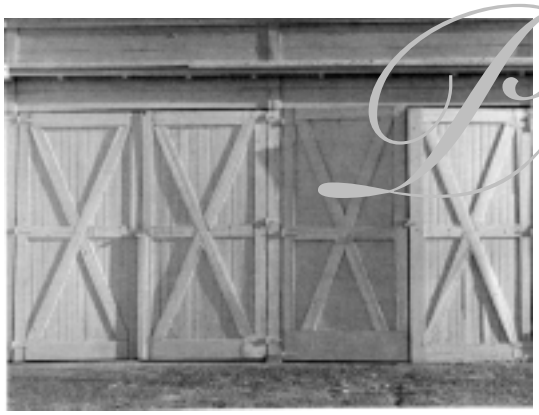
POSITIVE LIVING

A Practical Guide for People with HIV



People with HIV and AIDS are living longer and healthier lives than even a few years ago. New and promising treatments are now available which have the potential for changing HIV infection into a long-term treatable illness. Already, recent research shows that some people with HIV have been infected for over 15 years and have no symptoms at all. We now believe that it is possible that some people may survive this disease altogether. All of these things give people with HIV, and the people who love them, reason to hope.

This guide has been developed for people with HIV infection by health professionals and people living with HIV. This guide is intended to offer you three main things: hope for the future, information about how to take good care of yourself, and referrals to the many organizations and people in the community who are ready to help you when you need it.

If you have recently found out that you are HIV positive, you may find yourself in a state of shock. You may find that it is difficult to read this book, and even more difficult to remember what you have read.

Don't worry—most people feel the same way when they first learn that they have HIV.

You don't have to read this book all at once. It will be here when you are ready to know more.

Produced by

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Seattle & King County
HEALTHY PEOPLE. HEALTHY COMMUNITIES.

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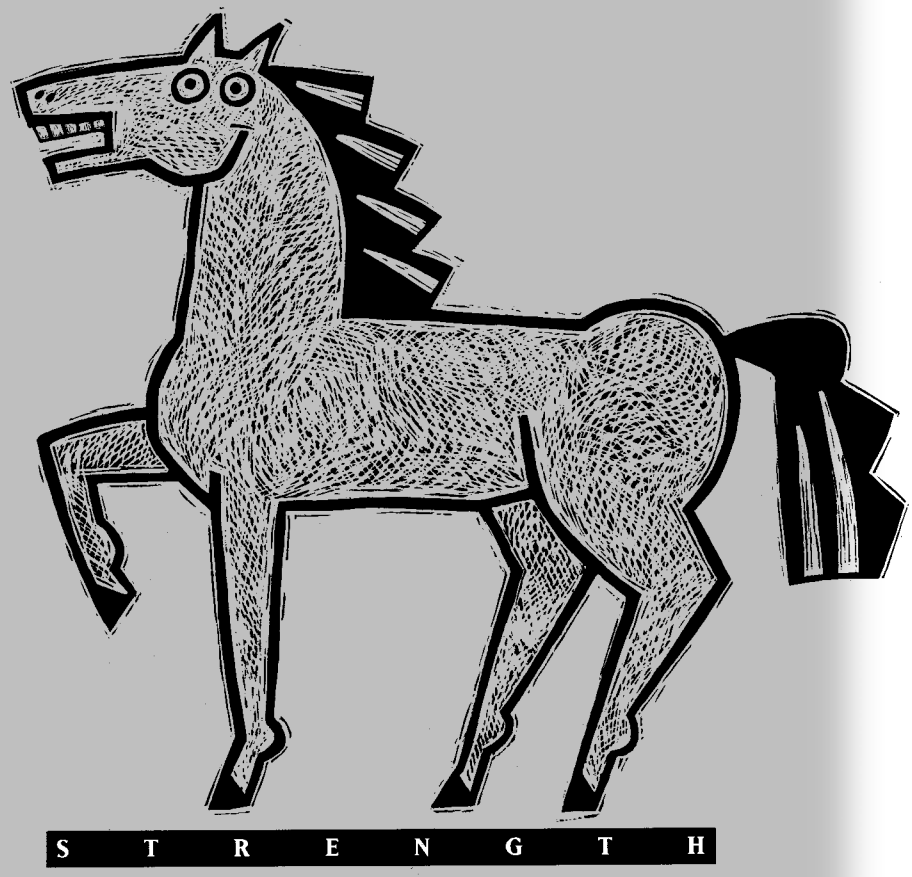
HOPE



Chapter 1

Coming to Terms with HIV

Whatever you are feeling right now, it is important that you know that having HIV does not necessarily mean you are going to get sick or die soon. HIV, the human immunodeficiency virus, causes AIDS by weakening the body's immune (defense) system, leaving people unable to fight off diseases. When a person's immune system has lost most of its ability to fight illness, they are said to have Acquired Immune Deficiency Syndrome (AIDS).

However, HIV works slowly in the body. Most people with HIV infection are healthy and fairly free from symptoms for over 5 years. Most people don't get an AIDS diagnosis for over 10 years. Even after an AIDS diagnosis, with proper treatment people are living more than twice as long as they were in the past.

Dealing with Fear, Anger, Grief and Depression

Because of recent advances in treating and monitoring the health of people with HIV, things are looking brighter. Even so, HIV is a very serious infection. It is natural to feel shock, grief, anger, fear, and sadness when you first learn you have HIV. You may be afraid of how your lover, friends, family, and coworkers will react to finding out that you have HIV. You may fear getting sick or losing control of your life. You may feel angry with or betrayed by the person who gave you this virus. Or, you may feel nothing at all. Some people feel a sense of relief when they learn they are HIV positive because so many of their friends and loved ones have HIV too, or because they can finally stop worrying about getting infected. All of these reactions are understandable, and for most people, theypass with time.

Whatever reaction or feelings you have upon learning you are infected, it is important to deal with them. Ignoring or "bottling up" your feelings may make things worse. The following are some suggestions about how to cope with your feelings.

Trust that things will get better. You may find that the first months after learning that you are HIV positive are the most emotionally difficult. Over time, the intensity of these initial feelings will probably lessen, and you will begin to feel like your old self again. The intense grief and anger about the loss of your HIV-free status, like grief over the loss of someone you love, generally lasts a few months. During the difficult times, it is important to have faith that things *will* get better. There are lots of ways of making certain that things will get better; playing a role in keeping yourself healthy is one way that you can start to get your old life back.

Crying

Sometimes things don't go well at all. Thoughts start twisting mostly in the wrong direction, rolling down and down, seeking back in memory every occasion of regret, turning even insignificant episodes into proof of failure, defeat.

Let your mind be as pessimistic as it can be. Then something begins to move, inside your body, in an indeterminate point between your throat and your stomach; like a bubble in the water this moving unidentified thing is trying to escape from the center of the ball, fighting to emerge on the surface; an itchy sensation around your eyes and it finally blows in the open air: yeah! you're crying!

It's good to cry. If it were wrong in any way, they wouldn't have put tears in our luggage. It can be a sort of personal counseling, alternative therapy, spiritual research, to cry without searching for a reason why. It's a question of practice. If you learn to cry, it doesn't weaken you, it doesn't dismay: crying rids fears from the load of rationalization, as a flood that sweeps away masks and good reasons. To cry keeps you in touch with your own feelings, those that you have hidden. To be in touch with your feelings is a source of strength.

I feel guilty sometimes, wasting time crying instead of responding, doing something useful, making me stronger. But I wonder if I could have passed through this mental hurricane that an HIV positive test means if I hadn't "wasted" all that time crying everywhere.

Cry for everything, everyone; don't cry only for yourself. Cry for your life. You'll be surprised by the ever improving quality of your laughter.

-Diana, HIV positive woman

Talk to other people with HIV. Whatever feelings or symptoms you are having, others are probably having them, too. This epidemic began in 1981, and people who have been living with HIV may have helpful advice. They can help – and they want to help. If you don't know of any other people with HIV, you can go to a support or social group to meet people and compare notes. You may also meet HIV positive people by volunteering with an HIV/AIDS service organization. Refer to the chapter "Getting Good Services" to find out about support groups and other HIV/AIDS organizations.

Continue to do the things you have always enjoyed. Sometimes, people who are depressed or anxious stop doing the things that make them happy. While you may need some time to get over the shock of learning you are HIV positive, doing the things you have always loved can help you avoid exaggerating or concentrating on your worries. Realize that you are still the same person you were before your HIV diagnosis.

