours of delivery can still protect the baby from getting HIV. Your baby will also need to take anti-HIV medications during the first six weeks of life.

Many infections can happen during delivery. Having your baby delivered by Cesarean Section can help protect your baby from getting HIV at birth. Talk to your doctor about this option.

Breast-feeding can also give your baby the virus. Therefore, if you are HIV positive, you should feed your baby with infant formula.

2. **Your infant will need testing for HIV.** Not all infants born to HIV positive women will actually become infected, especially if the mother has been receiving AZT or other drugs during pregnancy and delivery. However, all infants will test positive on the HIV antibody test. Newborns do not have fully developed immune systems and still carry their mothers' HIV antibodies. Until recently you would not know if your baby had HIV for over a year. However new tests have greatly reduced the time period. HIV can now be diagnosed in most infants by age one month and in virtually all babies by six months.
3. **Your infant will need a specialist.** It's important for an HIV positive woman's baby to be examined by a pediatric specialist at birth, and then frequently throughout the first year of life. There is a type of pneumonia that is highly fatal to infected babies in the first few months of life. However, there is a preventive treatment for that pneumonia. Examinations should continue until age two, even if your child doesn't have HIV infection.
4. **Your infant will also need a primary care doctor.** In addition to a specialist, you will need a regular doctor (pediatrician) or other provider for your child's routine care. The specialist and case manager will help in finding a primary doctor for your infant if you need it.
5. **Your child needs immunizations (shots).** It is important for infants born to an HIV positive woman to have all childhood immunizations, with most live-virus vaccines being avoided.

When a baby is known to be infected, help is available. Infected children have a high quality of life with good medical treatment. In fact, their life span continues to increase.

DO NOT breast-feed your baby. It could pass on the virus.

It can take between one and six months before you will know for sure whether your baby has HIV.

Your baby will need a specialist and a regular doctor.

Your baby will need to get shots.

Even if your child has HIV, he/she can have a good life and live many years.

Chapter 11

Hemophilia and Other Inherited Bleeding Disorders

Before 1985, some persons with inherited bleeding disorders, such as hemophilia, received blood products that were infected with HIV. If you have hemophilia and HIV infection, the following considerations may be helpful to you.

- Sometimes the symptoms of bleeds can be confused with the symptoms of HIV infection or opportunistic infections. For example, a kidney bleed or a kidney stone could cause blood in the urine, which is a side effect of some antiretrovirals. When a bleed does not resolve with your routine factor dosage, contact your hemophilia treatment center or infectious disease specialist.
- Opportunistic infections can contribute to bleeding problems. For example, thrush in the mouth can cause bleeding that requires treatment with Amicar and/or factor concentrate.
- Protease inhibitors have been associated with increased risk of bleeding episodes in persons with hemophilia. Keeping accurate bleeding (infusion) logs can help you and your physician monitor this potential problem.
- Whenever the treatment of your HIV infection requires an invasive procedure, such as a spinal tap, arterial stick, or biopsy, contact your hemophilia treatment center for treatment guidelines to prevent bleeding.
- Many persons with hemophilia and HIV also have been infected with Hepatitis B and/or Hepatitis C. These viruses affect the ability of your liver to function, including the processing of medications. Report any side effects, especially fatigue, rashes, nausea, dark urine, and jaundice to your infectious disease physician. Your physician may want to monitor your blood liver enzymes more frequently, even if you are feeling well.

Before 1985, some people with bleeding disorders such as hemophilia became infected with HIV through the blood supply.

HIV related illnesses and HIV drugs can cause bleeding.

Persons with HIV and hemophilia are at risk of becoming infected with Hepatitis.

Contact a hemophilia treatment center for help with bleeding problems due to HIV.

Chapter 12

Legal Issues for HIV Positive People

Although people who have HIV are living longer and healthier lives than ever before, you still need to face the possibility that at some point you may be too ill to make decisions for yourself. There are ways that you can keep control over important matters such as your money and your health care by choosing others to make decisions for you.

There are three powerful tools to help you. They are the (a) advanced directives (living will, medical power of attorney) (b) durable power of attorney and (c) a will. They let you choose someone to make your decisions, outline what medical care and how much care you want to have, and decide what you want done with your possessions after your death. If you would prefer to have friends making decisions for you rather than family members or a spouse, you can do that as well.

It is important to have these tools in place before you need them. If you do not take steps to make your wishes known, there are laws that outline who will make these decisions for you. The persons required by law may not be those who you would trust making these decisions.

Advanced Directives

Under Virginia Law, “every human being of adult years and sound mind has a right to determine what shall be done with his or her own body.” This means that you have the right to refuse or accept your doctor’s recommendations for medical treatment.

In some cases however, you may not be physically, emotionally or mentally able to discuss treatment options with your doctor. Advance directives allow you to make your choices about treatment known to your doctor, family and other concerned individuals in advance. There are two types of advanced directives, a living will and medical power of attorney.

Currently, all hospitals in the country are required to discuss living wills and ‘end-of-life’ decisions with every patient who is admitted. If you do not have an advance directive, your next of kin will be asked to make end-of-life decisions for you when you are unable to do so.

Living Will

A living will tells people how to care for you only if you have a terminal illness and can’t make decisions for yourself. A terminal illness is defined as an incurable condition in which death is imminent. (In other words you are terminal if you are very close to death and no medical treatment will help you.) However, it also applies to individuals who are in a persistent vegetative state (like a coma) even if death is not close at hand. In either case, a doctor has said that there is no medically reasonable hope for the recovery; the patient will not get better. A living will only deals with life-prolonging procedures. It allows you to tell your medical providers to withdraw or refrain from any “artificial actions” that may extend your life (i.e. inserting a breathing tube) when there is no hope for recovery. You can also say in your living will that you do want to have particular life-prolonging procedures given to you.

There are legal tools that can help you keep control over your health care and money even when you are very sick.

These three tools are; an Advance Directive, a Power of Attorney and a Will.

You should have these tools in place before you need them.

There are two advance directives, a living will and a medical power of attorney.

A Living Will tells your doctors what kind of care you want when you are close to death with no hope of getting better.

A Medical Power of Attorney lets you pick someone who will tell your doctors what kind of care you want whenever you are too sick to tell them yourself.

You need to think carefully about what type of medical care you want and who will make decisions for you.

Medical Power of Attorney

A medical power of attorney lets you name someone to make treatment decisions for you if at some point you cannot make them yourself. You do not need to have a terminal illness to use a medical power of attorney and it can cover any medical decisions, not just life-prolonging ones. In its broadest use, a medical power of attorney allows you to name someone to make any decisions about your health care that you could have made yourself.

You need to be clear on what you really value when you make this choice. Be gentle with yourself - take some time and think things through. When considering this choice, you may find it helpful to talk it over with a loved one, friend, spiritual counselor, case manager, or medical provider. However, it is important that the decision be based upon your own personal beliefs. Once you have decided, you should provide copies of your directives to your family, health care provider and anyone else you think needs to know what medical treatment you do or don't want.