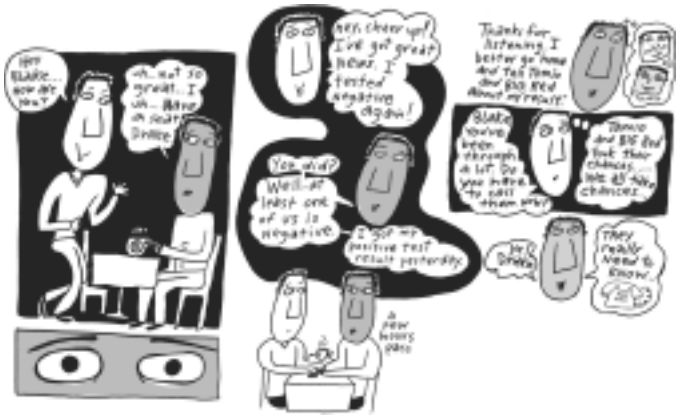
Take up some sort of exercise. Sometimes, people with HIV can feel angry with or betrayed by their bodies. Sometimes, they simply feel detached or disconnected from their bodies. Regular exercise at least three days a week is one way to help ease these feelings. It increases chemicals in your brain which helps you feel more energetic, calm, and optimistic. Exercising can be a great way to help you enjoy, appreciate, and feel in touch with your body. You don't have to be an Olympic athlete — even a brisk walk is great for your body *and* mind.

Cheaper than therapy!
Play sports with friends, Pet a dog, Go out to eat, Get a massage, Read a trashy novel, Cry in someone's arms, Volunteer with an AIDS organization, Yell and throw rocks into a lake, Take a nap, Dance naked in your apartment, Walk the city all day long,
Take up pottery

Avoid making any major life changes right away. Upon finding out they have HIV, some people have quit their jobs, sold their things, and run away from friends and family. Later, after the emotional crisis passed and they discovered that they could still live their lives fully, they regretted those decisions. Of course, your future plans may change as a result of your HIV infection; however, probably not as much as you might expect. Make changes slowly. This will be less stressful and will help you fully consider the pros and cons of making those changes.

Find out about HIV infection and about local resources. Learning about HIV and all the people and organizations available to assist you can help you feel more in control of your life. Check out the "Getting Good Services" chapter for ideas about where to start. Remember, you don't have to learn everything at once; take it at your own pace.

If your depression doesn't go away or gets worse, talk to a doctor or counselor. If you continue to feel depressed or anxious after several months, you may need some additional support. Counseling has helped many people get through a personal crisis, and there are low-cost counseling options available locally. Sometimes, doctors prescribe medication to treat people with anxiety or depression. Contact a doctor or counselor to help you figure out your options. *If you have any serious thoughts about suicide, call or visit a doctor or counselor right away.* These feelings will pass and you will be glad you got help.



Remember—you are not alone. There are more than half a million people in the United States who are living with HIV. In the Seattle area alone, there are several thousand people with HIV. You did nothing terrible or wrong to get this virus, and you have nothing of which to be ashamed.

Telling Others You are HIV Positive

Deciding whether, when, and how to tell your friends and loved ones about being HIV positive can be difficult. You may find yourself caught in a bind: wanting the love and support of those close to you, yet fearing their rejection. Though it is bound to be difficult and scary, you will probably find that most of those close to you will still love and support you after learning that you are HIV positive. Your friends and family will no doubt be upset. Yet, they will also likely feel honored to have been told, and your relationships may even strengthen and deepen as a result of your honesty. Telling others of your HIV infection also tells them that you trust them.

Some people with HIV initially tell only their spouse or partner. Others include their closest friends and family. Some people decide to wait to tell family or close friends, preferring to talk first with others in a support group setting. Ultimately, it's up to you to decide who should know about your status. Select people who you trust and who you think will support you. As time goes on and you get more comfortable dealing with your status, you may choose to tell a wider circle of people. Be sure to ask those you tell to keep the information private.

Consider the following questions in deciding whom to tell about your HIV infection:

- Is this person likely to be supportive of me? How have they dealt with problems I have had in the past?
- What do I hope to get out of telling this person?
- Could telling this person put me at risk of losing my job, children, or housing?
- Is this someone with whom I have had sex or shared needles, who may be infected but not know it?
- Might this person cause me physical or emotional harm if I tell them?
- Might this person feel hurt if I don't tell them, because they would want to help?
- Can I trust this person to keep the information private?
- Will I worry more if I don't tell this person?
- Does this person need to know so that I can get the best medical care or social services I may need?

There is no easy way to tell people that you have HIV, just as there is no foolproof plan to make sure that people will react with compassion. The following suggestions will help you prepare for telling others.

"It was a big relief...that there was now someone I didn't have to lie to." – Joe, an HIV positive man

Be ready for questions. Anyone you tell may ask you a lot of questions about HIV and AIDS, your health, and even how you got infected. Things will probably go best if you plan how to answer. Don't feel pressured to answer questions if you don't know the answer, or feel it's too personal. Be prepared to give the people you tell a brochure about HIV and AIDS or refer them to an informational hotline (see the "Getting Good Services" chapter for details). People who care about you may also want to give advice when they know you're having a difficult time. Feel free to tell people that what you really need is someone to listen; let them know that you and your health care provider are working on your specific plan to deal with the disease.

Be someplace comfortable. Telling someone that you are HIV positive can be a very emotional experience for both of you. The news may upset the person you tell, and you will want to be in a place where you feel comfortable, where you have privacy, and when you have plenty of time.

Remember that all reactions may not be supportive. Although it is unfair and illogical, some people may withdraw from you after you tell them you are HIV positive because they are afraid of getting HIV from you or because they feel betrayed; another reason for an unsupportive reaction may be their fear of eventually losing you. Be prepared to give people who need more information or support a referral to an HIV/AIDS hotline or a support group for friends and family of people with HIV. Some people simply need time to adjust and may come back into your life in the future.

Avoid feeling responsible for other people's reactions. You have shown a great deal of strength in choosing to tell people you are HIV positive. Some people may be stunned and unable to give you much support right away. Remember, you do not have to make everyone feel better about the news. Take care of yourself first.

TELLING SEXUAL PARTNERS AND NEEDLE-SHARING PARTNERS

Though it is hard to tell them, your past and current partners (both sexual and needle-sharing) need to know if they have been exposed to HIV. They must know so that, if they are infected, they can (1) be sure not to transmit the virus to others, and (2) get appropriate medical care and treatment. You do not need to tell people yourself; local Public Health Department staff can tell your past partners that they may have been exposed to HIV without giving your name. In addition, they can provide immediate counseling and HIV testing for

them. The Public Health Department will work with you to come up with a plan that protects your anonymity and your safety. See the "Getting Good Services" chapter of this manual for this resource.

It is also in your best interests to tell any future partners that you have tested HIV positive *before* having any contact with them that could transmit HIV. This is to protect you from legal problems and to allow them to make informed decisions. The chapter "Sex, Love and Relationships" includes more discussion about whether, how, and when to tell partners of your HIV status.

"He could have told me a long time before. He was scared that I would reject him. But the minute before he told me, he was my father. And the minute after he was my father. It didn't really change anything."
– Laura, daughter of HIV positive man

TELLING YOUR CHILDREN

Your children, especially if they are young, may be the hardest people to talk to about HIV. You may want to protect them from the news, and you may also want to be honest with them. Of course, there is no single perfect approach to whether, how, or when to bring up the subject; you will want to consider your children's ages, individual personalities, and prior experiences with illness and possible death as you make your decisions. You may want to get advice from a counselor or from family and friends who know your children in making these decisions. But, ultimately, it is you who know what is truly best for your children and your family.

There are good reasons for telling your children and good reasons not to. Some parents decide to tell their children about their illness because children can often sense when something is wrong in their immediate family. If they are not told what is going on, they may begin imagining things and may believe that the unknown problem is their fault. Additionally, keeping a secret from children is often a huge emotional burden for a parent. Parents may also want to be the ones to tell children about their illness before someone else does. As much as we try to guard this private information, it may still leak out and children may find out through the grapevine.

Other parents decide not to tell their children about their illness, or to wait until the children are older. Some parents feel that the information will be too frightening for a young child. To ease the fear, many parents first want to have plans in place for the child's future in case the parent becomes ill or dies. Another risk is that children may unintentionally tell others about the parent's illness. If the child is also infected, a parent may feel especially protective and worry that the child will be treated unfairly by others.

If and when you tell your children, they are bound to have a lot of questions. Common questions children ask include the following: *Why did this happen to you? Am I going to get sick? Did I make you sick? Can you get better? Are you going to die? What will happen to me? Who am I going to live with?* Children will need different responses depending on their age and maturity, and it can help if you have had the chance to think through how you plan to respond before telling them of your illness. Some people have found it helpful to "practice" with a friend or family member.

If your children are also HIV positive, this will present further challenges. There are people who can help you work this out—see "Getting Good Services" in the back of this guide.

Hope and the Future

People with HIV or AIDS often ask their doctor, "How long do I have to live?" There is no answer to this question because the length of anyone's life is unknown. There is no way to predict with certainty what is going to happen, how long we are going to live, or how we will die. Getting an HIV diagnosis may make you more aware of death. But, the cycle of birth, life, and then death has always been part of the human condition.

Along the same lines, statistics are often produced to show the life expectancy of people with AIDS. You should feel free to ignore these statistics for two reasons. The first is that statistics are only summaries of a large number of cases and don't apply to the individual. The second and more complicated reason is that studies of long-term survivors of HIV (as well as breast cancer), suggest that people tend to do better if they maintain a positive attitude, participate actively in their own health care, believe they can influence their own wellness, and have supportive relationships. Though the connection between how we feel emotionally and how we feel physically is not always consistent, it does seem that people's immune systems suffer when they are feeling hopeless about the future.

Remember that feeling hopeless is not the same as grieving, a natural process that can be healthy both emotionally and physically. Now that you know you have a serious illness, your future may feel uncertain. The most important thing to remember is that whether you live two more years or 50, they can be good years. And many people with HIV find that, although the disease does make them more aware of death, it can also makes them more aware of life.

With each passing day, there is more and more hope for people with HIV. Consider the following points:

- People with HIV are living longer than ever before, and some people may survive this disease altogether. About one in 10 people who have had HIV for more than 15 years have immune systems that are still functioningnormally. Others who do have symptoms or have AIDS are still living 10 years afterinfection. Nobody knows exactly why some people seem to do so well in the face of this disease, but extensive research is being done on the subject, and this may bring us closer to finding an ultimate cure.
- There are a number of new anti-retroviral drugs and treatments available that can reduce the amount of virus in the bloodstream and increase the functioning of the immune system. Though research continues, these are the most promising treatments for HIV infection so far, and there is new hope that living a long life with HIV may be possible.
- Scientists know more about HIV than about any other viral disease in history. The scale of the search for treatment and cure is vast. It is going on daily inmany different countries and involves some of the world's top scientists. With each new bit of information, a cure is one step closer.
- There are more and more resources available to people with HIV and AIDS, including financial assistance, housing options, and support groups. The chapter "Getting Good Services" in this manual lists many of these resources.

"After about 3 months I was no longer in shock, and at that point it dawned on me that not everyone is going to die from this disease. There are going to be survivors and if anyone is going to survive, it's going to be me."
– Arturo, HIV positive man

Chapter 2

Understanding and Dealing with your Medical Condition

Choosing a Health Care Provider

Choosing the right health care provider for you is a very important decision. People who get the best care for HIV tend to have close working relationships with their health care provider, and they are active and respected participants in health care decisions. Although you may now be quite satisfied with your current health care provider, some people later find providers who are better suited to their needs. Ultimately, you will want to find a provider who is knowledgeable about HIV and any other clinical problems you may have and, most importantly, one with whom you feel comfortable. Ask others you know who are HIV positive how well they like their health care provider; they may be able to give you good leads. If you don't have a provider or think you'd like to switch, there is a local agency listed in the "Getting Good Services" section of this guide that can help you find a health care provider.

It is a good idea to find a health care provider you believe will work with you over the long term. Staying with a provider for only a short time makes it hard to get good health care because you may never get to really know each other. You may feel comfortable simply choosing one of the referrals provided by this guide or a friend. Another option is to call a few providers and

set up visits with each of them in their offices. Let them know you are looking for a health care provider, and would like to briefly meet and talk with them. Ask if this interview can be free, and how much time you will have with the provider. The following questions can help you choose the right provider: How many HIV positive patients have you had? Which hospital(s) do you admit to? How do patients reach you after office hours? Who takes backup calls when you are on vacation? Are your on-call partners experienced and good at treating people with HIV/AIDS? How will you maintain patient confidentiality? Are you willing to work with my other providers? (This is important if you decide to work with alternative health care providers such as naturopaths or acupuncturists.) What do you think your patients appreciate most about you?

The most important thing is that the provider you choose should help you feel comfortable and a part of the decision-making team. Make sure they discuss medical terms and treatments in a language you understand, that they listen to you and take your ideas seriously, and respect you at all times. This may be very different than relationships you have had with previous doctors, in which they gave the orders and you followed them. It isn't always easy to speak your mind with a health care provider, even if they are perfectly nice, but it is worth it. Remember that you have hired your health care provider and you can fire them if they no longer meet your needs. If you have tried to talk to your provider about concerns you are having and you still feel unsatisfied or unsupported, it may be best to look for someone new.

HOW TO WORK WELL WITH YOUR HEALTH CARE PROVIDER:

Once you have chosen a health care provider with whom you feel comfortable, keep the relationship working smoothly. The following are some tips from HIV positive people and their doctors about working well together.

Before each visit, write down all your questions and take the list with you. This will help you to remember your concerns, and will help you to use time more effectively. If your list of questions is long, ask the most important ones first and any others if time allows.

Expect your first visit with your chosen health care provider to be a long one. When you schedule this visit, let the receptionist know that this is your first visit and that you will probably need a complete history and physical exam (this usually takes about 45 minutes). During a first visit, your provider will typically ask you a whole series of detailed questions and seek to learn about all medications you are taking, including treatments that other providers are prescribing. Questions often include any travel you have done recently, and any vaccinations and infections you have had in the past. You will also get a complete exam of your entire body including the eyes, mouth, rectum and genitals. Blood, chest x-ray and urine tests will generally be arranged, unless you have had them done recently. It will be helpful to get copies of your medical records from previous doctors and clinics, and may save the cost of repeating tests. If you are currently taking any medications, write down the names and the doses so you can remember them.

Ask your provider to clearly explain any problems found. Most health care providers try to speak in a language that their patients will understand, but they still may use technical words and phrases you don't know. Be sure to tell your provider when you don't understand something. In order to work as a team with your provider, you will need to understand your condition and the recommended treatment.

Use the phone effectively. Since health care offices are usually very busy, it will help if you have written down what you want to say ahead of time. You will often have to speak with a staff person who will relay the message to your primary health care provider and call you back. Take notes on what is said so you will remember it all.

If you have an unexpected or severe side effect from a medication, call your health care provider immediately. Your provider can recommend if you should stop taking the medication or switch to a different one. In general it is not a good idea to stop a medication without the knowledge of your health care provider, because your symptoms could return or worsen.

Get second and third opinions. If you are told you need surgery or a treatment that is not widely known about or is still being tested, consider getting a second or even a third opinion. Don't feel that you are insulting your health care provider by asking for a referral.

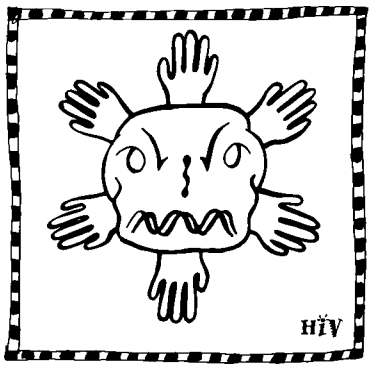
Remember your health care provider is human and has a life full of friends, family, and assorted legal, financial, and emotional problems just like the rest of us. Health care providers who care for people with AIDS have very stressful jobs, and some days they are more on top of things than others. In addition, as expert as they may be, health care providers can't fix everything and once in a while they are wrong. Sometimes a treatment works for nine people but not for the tenth. Your initial reaction may be anger, or a desire to switch providers. This is normal, but try to hang in there and communicate clearly. It is not a good idea to switch providers just because one interaction didn't go well, or because a single treatment didn't work.

Educate yourself about HIV by reading books, magazines and journals. Local AIDS organizations have resource libraries that you can use if you do not want to buy books. Learn as much as you can about your medical conditions, and share what you have learned with your health care provider. Trying to keep up with all the growing AIDS research is a huge job, and even the best health care providers often first hear of a new treatment from a patient who read about it elsewhere. Remember that there are some people who advertise a treatment or "cure" for HIV infection that has not been found to be effective. Your health care provider can help you determine which treatments may be useful to you.

IMMUNE SYSTEM BASICS:

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 lousy for a few days. But finally your immune system works to kill or control the virus, and you feel fine again. HIV is different from a cold virus because it directly attacks the infection fighting cells (called CD4 or T4 cells) in the "cellular" (as opposed to the "humoral") immune system. If your cellular immune system is severely weakened, it may not be able to fight off diseases (like infections and cancers) that healthy people don't worry about. People who have HIV and have weakened immune systems are sometimes called immuno-compromised or immuno-suppressed, which means their bodies cannot fight infections and cancers as well as an HIV-negative person.