Although you don't have to have a lawyer to create an advance directive, it is a good idea to discuss the issues over with someone knowledgeable about proper procedures. The law does require two witnesses of your signature. The witness cannot be related to you, cannot include the providers of your medical care and cannot be anyone entitled to part of your estate or holding a claim against your estate. You may also want to have these documents notarized, even though the state of Virginia does not require you to do so. If you want to make sure that your documents are valid in other states, having your signature and your witnesses' signatures notarized is a good idea.

Do Not Resuscitate Order

Even though you have a medical power of attorney and/or a living will, emergency medical personnel (rescue squads, ambulance teams, emergency room personnel) will not be able to follow your wishes if they are called to help you. If you have a terminal or serious condition, under certain circumstances you can make decisions in advance about refusing one type of medical care-resuscitation if your heart stops beating or you stop breathing. You do this by having your doctor complete a form called an "Emergency Medical Services Do Not Resuscitate Order" for you.

Power Of Attorney

A power of attorney is a legal document that simply allows someone else to act for you. In the power of attorney, you pick a trusted person to act for you and spell out exactly what that individual is empowered to do. That person becomes your 'agent' or 'attorney in fact' and you become the "principal." A power of attorney can give your agent the authority to manage all or any part of your money and business matters. It may also give your agent the authority to make medical decisions on your behalf. (See previous section on medical power of attorney.) Finally, in the power of attorney, you can name the person you desire to be your legal guardian if it ever becomes necessary to appoint one.

This legal relationship allows your affairs to continue even when you can't do business yourself. It allows a lover, a spouse, a special friend or family member to do things in your name, like buy or sell, bank, invest, enter into contracts, manage your business or general affairs. Your agent is only given the authority you specifically grant (there are some limitations in the law as well). Therefore, it may be beneficial to consult a knowledgeable individual when writing such an important document.

Sometimes AIDS causes people to become confused (mentally incompetent). Although this is unsettling, you need to think about this issue. The durable power of attorney can be a way to manage your affairs if you lose mental ability to conduct business yourself. It's possible to write a document that either lets your agent act for you at any time or makes someone your agent only after you've become incompetent. A power of attorney can only be written while you are legally competent.

A Durable Power of Attorney gives someone the power to take care of all or part of your financial and legal affairs.

The possibility, however far off, of mental incompetence is one of the most frightening things about HIV and AIDS. Just remember that planning for the possibility of some dreaded event doesn't make it happen. You are simply planning ahead. It means you know how to work the system to stay in charge even in the worst possible scenario. It is important to know that if you become incompetent and have no agent empowered with a power of attorney, the court could appoint a guardian to act for you.

In summary, durable power of attorney covers two possibilities:

- (1) your agent is empowered now and remains empowered if you become incompetent, or
- (2) your agent becomes empowered only if and when you become legally incompetent.

Powers of attorney can be in place all the time, or can only work when you are too sick to make decisions.

You should consult a lawyer before you create a power of attorney document. Though you can write one yourself, it is better to have the lawyer write one for you due to the far-reaching and significant powers granted in such a document. A lawyer can help you make sure that your document correctly expresses your wishes and is written in a legally correct manner.

Wills

A will is a signed document in which a person directs what is to be done with his/her property after death. It also allows you to name the person you want to handle your estate ("executor" or "personal representative") upon your death and thereby reduce the expenses of administering your estate. You can also appoint a guardian for your minor children in this document. Any mentally competent person who is at least 18 years old may make a will. If you do not have a will, a state statute directs who will receive your property regardless of your wishes. Each state has its own specific laws as to what is necessary for a will to be valid in that state.

You don't need a lawyer to set up any of these legal tools, but because they give someone great power over your life, it is smart to have a lawyer help you.

You don't need a lawyer or notary to execute a will, but you do need two witnesses to sign it. You can write your own document or buy a generic version at a stationery or office supply store. However, be careful. You should only consider doing it yourself if your estate is uncomplicated, you are able to pay off any debts, and no one is going to challenge your intent or wishes. If you choose that route, things will be a lot simpler when the will is filed if the witnesses have signed a notarized statement making the will "self-proving."

Your will is good until you revoke it, generally either by tearing it up or by signing a new will or written revocation. If you get divorced after signing a will, the law may consider the will partially revoked. If you are married, your spouse may have rights in your estate regardless of what you say in your will.

A Will tells people what you want done with your property after you die.

You can also name someone to take care of your children in your will.

Your will only takes affect after you die. You may change your will at any time.

You need to chose someone to be your executor. An executor makes sure your will is followed correctly.

You can write your own will, but it is better to have a lawyer help you.

Your will does not take effect until you die; therefore, it can be changed at any time during your life, as long as you are mentally competent. These four practical steps may help you to save time and assure a sound result as you prepare your will:

1. **Inventory your assets.** List in reasonable detail all of your property, personal belongings, life insurance policies and retirement plans, and what you think they are worth.
2. **Inventory your liabilities.** List all debts and obligations, including principal amounts, payees, and essential terms.
3. **List your family members and any other persons whom you wish to participate in your estate.** Determine who might be a good executor, trustee, or guardian for your minor children.
4. **Decide what you want to accomplish.** Determine what your objectives are, and to whom you wish your possessions distributed.

Then meet with your lawyer and other advisors to work out the details and prepare the necessary documents.

For a brochure on wills contact the Virginia State Bar or to obtain a “*Guide to Wills and Estates*” contact the American Bar Association. (Phone numbers are provided in the resource list in Chapter 13.)

Work Issues

There are laws to protect you if you have a job or are looking for one. One of the major laws that provides protection to HIV positive people is the Americans with Disabilities Act (ADA). Under the ADA, HIV is considered a disability and therefore, HIV positive persons who are working as well as those who are looking for work are given certain protections.

In Virginia, you are also covered under the Virginians with Disabilities Act, which extends protections to smaller companies with fewer employees that are not covered under ADA.

As a general rule, you should be very careful about revealing your HIV status to any employer or possible employer. Although the law does offer protections, it does not require your boss to be nice or sympathetic to you. Unless your illness is making it difficult to do your job, it is best not to share your HIV status with your employer.

Applying for a job

Employers cannot ask you if you have HIV infection when you apply for a job. The interviewer also cannot ask you about your health in general or any specific health problems you may be having before offering you a job. They may, however, ask if you have any physical problems that would make it hard for you to perform important job duties.

If you are asked questions about HIV or AIDS at a job interview or on an application it is better to tell the truth or not answer, even though these questions are illegal. If you do not get the job, it will be easier to prove discrimination. You will also be better protected if you do get the job.

You cannot be forced to take an HIV test in order to get (or keep) a job. However, an employer may ask you to take a drug test and can refuse to hire you (or fire you) because of the drug test. While the ADA protects you from discrimination based on your HIV status, it does not protect you from discrimination based on drug use.

There are laws that protect you if you have a job or are looking for a job.

There are two places where you can be required to take an HIV test. Anyone joining either the U.S. military or the Job Corps will be tested for HIV infection.

Once a job is offered

Once you are offered a job, an employer may ask you whether you have HIV infection or AIDS. However, they must ask everyone who is applying the same questions, not just someone they think may be sick. Even if they do find out that you are HIV positive, the fact that you are sick will almost never be a reason for taking back a job offer.

Even though the laws protect you, you should still be very careful about telling people at work that you are HIV+.