White blood cells (WBC) are primarily responsible for fighting infections in the body. The following are types of white blood cells: lymphocytes, neutrophils, eosinophils, basophils, and macrophages. Lymphocytes include B-cells and T-cells. The two most important types of T-cells are CD4 cells and CD8



cells. The CD4 cells are like army generals, coordinating different types of white blood cells in their respective battles. The CD4 cells are a primary target of HIV infection, because HIV attaches to and reproduces within them. The CD8 cells are the real trench fighters of the immune system. They directly attack both HIV and infected CD4 cells. B-lymphocytes create antibodies (for humoral immunity); these are proteins that protect the body from further attacks by germs the immune system has successfully battled in the past. Neutrophils are powerful warriors against most bacterial infections. Eosinophils and basophils are involved in allergies, and are not generally affected by HIV infection. Macrophages, which can also be killed by HIV, absorb germs that attack the body.

BLOOD TESTS

There are various blood tests that can help to show the strength of your immune system or how much HIV you have in your body. In the past most people with HIV infection learned about the T-cell tests (which measures CD4 cells), but in recent years the "viral load" test has become very important as well. These tests can be used to judge the danger a person is in – like a train on a track headed toward a cliff. In this metaphor, the T-cell test measures the distance from the train to the end of the tracks at the cliff; the greater the T-cell test number, the farther the train is from the cliff and the less danger there is to your health. The viral load test, on the other hand, is akin to the speed of the train; the higher the viral load, the faster the train moves toward the cliff and the more danger the person is in. Both tests help you and your health care provider to plan your treatments. But, blood tests are not the only markers of your HIV infection; how you feel is also very important in determining your health. In addition, both T-cell counts and viral load values can go up and down a lot, so changing results should not always worry a person greatly.

A person with a healthy immune system usually has between 700 and 1200 CD4 cells in a cubic milliliter of blood, but this can vary based on time of day, or following a simple cold or even sunburns. For this reason, you may need to repeat a CD4 count to get an accurate result. When CD4 counts drop below 500, danger may be more imminent; and below 200, you are at risk of developing opportunistic infections or tumors. The ratio of CD4 to CD8 cells can also be important. The ratio in a healthy body ranges from 0.9-3.5, but often this number is lower in HIV positive people. The total number of CD8 cells normally ranges between 240-1200 per milliliter of blood.

"Going down to the lab I'm a wreck. If there are people down there that I recognize then I'm fine. But it's more than just the physical part. It reminds me that I feel out of control, that I've got this." – Virginia, an HIV positive woman

As we said earlier, the viral load is the amount of HIV measurable in the blood. The test is a relatively new tool for determining how fast HIV is reproducing in the body. People with recent infection often have viral loads of a million or more particles in a milliliter of blood. After six months following initial infection most people will have antibodies to HIV in their blood and their immune system will have reduced the viral load in the blood to some lower level. Studies have shown that people with the highest viral levels after six months are those whose immune system cells are most rapidly destroyed; people with the lowest viral levels have the slowest progression of HIV infection. Thus, high viral load test results suggest that aggressive treatment for HIV is useful.

Complete Blood Count (CBC):

This is a routine series of tests that gives a very general picture of the health of the blood and is used in diagnosing many conditions. Specifically, the CBC gives information about the number and types of red and white cells in your blood. It can tell whether you have too many or too few infection-fighting white blood cells. It can also provide clues as to whether your blood is healthy or anemic, and whether or not you are currently fighting off an infection. There are two parts of the CBC that your health care provider will most likely focus on.

Red Blood Cells (RBCS)

RBCs are the cells that carry oxygen to all parts of your body. The part of the red cell that carries the oxygen and gives it its red color is called the hemoglobin. The RBC is a number that will interest your health care provider. Normal hemoglobin values for men range between 14-18 gm, and values for women range from 12-16 gm. People with HIV infection will sometimes have low levels of hemoglobin. Another test that is related to your RBCs is called the hematocrit, which is the percentage of the blood volume made up of red blood cells. Normal hematocrit values for men are 42-52% and for women 37-47%. Your hematocrit level will usually be about three times your hemoglobin value, and your health care provider may use these values interchangeably.

White Blood Cells (WBCs)

WBCs make up part of your immune system. Their main purpose is to fight infection, which is why it is important to keep a watch on them. The total WBC count is the sum of many different types of cells, including neutrophils, lymphocytes, monocytes, eosinophils and basophils. White blood cell counts in HIV positive people are often lower than normal. This can be due to HIV itself, or from drugs used to treat HIV infection or opportunistic diseases. A normal WBC ranges from 4,300-10,000.

SYMPTOMS

Thinking about symptoms a lot can drive an HIV positive person crazy. Many people worry a lot about symptoms when they are first diagnosed. Luckily, as people adjust to having the disease their panic often decreases. About half of those who are newly infected develop short-lived flu-like symptoms as their body becomes a factory for HIV and tries to ward off the new intruder. After

this, most people do not experience many symptoms of HIV infection for up to 8-10 years. Equally important is to keep in mind that HIV positive people still have allergies, mosquito bites and run-of-the-mill colds like everyone else; so, many symptoms experienced by people with HIV have little or nothing to do with HIV. Finally, people are often under stress and this can cause many of the same symptoms as HIV, including tiredness, difficulty breathing, loss of appetite, and headaches.

Don't worry about every symptom you may experience, but severe or prolonged symptoms mean it would be wise to call your health care provider's office to seek advice. The following symptoms can be caused by HIV or by other illnesses. If you experience any of them, tell your health care provider as soon as possible; there are effective treatments for many of these conditions:

- fever of at least 101° F lasting more than two days
- newly swollen glands in the neck, armpit, or pelvic area
- shortness of breath
- genital, anal, or vaginal sores, itching, discharge or irritation
- diarrhea lasting more than three days
- continued loss of appetite
- losing 10 pounds or more without trying
- sores or rashes that won't go away
- persistent yeast infections
- constant tiredness
- persistent headache
- weakness or numbness in arms or legs
- changes in memory or vision
- night sweats that soak your pajamas and sheets
- a dry, nagging cough.

AVOIDING MINOR INFECTIONS

For the most part, you can continue with daily activities as you always have. There are a few things, however, that you can do to reduce the risk of contracting infections around your home. Everyone, not just those who are HIV positive, would be better off following these guidelines:

Hand washing.

Many cases of the common cold and flu could be prevented if everyone washed their hands regularly. People who cover their nose and mouth when sneezing or coughing (as they should) contaminate their hands with the cold virus; when you touch their hands and then touch your own mouth, nose or eyes, you may get the cold yourself. Wash your hands often, especially if you have a cold or are around someone who does.

Cleaning.

Good, basic hygiene is as important for your home, as is good ventilation. Counters, sinks, and floors in the kitchen should be cleaned regularly and kept free from food particles. Sponges used to clean counters and dishes should not be used to clean the floor, or to clean bathroom spills. The interior of the refrigerator should be cleaned with soap and water to control molds, and old food should be thrown away regularly. The bathroom floor, toilet bowl, tub, shower, and sink should be cleaned weekly to prevent the growth of fungi. Common household detergents will do the job fine. If urine or other body fluids are spilled, mop or wipe up the area with hot soapy water first and then disinfect it with bleach. Sponges and mops used to clean up spills from body fluids should be thrown away or bleached.

Food Handling & Storage.

Be very careful handling any raw meat, including poultry, as these may often be contaminated with bacteria like salmonella, shigella, and e. coli, any of which could cause disease. Contaminated hands, bowls, and utensils can then spread the bacteria to other foods. Wash meat and cook it to the proper temperature to reduce the likelihood of getting these diseases. Leftover cooked food should not be out longer than one hour before refrigeration, and discard all leftovers after two days in the refrigerator.

Pets.

Pets may have diseases that can be passed on to you by contact with their feces or scratches to your skin. If you have cats, birds or fish, ask someone who is not HIV positive to clean the litter box, cage or tank for you. If you do it yourself, wear disposable gloves and a face mask, and wash your hands in hot, soapy water afterward. If you have a cat, change the litter box every day. You can get sick from toxoplasmosis, which grows in cat feces after several days. If you are pregnant, avoid handling turtles or cleaning up after animals because toxoplasmosis can affect the unborn child. Ask your health care provider for additional advice on pet care.

Gardening.

Always use gloves when working with plants, both indoors and out, because harmful germs can live in the soil. Wash your hands thoroughly after you finish gardening.