Employers can also ask for you to have a medical exam after they offer you a new job if the exam is job-related and if all other employees in similar jobs are also required to have an exam. Your employer must keep the results of the exam private.

On the job

If you already have a job, you have similar protections. Asking current employees whether they have HIV infection or AIDS or making them take an antibody test is almost never allowed under the ADA. Neither can your boss refuse you a promotion, demote you or force you to work apart from other employees because you have HIV. You are entitled to be treated like any other employee.

You cannot be asked to take an HIV test in order to get or keep a job. You can be asked to take a drug test.

Helping you keep your job

Under the ADA, your employer must make changes in order for you to continue working. This is called "Reasonable Accommodation." Examples include:

- Letting you change your schedule so you can go to the doctor, take medicine or go to counseling;
- Giving you additional time off; or
- Providing support services or equipment such as large print books for someone with AIDS who has developed a vision problem.

The ADA also protects your privacy. Any medical information relating to your HIV status must be kept in separate medical files and is considered confidential (private). It cannot be stored in your personnel file. There are only five situations in which your medical information can be shared with others. These include sharing your information with: supervisors about factors that would limit your work duties; safety personnel if you might need emergency treatment; government officials who are monitoring how a company follows ADA rules; state worker's compensation offices and insurance companies.

You cannot be asked if you are HIV+ during a job interview.

Insurance Issues

If you work for a company that has 15 or more employees, the ADA gives you the right to the same insurance coverage and benefit plans that all other employees have. (In Virginia, these rights are extended to companies with less than 15 employees as well under the Virginians with Disabilities Act.) This includes health, life and disability insurance. You cannot be fired or not hired because your employer is afraid your illness will lead to higher insurance costs for the company.

You can be asked to take a medical exam before you are offered a job, if everyone else must also be examined.

You cannot be fired because you are HIV+ and you must be treated like every other worker.

A big problem for persons with HIV who need insurance is that many insurance companies will not insure persons who have preexisting conditions or will make them wait a long time before they can use their insurance. A preexisting condition is a health problem that you had before you were covered by an insurance plan. Although HIV positive persons still have trouble finding good insurance coverage, recent action by Congress has helped by placing some limits on insurance companies and making an effort to expand coverage.

Under the new law (The Kennedy-Kassebaum Health Coverage Act) you have these protections.

You do have the right to ask your boss to make changes so you can keep working. For example, your boss must allow you time to go to your doctor or take your medicine.

- Insurance companies cannot refuse to insure you and must offer you the same insurance choices as persons who are not HIV positive.
- If you have been insured for at least 12 months in a row, you cannot be refused new insurance because of a preexisting condition.
- An insurance company cannot make you wait more than 12 months for your coverage to start if you have a preexisting condition and did not have insurance before.
- If you left your job, but kept your insurance for at least 18 months, an insurance company cannot deny you insurance because of your health.
- A preexisting condition means that you must have a medical diagnosis or treatment of a health problem during a six-month period before you enrolled for insurance. In other words, if you did not know you were HIV positive before you enrolled in the insurance, you could not be denied coverage once you knew your status.
- If you are pregnant or have a newborn child, you are completely protected from any preexisting condition rules.

Your medical files are private.

If you have questions about insurance coverage, the National Association of People with AIDS (NAPWA) has a consumer guide for people living with HIV/AIDS on the health insurance laws. A limited number are available free to people with HIV by calling the NAPWA Information and Referral Service at 202-898-0414.

Unfortunately, the law does not deal with the issues of what benefits a health plan must have and how much it should cost. Thus, there is no guarantee that health insurance coverage will provide enough care or that you will be able to afford it.

You have the right to the same insurance coverage as everyone else at your job.

If you leave your job

Under a federal law called COBRA you can keep your insurance coverage for up to:

- 18 months if you leave your job;
- 29 months if the Social Security Administration has said that you were disabled when you stopped working; or
- 36 months if you lost your insurance because you divorced or a family member died.

People with HIV often have a hard time finding insurance on their own. However, they do have some legal protection.

You must let your employer know and you must pay for the cost of the insurance yourself. However, these rules only apply to group plans. If your employer is self-insured they may be able to limit your coverage.

If you do not have insurance

If you are not covered by an employer's health insurance plan, you may be able to get help with your medical costs through federal programs such as Social Security, Medicare and Medicaid. If you are eligible for COBRA benefits but cannot afford to pay your insurance premiums, the Virginia HIV Health Insurance Premium Assistance Program can help you. The program pays the health insurance premiums of individuals who have been diagnosed as HIV positive and may be unable to work within the next year due to that diagnosis. To qualify for that program, you need not qualify for medical assistance (Medicaid) or any other assistance program. In addition, if you are enrolled in a plan that provides family coverage, the Department of Medical Assistance will pay for the premiums for your entire family.

If you are eligible for Medicaid and HIV positive, your premiums may still be paid under the Virginia Health Insurance Premium Payment Program (HIPP). For information on either of these programs, call 1-800-432-5924.

If you cannot afford your medication, you may also be able to get help through the Virginia AIDS Drug Assistance Program (ADAP). For more information on this program, call the Virginia HIV/STD/Viral Hepatitis Hotline 1-800-533-4148.

Now that you are HIV positive you will need good medical care. Some of it may be expensive. You should not have to go without treatment or medicine because you cannot afford it. If you have questions about your insurance, or need help paying your medical bills, ask for help. Contact your case manager, your local department of social services, your local health department or a local AIDS Service Organization for assistance. (See Chapter 13 to find help in your local community.)

Life insurance

If you have a life insurance policy, you may want to consider a viatical settlement. This means that you sell your life insurance policy for cash. Viatical companies buy life insurance policies from people who have potentially terminal illnesses. The amount of money you get depends on two things, the amount of your policy and the length of time the company thinks you will live. In the early days of the AIDS epidemic, viatical settlements were more popular. After the new drugs were introduced and people with HIV and AIDS were living a lot longer, their use and value declined. The industry is starting to come back now. The values have increased again and they do provide one way for someone with HIV or AIDS to get needed cash.

Be careful before you consider selling your life insurance policy. The money you receive may cause you to lose other benefits and there may be other ways to improve your finances. You also need to check with the Virginia State Corporation Commission, Bureau of Insurance (800-552-7945) to make sure that the company you are dealing with is licensed and legitimate. Finally, get several bids to make sure you are getting top dollar for your policy.

If you leave your job, you may keep your health insurance for a while.

Insurance questions are complex. Check with a local HIV/AIDS group to learn where you can find help.

There are programs that can help you pay for your medical bills.

Social Security, Medicare, Medicaid, and the Virginia Health Insurance Premium Assistance Program can help.

You can get help paying for your HIV medicines through the Virginia ADAP Program.

***Don't neglect
your medical care
because of the cost.
Ask for help!***

***If you have life
insurance, you may
be able to use it to
pay some of your
bills.***

***If you get into debt
the Consumer Credit
Counseling Service
can help you.***

***You cannot be forced
to leave your
apartment because
you have HIV.***

***You cannot be denied
service in public
places because you
have HIV.***

Other Issues

Bankruptcy

Many times, if HIV disease leads to loss of employment and a sudden decrease in income, the possibility of bankruptcy arises. In most cases, bankruptcy is unnecessary. For help paying off debts, contact the Consumer Credit Counseling Service of Virginia (804-780-9042). They will help arrange payment plans with your creditors.