HIV-RELATED DISEASES

There are more than 25 different diseases that people with HIV can get when their immune systems are weak. These are called "opportunistic infections" (OIs) because they take advantage of the opportunity to attack a weak immune system. Some are caused by bacteria, viruses or fungi, and some are caused by HIV itself. Though most of these opportunistic diseases do not pose a risk to people with healthy immune systems some, such as tuberculosis, can be passed on to non-HIV-infected persons. Your health care provider will tell you whether you should take precautions not to infect others, in the event you develop any of these diseases.

TREATMENT

The good news is that there are increasingly effective treatments that slow HIV disease (i.e., reduce the viral load) and prevent or control the loss of cellular immunity that leads to many of the opportunistic diseases. And, even for persons who have lost much of their immune system, there are medications that can prevent or forestall complications. For example, the chances of getting *Pneumocystis carinii pneumonia* (PCP), a potentially life-threatening lung infection, can be nearly eliminated even for those with full-blown AIDS by PCP-prevention treatment.

Anti-retrovirals designed to attack HIV and prevent it from multiplying now come in four basic varieties:

- Nucleoside reverse transcriptase inhibitors (NRTI) were the first anti-retrovirals used to treat HIV infections. They keep HIV from reproducing

by interfering with an enzyme called reverse transcriptase.

- Non-nucleoside reverse transcriptase inhibitors (NNRTI) also interfere with reverse transcriptase and keep HIV from multiplying.
- Protease inhibitors (PIs) were first approved for the treatment of HIV in 1996. They appear to be the strongest drugs available, capable of reducing viral production by factors of hundreds or thousands, but they are used only in combinations with the other drugs (above). In contrast to NRTIs and NNRTIs, which act at the front end of the viral replication cycle, PIs work at the tail end, after the virus has made copies of itself and is trying to package new viral particles. PIs interfere with the enzyme "protease" and keep HIV from budding out of the CD4 cells.
- Hydroxyurea, a drug which interferes with reproduction of immune system cells, is in a class by itself. An older drug, long used in cancers like leukemia, hydroxyurea has been shown to be quite effective in combination with ddI and some other NRTI drugs, in reducing HIV viral loads. Hydroxyurea should not be used by pregnant women.

Use of anti-retroviral drugs in combination is a recent development in the treatment of HIV, first shown to improve treatment effectiveness in 1995. Most health care providers recommend a combination of three drugs because studies have shown that with only one or two drugs, HIV can continue to multiply. When HIV multiplies in the face of such a treatment regimen, the new virus particles that are formed can become resistant to the drugs the patient is taking. The goal in all HIV treatment is to try to halt HIV multiplication as much as possible, and three drugs or more used in combination are the best way to do that.

With any of these new treatment regimens, it is crucial that you do not stop your treatment without first conferring with your health care provider – don't even take one "day off." Generally, it is also best to stop all drugs rather than stopping only one or two of the drugs; otherwise the virus, which will be able to start growing again, will become resistant to whatever drugs remain. If you quit taking some or all of your anti-retroviral medications, the HIV in your body could become resistant to treatment; if this happens, future treatments attempts could be ineffective.

Preventive treatment (or prophylaxis) is used to keep an infection from starting. Preventive treatment exists for two of the most common and dangerous opportunistic infections: *pneumocystis carinii* pneumonia (PCP) and mycobacterium avium complex (MAC, also called MAI, the 'I' for "*intracellulare*"). In addition, some people take preventative therapy for fungal and other viral diseases (e.g. CMV), but these forms of treatment are more controversial. Research continues to develop additional treatments and vaccines. You may feel more knowledgeable about your options by keeping abreast of new treatments, talking to other HIV positive people, calling treatment hotlines, or subscribing to treatment newsletters. If something you read or hear about appeals to you, tell your health care provider. It may be something that they have not yet heard about, and they can help you to determine if the treatment is worth trying.

THE HOSPITAL

From time to time it may be necessary for you to be admitted to a hospital for HIV-related medical tests or treatment which can only (or best) be done there. Many people are frightened of hospitals, because going there means leaving home and possessions and being among strangers. Hospital staff will usually do their best to help you feel comfortable and happy. Bring along a few things and ask friends and family to visit, and then you may find a stay in the hospital quite tolerable, even pleasant.

When friends and family ask if they can bring you something, by all means let them! Ask them to bring fruit, a favorite magazine, some chocolates, a milkshake, an exciting novel, flowers (unless you are allergic), a poster to put on your wall, or—anything you can think of to pamper yourself. Your friends will feel good if they can help you. Of course it is also fine for you to say that you do not want visitors, and you shouldn't be shy about asking them to come back another time.

Perhaps the worst part of being in the hospital is the feeling that you have lost control over your own life and body. A way to counter this is to actively ask questions about your treatment options. Ask the people who are examining or helping you what they are doing and why. Write down all of the questions you can think of in-between visits from doctors, and write down the answers. Remember that you have the right to refuse treatment or drugs, but be sure that you have a good reason for doing so, and that you talk it over with your health care provider and other important people in your life.

Especially in large teaching hospitals, groups of student doctors may wish to observe your condition and make examinations. Whether you find this an invasion of your privacy, or just want to be left alone, you can refuse. Finally, hospitals can be noisy. Ask to have your door closed, or to be moved if your room is particularly noisy.

DENTAL CARE

Diseases of the teeth, gums, and mouth are common among people with weakened immune systems. Taking extra good care of these parts of your body may prevent these diseases, or at least lessen their severity. Of course, few people brush, floss or visit the dentist as often as they should. For you the stakes are now higher and the payoff greater if you commit to daily brushing and flossing and *dental visits every 6 months*.

The best plan is to get a dentist who has experience treating people with HIV and who can easily recognize diseases in your mouth. Symptoms of disease may include pain in the gums or face, bleeding gums, sores, swollen bumps. There is a local service that refers HIV positive people to dentists (see "Getting Good Services" in this guide).

CLINICAL TRIALS

Clinical trials are carefully controlled experiments that test the good and bad effects of drugs in people. The ultimate goal of these trials is to test an unproven drug, not to treat individual patients. For this reason, participating in a clinical trial cannot replace your need for a health care provider. However, such trials can provide important services and results that your provider may find valuable. Each clinical trial is different; if you are considering joining a trial, be aware of the specific benefits and risks involved.

No one has to join a clinical trial; it is completely up to you. Most trials have some risk, some are riskier than others. Participating in clinical trials may or may not help you personally, but are a service to others with HIV, now and in the future. The people who run clinical trials will be happy to talk with you about the specifics if you are interested. The benefits of participating include:

- Sometimes there are no approved drugs known to help a condition, and the only way to get a possibly effective drug is by joining a trial.
- Even if there are effective treatments, you may not be able to take them, because of side effects or allergies. You may want to try an experimental treatment regimen that just may work better than what you are taking.
- You may get additional or better medical care through a clinical trial, and drugs and medical care are often free.
- You will be helping others with AIDS and HIV find out if a drug works.

The drawbacks of participating include:

- The drug could have bad side effects and could even be unsafe (though this is rare).
- You may have to stop taking other drugs that are helping you.
- Joining a clinical trial does not mean that you will always get the new drug. You may get another drug or a placebo (a placebo looks and tastes like the drug being tested, but has no effect on the body).

MEDICAL INSURANCE

It is extremely important for you to get, keep and use your health insurance. There are lots of local, state and federal resources to help you do this; check the chapter called "Getting Good Services." Lack of money should never prevent you from getting the medical care you need. Something can almost always be worked out, whether you have insurance now or not, and no matter what your present health condition is.

If you have medical insurance through your job, you are in good shape. If you obtained the job recently, you will want to find out when coverage begins, and whether pre-existing conditions are exempted. If you leave or change jobs because of disability or any other reason, you have the option of continuing your health insurance coverage by paying your own premiums through the federal COBRA law. If you are unable to afford these premiums, there is a local service to assist you. Be sure that you do not leave or change jobs without first exploring these options, because individual insurance policies can be difficult to find.

If you do not currently have medical insurance, there are local and state programs that will cover AIDS care services, other medical conditions, and prescription drugs at low or no cost. We cannot stress enough that medical services are available, regardless of job, money or current insurance coverage. Getting hooked up with medical care as early as possible will greatly improve your chances of having a long and healthy life.

ALTERNATIVE AND COMPLEMENTARY MEDICINE

Having consistent, effective health care is very important for you now. We recommend that everyone who is HIV positive find and work with a conventional Western medical provider such as a doctor or a nurse practitioner. Some HIV positive people are also interested in learning about and working with natural,

holistic, or other alternative care providers.

In the interests of clarity, we will be using the term "conventional" to refer to orthodox medicine as it is commonly practiced by doctors of medicine and osteopathy and nurses in the U.S. The term "alternative" will be used to encompass various less conventional types of medicine including naturopathy, homeopathy, chiropractic care, and acupuncture.