Housing

You cannot be evicted from your apartment because you are HIV positive. The law absolutely prohibits it. Federal law (the Fair Housing Amendments Act of 1988) protects people who are handicapped, which includes any stage of HIV infection. No one can evict you, refuse to rent you an apartment, refuse to renew your lease, or harm you in any way because of your HIV-related condition. If that happens, you have the same right to file a discrimination complaint with the state or city as you would for employment discrimination, or to sue in federal court under the Fair Housing Act.

Federal laws also prohibit discrimination in "places of public accommodation." This means that if a service is offered to the general public, it must also be offered to persons who have HIV infection. Public accommodations include hotels, restaurants, stores, theaters, and most other such places.

Chapter 13: Additional Health Concerns

As people who are HIV positive live longer lives, there are also new complications.

New HIV Drugs in the Pipeline

HIV research continues to develop new treatment options. There are new NRTIs (Nucleoside reverse transcriptase inhibitors), NNRTIs (Non-nucleoside reverse transcriptase inhibitors) and PIs (Protease inhibitors) in the pipeline. Also, additional classes of HIV antivirals are in the pipeline. These include:

- Maturation Inhibitors
- Integrase Inhibitors
 - Entry Inhibitors
 - CXCR4 Inhibitors
 - CCR5 Inhibitors
 - Fusion Inhibitors
 - Attachment/CDR Binding Inhibitors

HIV Positives Living Longer: New Challenges of HIV as a Long-Term Chronic Illness

Combination drug therapy for HIV positives is proving to be effective for many. As more people with HIV/AIDS are living longer, healthier lives because of these improvements in treatment for HIV infection, the nature of HIV is changing. HIV infection is becoming more of a long term illness, a manageable chronic disease.

Routine health checks are important.

As people who are HIV positive live longer lives, there are also new complications:

- Health conditions caused by HIV infection, such as opportunistic infections
- Health conditions that are possible side effects of HIV medications, such as heart disease and diabetes, kidney diseases, liver and pancreatic diseases, cancers and other harmful growths (notably prostate and colon), as well as mental and memory complications
- Health conditions that develop independently of HIV as people age.

This means that routine health checks need to be included in your treatment. These include the periodic physical exams (physicals) and regular lab and radiographic (such as x-rays) studies that are recommended for all adults.

Heart Disease

Elevated triglycerides (a type of fat found in the blood) are associated with some HIV medications, especially Protease Inhibitors. This in turn can lead to high cholesterol, plaque (build up of fatty material on the inner lining of an artery), and resulting heart disease.

Diabetes

HIV infection and HIV medications have been associated with increased insulin resistance and type 2 diabetes. Insulin is made by the body to control blood sugar. Diabetes can lead to many other health conditions, including eye problems, kidney disease, foot and skin problems, heart attack and stroke.

A healthy lifestyle lowers the risk of many diseases, and helps you to enjoy your life more.

Kidney Diseases

HIV disease can result in kidney failure due to HIV infection of kidney cells or other causes. The protease inhibitor indinavir (crixivan) was the first HIV medication clearly linked to kidney problems. When taken unboosted, indinavir could cause a painful buildup of drug crystals in the kidneys. This was especially true of people who did not drink enough water. This was often called indinavir “sludge” or kidney stones, although true stones were sometimes not present. This is much less of a problem when indinavir is boosted with ritonavir. The nucleoside tenofovir (virid) has been linked to kidney issues as well.

What Should You Do?

When you are on HIV medications, it is very important to see your doctor regularly, and not miss medical appointments. Your doctor will provide regular, routine screenings to monitor for all of these potential medical problems. This will also provide the information needed to make adjustments in medications, and to insure that you receive appropriate treatment for any related conditions that develop.

Healthy Living

Since people with HIV live, on average, 24 years after diagnosis, and there is every reason to believe that the number of years will continue to increase, it is important to take good care of yourself. This means that in addition to treating your HIV disease, you will also want to take good care of your whole body. Health is not just about avoiding disease. It includes physical, mental and social well being. A healthy lifestyle lowers the risk of many diseases, and helps you to enjoy your life more. A healthy lifestyle includes:

- Regular health screenings
 - For women, this includes regular pap tests and breast exams
 - For men, this includes age appropriate prostate screening
- Maintain a healthy weight
- Eat a variety of foods, limit calories and saturated fat
- Be physically active and include physical activity in your daily routine
- Control your blood pressure and cholesterol
- Learn to manage stress
- Get a good night's sleep
- Take good care of your teeth and mouth, brush and floss every day, see a dentist regularly
- Stop smoking
- Limit use of alcohol and recreational drugs
- Protect yourself from too much sun, use protective clothing and sunscreen
- Enjoy activities with friends and family
- Keep a good balance in your life and remember that laughter can be the best medicine!

Resources

For further help or information about these healthy living recommendations— nutrition, lowering cholesterol and so forth— you are welcome to call the Hotline at 800-533-4148, or go to the Virginia Department of Health website at: <http://www.vdh.virginia.gov>.

Another excellent source of healthy living information is the Center for Disease Control (CDC) website at: <http://www.cdc.gov/>

Please consider the need to reduce your risk for lung disease and cancer if you smoke. One resource is:

Quit Now Virginia

<http://www.vahealth.org/cdpc/tucp/quitnow.htm>

1-800-QUIT NOW (1-800-784-8669).

Pets are wonderful companions...

Pet precautions*

- Although owning a pet may have risks for people with HIV, many of the risks can be avoided. Pets provide emotional benefits, so don't be hasty about deciding to give up your pet. Here are some tips to keep you and your pet healthier:
- Take your pet to the vet right away if it gets diarrhea. Your vet will want to check to see if the diarrhea is caused by a germ that might be harmful to you. If possible, have a friend take care of your pet when it has diarrhea.
- Always wash your hands after handling your pet, especially before you eat. Avoid contact with your pet's feces. Avoid direct skin contact with contaminated soil or sand, especially if it's likely the soil may be contaminated with animal feces. If your child has HIV, make sure your child washes his or her hands after playing with the pet.
- If you want to get a new dog or cat, to reduce your risk of cryptosporidiosis, commonly known as "crypto", the animal should be at least 6 months old (a year old for cats) and it shouldn't have diarrhea. The parasite, cryptosporidium, may be found in soil, food, recreational water (swimming pools, hot tubs, jacuzzis, fountains, lakes, rivers, springs, ponds, or streams) that can be contaminated with sewage or feces from humans or animals. Avoid ingesting water from these sources.
- Be careful about where you get your pet. Some pet-breeding facilities, animal shelters or pet stores have better hygiene than others.
- Avoid stray animals. If you decide to adopt a puppy or kitten, your vet should check the pet to be sure it doesn't have any germs that you could get.
- If you have a cat, the litter box should be cleaned every day, preferably by someone who doesn't have HIV/AIDS and isn't pregnant. If you must clean the litter box it is advisable that you wear gloves and possibly something covering your nose and mouth if there is dust. Keep your cat inside, and don't let it hunt. Don't feed it raw or undercooked meat. Always wash your hands after cleaning the litterbox.
- Avoid the kind of play that may result in cat scratches or bites. If you do get bitten or scratched, wash the site right away. Never let your cat lick an open scratch or wound on your body. Flea control is also an effective way to help keep your cat and yourself healthy.
- Limit your contact with reptiles (snakes, lizards, iguanas, turtles) to reduce your risk of salmonella infection. Wear rubber gloves if you must clean an aquarium or bird cage. Avoid contact with exotic pets such as monkeys and exotic birds.

...But take precautions

...Especially with litter boxes.

Travel tips*

***Talk with your doctor
before you travel.***

Travel may be riskier for people with HIV/AIDS, especially if their immune suppression is severe. Travel to developing countries may put you at higher risk of food borne and waterborne illnesses than traveling in the United States. Talk with your doctor before you travel.

- Remember to be very careful with food and drinks. Avoid ice, raw vegetables and fruits, tap water, raw or undercooked seafood or meat, milk and dairy products and food bought from street vendors.
- Items that are generally safe include steaming-hot foods, fruits that you peel yourself, bottled (especially carbonated) beverages, hot coffee or tea, beer, and water that have been boiled for one minute.
- Treating water with iodine or chlorine may not be as effective as boiling it, but it may help, perhaps with filtration, when boiling isn't practical.

Although some studies have shown that medicine to prevent traveler's diarrhea may reduce the risk, none of the studies have specifically included HIV-positive patients.

It isn't generally recommended that you take medicine to prevent an upset stomach or diarrhea before traveling, but you may want to talk with your doctor about this. You should bring an antibiotic with you to take if you do get diarrhea.

See a doctor right away if your if your diarrhea is severe and doesn't get better with medicine, if you have blood in your stool, if you get dehydrated, or if you have a fever (with or without chills).

Avoid direct skin contact with soil or sand, especially if it's likely the soil may be contaminated with animal feces. Wear shoes and protective clothes. Sit on towels if you go to a beach.

Talk with your doctor about the vaccinations you need. Many vaccinations are okay for people with HIV/AIDS, but some common vaccinations shouldn't be used in people with HIV/AIDS. If you can't have certain vaccinations, your doctor may need to give you special instructions. Your doctor will also want to talk with you about avoiding exposure to fungal infections and protozoal infections, depending on where you want to travel.

There are no restrictions on vacation travel to most foreign countries, however, many countries do require HIV testing for work permits/visas, etc. You can go to <http://www.travel.state.gov/> for information on traveling overseas for HIV+ people.

**The information in this section was obtained from family doctor.org. The information provides a general overview on avoiding infection if you're HIV Positive and may not apply to everyone. To get more information on this subject you can visit the web site at <http://family doctor.org>*

Chapter 14 Resources

HIV/AIDS Resources

Virginia Department of Health Services Virginia HIV/STD/Viral Hepatitis Hotline	800/533-4148
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Virginia AIDS Drug Assistance Program (ADAP)	866/392-1309
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Ryan White (RW) Resources

Ryan White Part B Consortia information is as follows:

Region I – Northwest – receives RW Part B & C Northwest HIV Care Consortium	540/568.8166
Institute for Innovation in Health and Human Services James Madison University, 601 University Boulevard, MSC 9009, Harrisonburg, VA 22807	

Region II – Northern – receives RW Parts A, B, C & D Northern Virginia HIV Consortium	703/642-0700
Northern Virginia Planning District Commission 3060 Williams Drive, Suite 510, Fairfax, VA 22031	

Region III – Southwest –receives RW Parts B & C Council of Community Services	540/985-0131
502 Campbell Avenue, SW, P.O. Box 598, Roanoke, VA 24004	

Region IV - Central - receives RW Parts B, C & D Central Virginia HIV Care Consortium	804/828-8844
Community Health Research Initiative, 921 West Franklin Street Box 843065, Richmond, VA 23284-3065	

Region V - Eastern - receives RW Parts A & B Eastern Virginia HIV Care Consortium	757/446-6170
Eastern Virginia Medical School, P. O. Box 1980, Norfolk, VA 23501-1980	

The Part A providers are:

Northern Virginia Regional Commission	703/642-0700
3060 Williams Drive, Suite 510, Fairfax, VA 22031	

City of Norfolk	757/823-4405
741 Monticello Avenue, Norfolk, VA 23510	

The Part C providers are:

Mary Washington Hospital/Medicorp	540/374-3277
1101 Sam Perry Blvd, Fredericksburg, VA 22401	

University of Virginia Infectious Disease Clinic 1001 Emmet Street, N, Charlottesville, VA 22903	434/982-1688
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Inova Juniper Program 8001 Forbes Place, Suite 200, Springfield, VA 22151	703/321-2600
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Carilion Medical Center 2001 Crystal Spring Avenue, Suite 301, Roanoke, VA 24014	540/981-7674
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Centra Health Inc. 1920 Atherholt Road, Lynchburg, VA 24501	434/947-5565
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Central Virginia HIV Care Consortium Community Health Research Initiative 921 West Franklin Street, Box 843065, Richmond, VA 23284-3065	804/828-8844
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The Part D providers are:

Inova Juniper Program 8001 Forbes Place, Suite 200, Springfield, VA 22151	703/321-2600
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Virginia Commonwealth University Family Infectious Disease Clinic 1101 East Marshall Street, West Hospital, Room 7079, Richmond, VA 23298	804/828-9711
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AIDS Service Organizations in Virginia

AIDS Response Effort (ARE) 333 West Cork Street, Winchester, VA 22601	540/536-5290
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AIDS/HIV Services Group, Inc. (ASG) 963 2nd Street S.E., Charlottesville, VA 22902	800/752-6862
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Appalachian Assistance Coalition 201 E. Main Street, #110 Marion, VA 24354	276/781-0500
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Blue Ridge AIDS Support Services 331-B King George Avenue, Roanoke, VA 24013	540/344-6705
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ACCESS AIDS CARE 248 West 24th Street, Norfolk, VA 23517	757/640-0929
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Council of Community Services (CCS) 369 Church Avenue, Roanoke, VA 24016	540/985-0131 800/354-3388
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Fan Free Clinic, Inc. 1010 North Thompson Street, Richmond, VA 23230	804/358-6343
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Fredericksburg Area HIV/AIDS Support Services, Inc. (FAHASS) 415 Elm Street, Fredericksburg, VA 22401	540/371-7532
K.I. Services, Inc. 3333 Duke Street, Alexandria, VA 22314	703/838-0205
Minority Health Consortium (MHC) 208 East Clay Street, Suite B Richmond, VA 23219	804/225-0820
Newcomers Community Services Center 6131 Willston Drive, Room 8, Falls Church, VA 22044	703/241-0300
Northern Virginia AIDS Ministry (NOVAM) 803 West Broad Street, Falls Church, VA 22046	703/533-5505
Piedmont Access To Health Services 705 Main Street, Danville, VA 24541	434/791-3630
Tidewater AIDS Community Taskforce (TACT) 9229 Granby Street, Second Floor, Norfolk, VA 23503	757/583-1317
Urban League of Hampton Roads 3225 High Street, Portsmouth, VA 23707	757/627-0864
Valley AIDS Network (VAN) 601 University Blvd., Suite 322-324, Harrisonburg, VA 22801	540/564-0448 800/648-5302
Williamsburg AIDS Network 479 McLaws Circle, Suite 2, Williamsburg, VA 23185	757/220-4606