Differences Between Conventional and Alternative Medicine

With respect to HIV infection, the main goals of conventional medicine are to fight HIV itself through antivirals such as AZT, and to prevent and treat opportunistic diseases (such as Pneumocystis carinii pneumonia) through drugs such as Septra and pentamidine. In contrast, the goal of alternative medicine is primarily to encourage the immune system to function more effectively so that the body will heal itself.

Treatment development in conventional medicine is based on the scientific method which requires that experiments be carried out in a carefully regulated fashion. The experiments are generally:

- controlled – the test drug is compared to either an existing drug known to be effective or to a placebo (something that resembles the drug but has no active ingredients),
- blinded – no one involved in the experiment knows who is receiving the drug and who is receiving the placebo until the experiment ends,
- statistically "powerful" – there must be enough people trying the new drug over time to draw meaningful statistical conclusions and
- reproducible – other experiments must be able to produce the same results following the same processes.

Alternative medicine has primarily developed treatments through clinical experience rather than using the scientific method. For example, Oriental medicine physicians may have observed and documented over the years that patients experiencing certain symptoms will improve if given a specific herb. Or a naturopathic physician may give half of her/his patients one vitamin and the other half another and note which group gets over their colds faster. In the past few decades, alternative providers have also begun performing studies based on the scientific method, and many are advocating for more funding to continue and expand these studies.

Advantages and Disadvantages of Combining Conventional and Alternative Treatments:

On the positive side, combining treatments gives you more options and allows you to obtain information from a number of different perspectives. This may help you feel more in control of your condition, which can have a positive effect on your mental and emotional health. In addition, alternative treatments may be beneficial, particularly in reducing toxicity or providing relief from side effects of conventional drugs. On the down side, it may be difficult to judge the value of various treatments, particularly when they are used at the same time. In addition,

adverse side effects may occur when alternative treatments are used in conjunction with conventional medical therapies. It is also possible to feel confused by conflicting information given to you by your various practitioners. Finally, combining treatments and seeing multiple health care providers can become time consuming and expensive, especially because neither health insurers nor welfare cover most alternative medical treatment. (Check your own policy for limitations.)

Working with Conventional and Alternative Providers

When choosing your health care team, identify your needs and desires carefully to ensure that they can all be addressed in an effective way by your providers. We recommend that, at minimum, HIV positive people should establish a relationship with a conventional primary care provider such as an MD, a physician's assistant, or a nurse practitioner. Only these providers can write prescriptions or admit you to the hospital if necessary. Because individuals with weak immune systems tend to develop more severe symptoms, it is important that these symptoms be evaluated carefully by a conventional provider, particularly one who has experience in evaluating and treating persons with serious illness.

In addition to working with a conventional provider, people who are interested in alternative treatments such as herbal medications, homeopathic remedies, or acupuncture will generally receive the best care in these areas from a naturopathic physician or acupuncturist who has experience regarding current HIV and AIDS diagnostic and therapeutic issues. Always be wary of any practitioner who claims to offer a cure.

Get a commitment from everyone involved in your treatment to communicate openly and clearly about your case and health care issues. Each provider must know all of the treatments you may be using for your condition in order to have a complete understanding of your case and to assure that harmful interactions are avoided. Upon your authorization, your health care providers will either communicate about your case by telephone or letter, and you have the right to ask and expect them to do so.

"It took me just sitting down with my doctor and my nurse practitioner and saying 'These are the things I want to do for myself. And I don't want you to condemn them or condone them, I just want you to know what I'm doing.'" – Donna, HIV positive woman

Choosing an Alternative Health Care Provider

If you choose to work with an alternative provider (such as a naturopath, homeopath, acupuncturist, or chiropractor) as well as a conventional medical provider (such as a physician, nurse practitioner, or physician's assistant), it is important that your alternative provider be licensed, as well as knowledgeable and experienced about HIV/AIDS. In addition, it is crucial that all your health care providers be comfortable working as a team and able to communicate openly with each other. Here are some suggested questions to ask when seeking an alternative health care provider:

- Are you licensed in this state?
- Do you support combining conventional and alternative treatments? Are you willing to work with my other providers?
- What types of alternative treatments do you recommend? What evidence is there that this treatment is effective?
- Do you have any referral sources in the conventional medical community? Do you communicate openly with them?
- Do you believe in any miracle cures for HIV infection or AIDS? (Be wary of this, as comforting as it may seem.)

The chapter "Getting Good Services" lists resources for providers of alternative medicine.

Chapter 3

Looking After Yourself

Nutrition

Good nutrition is important for everyone. A balanced diet keeps our bodies strong and our immune systems healthy, making it harder for us to get sick. HIV positive people are more susceptible to infectious agents in food and water, so it is especially important to follow safe cooking guidelines, drink water that has been purified, and be careful when dining out. Additionally, it is important for you now to maintain your body weight and muscle. Finally, people with illnesses like HIV and cancer often hear and read about diets which claim to "cure" illness, and though it can be hard to resist these promises, it is important to avoid being taken advantage of.

Individual needs can vary when you have HIV so you may want your medical provider to refer you to a registered dietician who has experience working with HIV positive people. Changes in your health status may require more (or less) calories in your diet. Your dietician can help you achieve this with a balanced diet. In addition, the combination anti-retroviral therapies require a strict regimen regarding food intake, which can greatly affect your individual nutritional needs.

GENERAL NUTRITION

The "Eating Right Pyramid" (on the next page) shows what we've all been taught about the basic food groups, but in a visual format. The basic message for HIV positive people is to eat a variety of foods and get regular exercise in order to maintain a healthy weight while conserving lean body muscle.

Grains.

Grains and cereal provide a variety of vitamins and minerals. They also provide some fiber, protein and carbohydrates. *Try to get between six and eleven servings per day.* One serving is a slice of bread, a cup of cereal, or a half-cup of pasta, rice or grits.

To make oatmeal or grits more interesting add dried fruits, milk, or grated cheese. If you have a freezer and a toaster, frozen waffles make a great quick meal or snack. You can always add fruit on top to help boost your daily fruit intake. Try cold macaroni salad with added vegetables, a chopped hard-boiled egg and dressing. All of these combinations boost protein and might help fight food boredom.

Fruits and Vegetables

Fruits and 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, and research has suggested that eating fresh fruits and vegetables may offer some protection against strokes and cancer. However, cut back on fresh fruits and vegetables if you are having diarrhea.

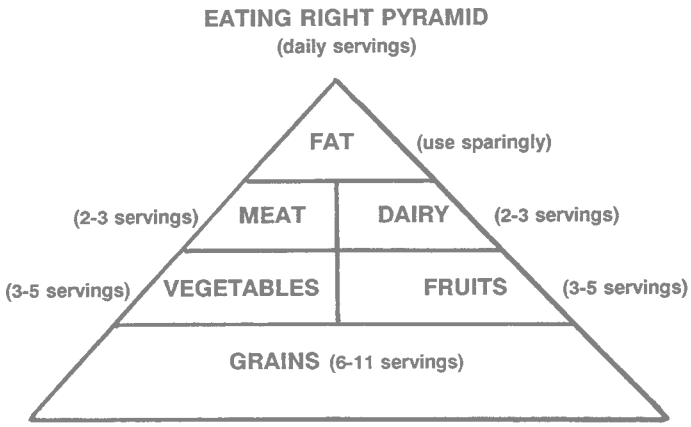
A good goal is to eat three to five servings of fruit and vegetables each day. A serving of fruit is one piece of raw fruit or a cup of canned fruit; fruit juices are good for you but they don't count as a serving. One serving of vegetables is one half cup of cooked or a whole cup of raw vegetables.

Fruit is a perfect snack. You can always carry a banana, apple, or orange with you for when you get hungry on the run. Adding raisins to cereal is another way to boost your intake. Canned fruit is also great because you can get it any time of year. The nutritional value may be a little lower, but it still counts. The fruit cocktail "snack packs" in the stores are great things to keep around or throw in your purse or backpack for when you get a craving. Boxed fruit juice (100% juice) is another good traveling companion. In summertime, freezing juice in ice cube trays is a great way to beat the heat.

Vegetables are a wonderful source of fiber and vitamins. Melting cheese on top of broccoli or other vegetables not only adds some zip, but gives you extra protein, too. Carrots and celery are a great snack and, like fruit, can be carried with you almost anywhere for when you get the urge to eat. They provide lots of fiber but almost no calories. Salads can be very tasty; just add cheese or cooked beans, tuna or hard-boiled eggs. All of these things not only make your vegetables more exciting, but they boost the protein, and our main goal is to keep body weight stable. Potatoes are another wonderful vegetable option. Mashed potatoes are great with extra cheese and milk added in. Try new kinds of potatoes, like sweet potatoes or yams. When it comes to variety in your diet, more is better.