Local Health Departments

A

Accomack County Health Department	757/787-5880
Albemarle/Charlottesville Health Department	434/972-6219
Alexandria Health Department	703/838-4400
Alleghany/Covington Health Department	540/962-2173
Amelia County Health Department	804/561-2711
Amherst County Health Department	434/946-9408
Appomattox County Health Department	434/352-2313
Arlington County Health Department	703/228-5580
Augusta/Staunton Health Department	540/332-7830

B

Bath County Health Department	540/839-7246
Bedford County Health Department	540/586-795
Bland County Health Department	276/688-3642
Botetourt County Health Department	540/473-8240
Bristol City Health Department	276/642-7335 or 7345
Brunswick County Health Department	434/848-2525
Buchanan County Health Department	276/935-4591 or 4592
Buckingham County Health Department	434/969-4244
Buena Vista City Health Department	540/261-2149

C

Campbell County Health Department	434/592-9550
Caroline County Health Department	804/633-5465
Carroll County Health Department	276/730-3180
Charles City County Health Department	804/829-2490
Charlotte County Health Department	434-542-5251
Chesapeake Health Department	757/382-8600
Chesterfield Health Department	804/748-1743
Clark County Health Department	540/955-1033
Clifton Forge City Health Department	540/862-4131
Colonial Heights City Health Department	804/520-9380
Craig County Health Department	540/864-5136
Culpeper Health Department	540/829-7350
Cumberland County Health Department	804/492-4661

D

Danville City Health Department	434/799-5190
Dickenson County Health Department	276/926-4979 or 6661
Dinwiddie County Health Department	804/469-3771

E

Essex County Health Department	804/443-3396
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F

Fairfax County Health Department	703/246-2411
Fauquier County Health Department	540/347-6400
Fredericksburg City Health Department	540/899-4142
Frederick/Winchester Health Department	540/722-3470
Floyd County Health Department	540/745-2141
Fluvanna County Health Department	434/591-1960
Franklin City Health Department	757/562-6109
Franklin County Health Department	540/484-0292

G

Gloucester County Health Department	804/693-2445
Galax City Health Department	276/236-6127
Giles County Health Department 540/921-2891	
Grayson County Health Department	276/773-2961
Greene County Health Department	434/985-2262
Greensville/Emporia Health Department	434/348-4210 or 4235
Goochland County Health Department	804/556-5843

H

Halifax County Health Department	434/476-4863
Hampton City Health Department	757/727-1172
Hanover County Health Department	804/365-4313
Henrico County Health Department - Clinical Services	804/501-4651
Henry/Martinsville Health Department	276/638-2311
Highland County Health Department	540/468-2270
Hopewell City Health Department	804/458-1297 or 6523

I

Isle of Wight County Health Department	757/357-4177
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J

James City County Health Department	757/594-7305
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K

King George County Health Department	540/775-3111
King & Queen County Health Department	804/785-6154 or 3488
King William County Health Department	804/769-4988 or 3422

Local Health Departments (cont.)

L

Louisa County Health Department	540/967-3703
Lancaster Health Department	804/462-5197
Lee County Health Department	276/346-2011 or 2014
Loudoun County Health Department	703/777-0234
Lunenburg County Health Department	434/696-2346
Lynchburg City Health Department	434/947-6777

M

Madison County Health Department	540/948-5481
Mathews County Health Department	804/725-7131
Mecklenburg County Health Department	434/738-6333
Middlesex County Health Department	804/758-2381
Montgomery County Health Department	540/381-7100

N

Nelson County Health Department	434/263-8315
Newport News City Health Department	757/594-7305
New Kent County Health Department	804/966-9640
Norfolk City Health Department	757/683-2796
Northampton County Health Department	757/442-6228
Northumberland County Health Department	804/580-3731
Nottoway County Health Department	434/645-7595

O

Orange County Health Department	540/672-1291
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P

Page County Health Department	540/743-6528
Patrick County Health Department	276/694-3188
Petersburg City Health Department	804/863-1652
Pittsylvania County Health Department	434/432-7232
Poquoson City Health Department	757/594-7305
Portsmouth City Health Department	757/393-8585
Powhatan County Health Department	804/598-5680
Prince Edward County Health Department	434/392-8187
Prince George County Health Department	804/733-2630
Prince William County Health Department	703/792-6301
Pulaski County Health Department	540/994-5030

R

Radford City Health Department	540/831-5774
Rappahannock County Health Department	540/675-3516
Richmond City Health Department	804/205-3751 or 804/482-5500
Richmond County Health Department	804/333-4043
Roanoke City Health Department	540/857-7600
Roanoke County/Salem Health Department	540/387-5530
Roanoke County/Vinton Health Department	540/857-7800
Rockbridge/Lexington Health Department	540/463-3185
Rockingham/Harrisonburg Health Department	540/574-5100
Russell County Health Department	276/889-7621 or 7623 or 7624

S

Scott County Health Department	276/386-1312
Shenandoah County Health Department	540/459-3733
Smyth County Health Department	276/781-7460
Southampton County Health Department	757/653-3040
Spotsylvania County Health Department	540/507-7400
Stafford County Health Department	540/659-3101
Suffolk City Health Department	757/514-4700
Surry County Health Department	757/294-3185
Sussex County Health Department	434/246-8611

T

Tazewell County Health Department	276/988-5585 or 5586 or 2076
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V

Virginia Beach City Health Department	757/518-2700
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W

Warren County Health Department	540/635-3159
Waynesboro City Health Department	540/949-0137
Washington County Health Department	276/676-5604
Westmoreland County Health Department	804/493-1124
Williamsburg City Health Department	757/594-7305
Wise/Norton Health Department	276/328-8000
Wythe County Health Department	276/228-5507

Y

York County Health Department	757/594-7305
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National AIDS Organizations & Services

CDC National AIDS Hotline, English/En Español 24 hours/daily	800/CDC-INFO (232-4636) 800/232-6348 TTY
Gay, Lesbian, Bisexual and Transgender National Hotline	888/843-4564
National AIDS Information Clearinghouse	800/458-5231
National Association of People with AIDS (NAPWA)	866/846-9366
Drugs undergoing clinical trials AIDS Info (Clinical trials information)	800/874-2572
Help with Hemophilia National Hemophilia	800/424-2634
Treatment information AIDS Info	800/448-0440
National HIV Treatment Hotline	800/822-7422

Other Resources

Finances

Consumer Credit Counseling Service Virginia VA	888/502-3907
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Insurance

Virginia HIV Health Insurance Premium Assistance Program	800/432-5924
Virginia State Corporation Commission	

Bureau of Insurance, Premium Assistance Program	800/552-7945
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Rehabilitation Services	800/552-5019
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Equal Employment Opportunity	800/533-1414
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Legal Services

American Bar Association	800/285-2221
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Americans with Disabilities ACT Information Assistance Hotline	800/949-4232
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Department for Rights of Virginians with Disabilities	800/552-3962
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Virginia Lawyer Referral Service	800/552-7977
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Virginia State Bar	804/775-0500
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Social Security

Social Security Administration	800/772-1213
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Social Services

Call your local Social Security for assistance.

Information about Food Stamps, Disability and Fuel Assistance	800/552-3431
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Substance Abuse Services

Alcohol/Drug Treatment Referral	800/252-6465
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National Drug Abuse Hotline	800/662-4357 (HELP)
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Virginia Substance Abuse Services Information Line	800/451-5544
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**The information in this section, especially phone numbers and addresses, changes often.*

If you have trouble contacting any of the agencies we have listed call the Virginia HIV/STD/Viral Hepatitis Hotline at (800) 533-4148 for updated information.

HIV/AIDS on the Internet

The Internet or World Wide Web is an excellent source for information for people with HIV disease. The Web allows you to find current information in a private and easily accessed manner. However, it is easy to become overwhelmed by the sheer volume of information that is available to you on the Web. The best way to begin is to find a few sites that give you good information in a well-organized manner. Usually these sites will provide you with “links” to other sites with helpful information. The following list provides HIV related Websites that are good places to begin your Internet search.

AIDS Action

www.aidsaction.org

AIDS Education Global Information System

www.aegis.com

AIDS in Prison Project (The Osborne Association)

www.osborneny.org/health_services.htm

AIDS Info

www.niaid.nih.gov/daids

AIDSmap

www.AIDSmap.com

AIDS.org

www.aids.org

AIDS Project LA

www.apla.org

AIDS Research Information Center

www.critpath.org

AIDS Treatment News

www.aidsnews.org

American Dietetic Association

www.eatright.org

AmFAR AIDS Research

www.amfar.org

Being Alive

www.beingalive.org

The Body

www.thebody.com

Canadian AIDS Treatment Information Exchange (CATIE)

www.catie.ca

CDC AIDS Page

www.cdc.gov/hiv/dhap.htm

Children With AIDS Project

www.aidskids.org

Gay Men’s Health Crisis

www.gmhc.org

Gay, Lesbian, Bisexual and Transgender

www.glbtnationalhelpcenter.org

Kaiser Family Foundation

www.kkff.org/hiv aids

Know HIV AIDS

www.Knowhiv aids.org

National Association of People with AIDS

www.napwa.com

New England Association on HIV Over Fifty

www.hivoverfifty.org

National Council Against Health Fraud

www.ncahf.org

National Hemophilia Foundation

www.hemophilia.org

National HIV and STD Testing Resources

www.hivtest.org

National Minority AIDS Council

www.nmac.org

National Native American AIDS Prevention Center

www.nnaapc.org

National Women’s Health Information Center

www.womenhealth.gov

Positive Women’s Network

www.pwnetwork.org

Project Inform

www.projinf.org

SisterLove

www.sisterlove.org

TEENAIDS - PeerCorps

www.teen aids-peer corps.com

Virginia Department of Health, Division of Disease Prevention

www.vdh.virginia.gov/epidemiology/diseaseprevention/

Glossary

AIDS: Stands for Acquired Immune Deficiency Syndrome and is the last stage of HIV disease. Characterized by numerous opportunistic infections and cancers or a CD4+ cell count below 200/mm³ that, in the presence of HIV, constitutes a diagnosis of AIDS.

AIDS defining conditions: The opportunistic infections that seize on a body when the immune system has been disabled. There are 25 infections that qualify a person for state, city, and federal AIDS benefits.

AIDS dementia complex (ADC): A condition causing loss of coordination, depressed moods, memory lapses, personality changes.

ACTG 175: A government-supported trial that compared two drugs taken together to AZT taken alone (monotherapy), which was the norm at the time of the study. Data showed that drugs taken together work better at slowing HIV in the body. ACTG stands for "AIDS Clinical Trials Group."

Analog: A chemical compound with a structure similar to that of another compound, but differing from it in respect to a certain component.

Anemia: A condition caused by a lack of red blood cells or hemoglobin and characterized by weakness or fatigue.

Antiretroviral therapy: Treatment aimed at slowing or stopping the activity of HIV in the body.

Assay: Another word for test.

Asymptomatic: Without any sign of illness.

Bacterial pneumonia: A lung infection common in women with HIV disease.

Baseline viral load measurement: The first measurement of HIV in the blood against which later measurements are compared.

Branched DNA (bDNA): The branched-DNA technique amplifies a special signal given off by detector molecules. Each copy of HIV RNA is bound to multiple copies of a large, synthetic DNA molecule. In a series of chemical reactions, light is given off in an amount that represents the actual quantity of HIV RNA.

Case Manager: A social worker who can help access community resources, public benefits and other services.

CD4+ cell counts: The number of white blood cells that are fighting HIV in the blood. Counts are taken approximately every 3 to 4 months and can be used to determine how well the immune system is holding up within the course of HIV disease.

CD4+ cells: A type of white blood cell that carries the CD4+ surface marker and helps the body fight infection. Also known as T-cells or T-helper cells. When infected by HIV, these cells incorporate HIV RNA into their DNA and then manufacture new HIV particles; also used as a surrogate marker to measure HIV disease progression.

HIV Drugs

New HIV drugs are being added all the time. Use the lines at the bottom of the list to add any new NRTI drugs you learn about.

NRTIs

Zidovudine

AZT, ZDV,
Retrovir

Didanosine

dd1, Videx

Zalcitabine

ddC, HIVID

Stavudine

d4t, Zerit

Lamivudine

3TC, Efavir

Abacavir

ABC, Ziagen

Viread

Tenofovir

Enzyme: A protein in the body that causes chemical changes inside cells.

Estrogen: A hormone present in higher quantities in women than in men.

Food and Drug Administration (FDA): An agency of the U.S. Department of Health and Human Services that regulates the testing of experimental drugs and approves new medical products for marketing based on evidence of safety and how well it works.

Fusion Inhibitor: New class of anti-HIV medication, works by blocking HIV from getting into immune system cells. Injection drug only, used when all other medication options have been exhausted.

Granulocytopenia: Reduction in white blood cells that can cause such health problems as fatigue and malaise (bodily discomfort).

Hematologic toxicity: Disorders of the bone marrow that affect the production of red and white blood cells and platelets.

HIV (Human immunodeficiency virus): A virus that weakens the human immune system and allows other infections to harm the body and cause disease.

HIV disease progression: The natural forward motion of HIV disease from early infection and health to a disease, opportunistic infections, and possibly death.

HIV RNA: The chemical code at the heart of HIV that, when incorporated into your CD4+ cell's chemical code (called DNA), causes that cell to begin making more HIV particles. New tests measure the amount of virus in a person's plasma (a component of blood) and specifically measure HIV RNA as an indication of disease progression.

HIV viral replication: The process by which HIV makes copies of itself.

Immune system: The set of cells and other chemicals that allow the body to find harmful matter (i.e., germs, viruses, funguses, bacteria,) that may enter your blood, to stop them, and to do the same in the future, should more such matter enter your body.

Interactions: The negative reaction that some drugs have when taken at the same time. For instance, some antidepressant medicines can interact with protease inhibitor drugs.

Interleukin-2 (IL-2): An immune modulating substance.

In vitro: Latin for test tube experiment.

Life cycle: The process by which HIV copies itself and passes on its genetic material.

Lymph nodes: Sometimes called lymph glands. Bean sized organs made up mostly of lymphocytes, lymph fluid and connective tissues. Widely distributed in the body, clusters of lymph nodes are essential to immune function.

Logs: A measure used to report viral load results. Also, a short name for logarithms, which are math measures that simplify large numbers in multiples of 10. In other words, the number of times 10 must be multiplied by itself to equal a number, (i.e., 100,000 is 5 logs).

HIV Drugs

New HIV drugs are being added all the time. Use the lines at the bottom of each list to add any new protease inhibitor drugs you learn about.

Protease Inhibitors

Indinavir

Crixivan

Ritonavir

Norvir

Saquinavir

Invirase

Fortovase

Nelfinavir

Viracept

Fusion Inhibitors

Fuzeon

T-20

Malaise: A feeling of bodily discomfort.

Monotherapy: Taking one anti-HIV drug by itself. No longer the standard-of-care in HIV treatment as many drugs used in combination cause resistance very quickly when used alone.

Multicenter AIDS Cohort Study (MACS): The largest HIV natural history study that observed the course in different populations of infected men only. The study occurred in several university-based centers throughout the United States.

Mutation: An error in HIV genetic material that allows new strains of HIV that may be able to multiply when you are taking anti-HIV treatment.

Mycobacterium-avium complex (MAC): A serious opportunistic infection in HIV, which can cause night sweats, high fevers, cough, weight loss, tiredness, malnutrition, and diarrhea. An AIDS-defining illness.

Neutropenia: Reduction in infection-fighting white blood cells.

Non-nucleoside reverse transcriptase inhibitors (NNRTIs): The name of a class of compounds, including the drugs delavirdine and nevirapine. These drugs block HIV copying by binding with a part of HIV called “reverse transcriptase.”

Nonthymidine analog: A specific kind of chemical makeup that describes a type of nucleoside reverse transcriptase inhibitor. Ddl, ddC and 3TC are agents comprised of nonthymidine.

Nucleoside/Nucleotide analog: A synthetic compound used in HIV drugs (ddl, ddC, d4T) that mimics one of the building blocks of DNA. These compounds suppress retroviral replication by interfering with the reverse transcriptase enzyme and causing the virus to quickly stop reproducing. Also referred to as nucleoside reverse transcriptase inhibitors or NRTI.

Nucleoside reverse transcriptase inhibitors (NRTIs): A name of a class of drugs used to fight HIV disease. Current nucleoside analog drugs include: AZT, ddl, ddC, d4T, and 3TC. The name is based on the parts of HIV that serve as building blocks for its genetic material (i.e., RNA and DNA).

Opportunistic infection (OI): An infection or condition that takes place when the immune system gets weak due to AIDS, cancer, HIV, or certain medicines. Examples include PCP, MAC, cytomegalovirus, vaginal thrush, and wasting.

Oral Ulcers: A painful condition of the mouth involving cuts and sores.

Pancreatitis: Inflammation of the pancreas.

Peripheral neuropathy: Nerve pains or a numb feeling in the arms, legs, hands and feet. A side effect of some NRTI drugs.

Plasma: The part of blood in which red and white blood cells are suspended.

Polymerase chain reaction (PCR): An enzymatic process that allows the amplification and identification of specific DNA or RNA sequences, in this case HIV- I RNA. PCR is repeated for many cycles in order to create millions of copies of the targeted sequence. The final step is the calculation of HIV RNA, using predetermined ratios.

Pneumocystis Carinii Pneumonia (PCP): A preventable lung infection in people with weakened immune systems. When a person develops PCP, he/she can be treated, though PCP may return. The organism that causes PCP is found in nearly 80% of all AIDS patients at some time during the course of the disease and can be a major cause of death.

Primary infection: The flu-like symptoms that occur immediately after a person contracts HIV. This initial infection precedes seroconversion (going from HIV-negative to HIV-positive) and is characterized by fever, sore throat, headache, skin rash, and swollen glands. Also called acute infection.

Prophylaxis: Treatment to prevent the onset of a particular disease (primary prophylaxis) or recurrence of symptoms in an existing infection that has been brought under control (secondary prophylaxis or maintenance therapy).

Progression: The advancement of HIV disease from early infection to a disease state associated with failing health and opportunistic infections.

Protease: A piece of HIV involved in making more virus during later stages of HIV's copying process.

Protease inhibitors (PIs): A class of drugs used to treat HIV disease that bind to and block HIV protease in order to prevent the production of new HIV. Current protease inhibitors include Saquinavir (Invirase), Ritonavir (Norvir), Indinavir (Crixivan), and Nelfinavir (Viracept).

Quantitate: Another word for count.

Reproductive Tract: The genitals (sex organs) plus organs inside a woman's body used in child bearing. Includes the uterus or womb, fallopian tubes, and ovaries. Can be susceptible to HIV-related infections and conditions.

Resistance: The ability of HIV to multiply even when you are taking anti-HIV drugs. The result is that HIV disease is no longer stopped by the drug treatment.

Reverse transcriptase: Enzymes that help turn viral RNA to cell DNA during the early stages of replication (making copies of itself).

RNA (ribonucleic acid): A single-stranded molecule made up of nucleoside sequences similar to double-stranded DNA. RNA sends the code that tells the cell's chemical machinery to make structural proteins and enzymes. The RNA segments in the cells represent copies of portions of the DNA sequences in the nucleus (center of the cell). In HIV RNA contains the viral gene codes and allows the gene to reproduce.

Seroconversion: Describes the process by which a person goes from HIV negative to HIV positive.

Set point: Measurable holding point or balance between the virus and the body's immune system. Usually established when first diagnosed with HIV infection and reported as a viral load measurement.

T-lymphocytes: White blood cells of the immune system that help the body fight HIV. Also called CD4+ cells or CD4+ lymphocyte cells.

Thymidine analog: A specific kind of chemical makeup that describes a type of nucleoside reverse transcriptase inhibitor. Both d4T and AZT are comprised of thymidine.

Treatment experienced: A description of someone who has taken antiretroviral therapy.

Treatment failure: When drugs stop working well to slow the virus. Usually marked by a spike in viral load. Can be caused by resistance.

Treatment naive: A description of someone who has never taken antiretroviral therapy.

Vaginal thrush: Also called a yeast infection or candidiasis. This is common in women with HIV.

Viral load: The amount of HIV RNA in the blood plasma.

Viral load tests: A test to count the actual amount of HIV RNA, or genetic material, in the blood. It is currently used as a way to measure resistance, too, since a rise in viral load, after a drop when starting a new combination regimen, usually means resistance is present.

Viral replication: The process by which HIV is able to invade a CD4+ cell or other cell and use the cell nucleus to make more copies of HIV.

Viral set point: The point of balance between the virus and the body's immune system. A healthy state in HIV infection during which disease is fought off.

Virions: Complete viral particles.

Virus: An agent that can enter your body and cause disease. Examples include a strain of common cold, HIV, or herpes.

Wasting: The loss of more than 10% of a person's ideal body weight; an AIDS-defining illness.