Meat and Beans

Meat and vegetarian substitutes provide your body with the energy that it needs. Additionally, red meat, fish and poultry are excellent sources of iron, which may prevent anemia, especially in women.



Two or three servings a day of extra-lean beef, fish, seafood, poultry, cheese or beans will give your body a lot of protein and vitamins and minerals. One serving is three ounces of meat, seafood, fish or poultry (about the size of a deck of playing cards); two eggs or two ounces of cheese; one cup of dried beans, peas or nuts, or four tablespoons of peanut butter. If you don't eat meat, it will be important that you increase your protein intake by eating more tofu, nuts, eggs and beans. If you have any questions about whether you're getting enough protein, be sure to ask your health care provider or dietician.

Dairy

Dairy products are an excellent source of calcium and protein. *Two or three servings a day of milk or other dairy products provides minerals and protein.* One serving is a cup of milk, one-and-one-half ounces of cheese, or two cups of yogurt, cottage cheese or ice cream.

Dairy products can be added to many foods. Use milk to make your favorite puddings. Use milk instead of water to make hot chocolate. Add extra cheese to pizzas. Mix ice cream with milk and maybe some fruit for a terrific milkshake. Add canned milk or dried milk to mashed potatoes, cornbread or pancakes for an extra dose of protein. And remember that chocolate milk gives you just as much protein as regular milk.

Some people do not tolerate lactose, a sugar found in milk and other dairy products, and HIV can also increase a person's lactose intolerance. Symptoms of lactose intolerance include gas pain, diarrhea or cramping after eating or drinking a dairy product. If you think dairy products may be the source of some physical problems, juggle your diet around a bit, reduce your dairy intake and see if this helps. You can also buy milk with reduced lactose in many grocery stores.

Fat

A general rule to follow is to limit fat intake to less than 30% of your total diet. A low fat diet is not necessarily advocated, but keep in mind there is good fat and there is bad fat. Limit your intake of saturated fats and eat in moderation those foods containing essential fatty acids, like those found in fish, avocados and nuts.

WATER

Water is essential for your body. *It's important to drink at least eight glasses a day. It's also important that the water be safe.* Some opportunistic infections, such as cryptosporidiosis, can be contracted from bad water. Drinking untreated water from streams or lakes is dangerous for everyone. Most areas in the US do not have contaminated water supplies, but it still would be safest to drink treated water, especially if you have a low CD4 cell count. The best option is to boil tap water for 1 full minute. Another more expensive option is to filter your water with a filter that attaches to your faucet or under your sink. Make sure the filter is capable of removing particles $\leq$ 1 micron in size. The best filters in this category produce water by reverse osmosis, are labeled as "Absolute" 1 micron filters, or are labeled as meeting the ANSI/NSF International standard #53 for "cyst removal." Watch for these descriptions on filtered water and filtering products. Use disposable gloves when changing the filter cartridges. Bottled water is another option, if purified by distillation or reverse osmosis.

VITAMINS AND NUTRITIONAL SUPPLEMENTS

Many people take vitamins. Though it is recommended that you first try to get your nutritional needs met with a well balanced diet, there are times when vitamins are needed to "fill the gap." Do not take the attitude "if one vitamin is good, then two or three would be even better." Having too much of some vitamins can harm your health. The current recommendation is to take one or two multi-vitamins per day with less than 10-mg. iron. Be sure to tell your health care provider about your current vitamin intake.

There are many products on the market (such as Ensure and Advera) that have proven to be reliable sources of nutrients for people with HIV or AIDS. These supplements, which often come in liquid form, can be great food on the run, if you don't feel like cooking, or if you just want to boost your protein a bit. It's important to remember these products are not meant to replace meals, they are *supplements*. It is very important that you maintain a balanced diet to the best of your ability.

FIGHTING HIV SYMPTOMS WITH FOOD

Diarrhea

Diarrhea is a fairly common problem, and becomes even more so with HIV disease. If you have chronic diarrhea, it's even more important that you get good nutrition and liquids into your body. Check with your health care provider to see if any parasites or your medications may be causing the diarrhea. Here are some nutrition suggestions for helping to reduce diarrhea:

- Avoid high fiber foods such as raw vegetables, fresh fruits, dried beans, and bread, cereal or pasta made from whole grain because they will make your stools looser. Eating white bread, white rice and pasta is helpful because they are processed and they will stay with you better. Potatoes, applesauce, canned fruits, cooked cereals, melons and skinless fruits are all good options. Avoid prunes or any other fruit with seeds.
- Avoid hot spices - peppers, chili powder or Tabasco can make diarrhea worse.
- Try to stay away from foods that cause gas, such as beans, broccoli, cabbage, green peppers and onions.
- Avoid citrus fruits and try to drink fruit nectars, such as apricot, instead.
- Switch to decaffeinated drinks. Caffeine will make food and water go through your system faster.
- If you are at all lactose intolerant, you will probably be experiencing a lot of bloating, gas and cramping. You might try a lactose reduction aid like Lactaid, or stay away from dairy products until the diarrhea passes.
- Sometimes greasy or fried foods, butter and oils can cause diarrhea. There are now a lot of fat free foods on the market you may want to try.

Diarrhea causes dehydration so drink lots of fluids. Try to drink eight or more glasses of juice or calorie-rich liquids each day. Water is best. Severe diarrhea can cause a lack of protein. Check with your health care provider to make sure that you are getting enough protein in your diet.

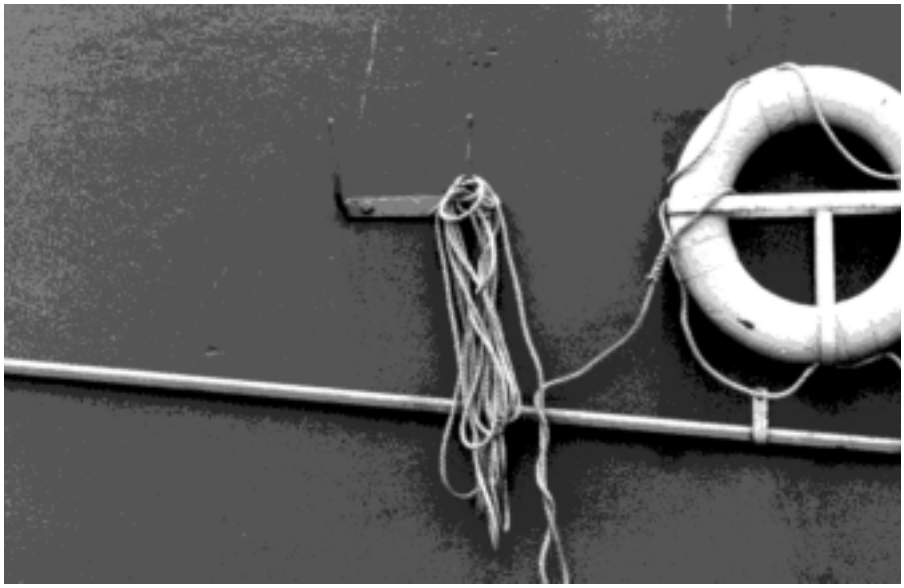
Nausea

For most people, feeling sick and throwing up is related to infection, stress, medication or medical treatment. If nausea lasts for more than two days, call your health care provider. Here are some tips for dealing with nausea:

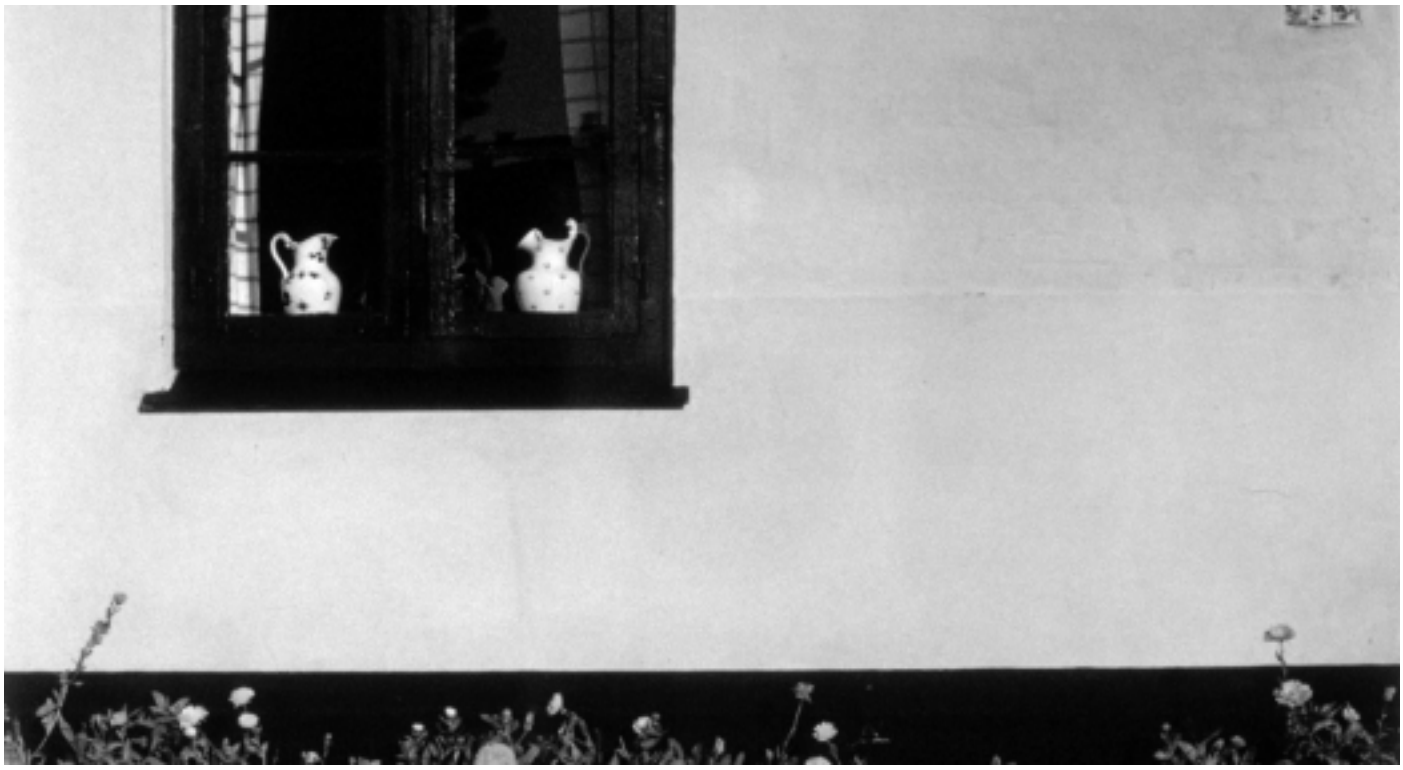
- Drink clear and cool beverages; sip them slowly using a straw.
- Eat small amounts of food many times during the day – a few mouthfuls every 2 hours.
- Eat bland foods such as potatoes, rice, bread, noodles and fruit. It's good to go by the "BRAT" formula: bananas, rice, applesauce and dry toast.
- Avoid skipping meals - an empty stomach will make you feel sicker.
- Avoid fried or greasy foods, very sweet foods, spicy foods, and strong-smelling food.
- Do not lie down for at least one hour after eating.

Candida (Thrush)

Unfortunately, the mouth is a breeding ground for all sorts of opportunistic diseases. And since that's where your food goes first, the infections can be a real annoyance and can keep you from getting the nutrition you need. Fortunately, thrush and other mouth infections can be treated with medicine and sometimes by a change in diet. Here are a few suggestions to help with eating if you have a mouth infection:



- Don't eat food with a lot of acid in it. Stay away from lemons, limes, tomatoes, oranges, grapefruits, etc. Apple juice, milk, soy or rice milk, and supplements will reduce a lot of the sting that you might get from more acidic foods.
- Try to avoid carbonated drinks (soda pop, sparkling water), hot coffee or tea, and alcohol because they can cause severe mouth pain.
- To relieve dry mouth caused by medication try gum, hard candy, or breath spray. Avoid candy and chewing gum containing Sorbital - it may cause diarrhea.



- Eat softer foods like stews, casseroles, ice cream, bananas, etc. If a food is too hard, make it softer. Try dipping your bagel in coffee or your cookies in milk. Add butter and cream sauces to pasta dishes; this makes them easier to chew and swallow.
- Ice cream, popsicles or ice cubes can numb your mouth for a while and provide some relief.

Weight Loss

Weight loss is common and can be a serious problem in HIV disease. Sometimes what seems like a few pounds lost can quickly turn into twenty or thirty pounds. It is *very difficult* to regain this weight. If you experience a loss of 10-15 pounds without intending to do so, consult your doctor or a nutritionist.

You might want to consider nutritional supplements such as Ensure. You need as many calories as possible and these drinks are easy to carry around with you. If you haven't already, check with your health care provider to figure out which supplement is best for you. Additionally, health care providers can prescribe an appetite stimulant if they feel it is needed.

COOKING AND EATING DEFENSIVELY

People with HIV get sick more often from food-borne illnesses than other people. Everyone can get food poisoning, but people with weakened immune systems can get a lot sicker. Once someone with HIV gets sick from a food-borne illness, it can be very hard to treat and can come back again and again.

Know how to protect yourself from food-borne illness. Diseases such as salmonella, botulism or hepatitis-A can cause serious infections or even death. Most of these diseases are caught directly from an infected person, but you can also be infected by raw or poorly cooked food, improperly canned food, food contaminated by insects, and food that has been handled by someone who has not followed proper food handling practices.

Cook food thoroughly to kill bacteria and germs. Red meat is not properly done for someone with HIV until it is brown; fish should flake; egg whites and yolks should be firm, not runny; and chicken juices should be clear, not pink.

Tips for shopping

Know your market. Are you comfortable with how clean and fresh the meat, produce and dairy products are? Does your market put raw meat next to raw or lightly steamed fish or shellfish? These are unsafe practices. If you are uncomfortable with the conditions and you can change stores, do so. If you can't change to another store, ask the market manager directly about how things are kept and ask how the store complies with guidelines for food-borne illness regulation.

Read the labels on packages and cans, not only for nutritional values, but to make sure you are buying them before their expiration date. Stay away from the carts overflowing with on-sale cans that fell off the display and are dented. Dented cans are often a sign of contaminated food.

If you have any questions about your store, you should always feel comfortable asking. People are usually more than happy to help.

Tips for cooking

- ALWAYS wash your hands before and after you touch or prepare food.
- Wash all of your fresh fruit and vegetables to get rid of chemicals, pesticides, and infectious microbes such as E. Coli.
- Double bag fish, chicken, and packaged meat and place them in the freezer if you don't plan to use them right away. This will help keep bacteria from growing.

- NEVER cut raw meat or poultry on the same surface that you use to cut fruit and vegetables. This is very dangerous because raw meat is often contaminated with bacteria.
- Whether you're using a microwave or a conventional oven, follow the directions carefully. Allow for plenty of standing time after cooking because the food is *still* cooking. Use a *meat thermometer* rather than guess. Shortcuts can lead to illness.
- Fill a spray bottle with water and a capful of bleach. Have it handy for cleaning counters and cutting boards.
- Always wash the tops of cans before opening them to avoid getting germs in your food.

Dining Out

Food safety problems are especially scary when you are in a restaurant because you have little or no control over how food is prepared. Since you don't know who is handling your food, or how, the best thing you can do is to remember this motto: `Boil it, cook it, peel it, or forget it!`

Don't take chances dining out. It's smart to ask how a particular dish is prepared and whether it contains raw ingredients. It's good to stay away from creamy salad dressings if you're not sure they're fresh - remember that Caesar dressing often has raw egg in it. Stay away from anything prepared with raw eggs (eggnog, hollandaise sauce). Stay away from sushi and steak tartar. If your steak is too rare, or if your chicken is pink near the bone, SEND IT BACK. Don't let a surly waiter or waitress make you feel bad. You are paying for the food and it should be prepared in a way that is safe for you.

PREGNANCY AND NUTRITION

If you're pregnant, it is even more important to keep your body strong. This will help you maintain energy and will reduce infections, making your pregnancy easier. Most pregnant women need to gain about 30 pounds during their pregnancy to help the baby get to a healthy weight. Following the basic nutritional guidelines is a great start toward keeping you and your baby healthy. If you notice you aren't gaining weight or that you are having trouble keeping your diet balanced, check in with your health care provider for some good suggestions on helping you gain weight. Your health care provider will also recommend a prenatal vitamin pill for you and your baby. It's very important to tell your health care provider if you are taking any other vitamins because too many vitamins may be harmful to your baby.

FOOD GIMMICKS: WHAT TO WATCH OUT FOR

It's important to be careful when you are shopping for diet supplements. There are a lot of products out there that will claim to "cure it all" when in fact they don't have a lot of important nutrients. On the other hand, there are some good diet supplements on the market that could be helpful in making sure your diet is balanced. If a product seems too good to be true, it probably is. If the answer is "yes" to any of the questions below, it would be wise to look into the product further before buying it. Contact your health care provider or a dietician.

- Does the promoter of the product, book or diet leave out entire food groups?
- Does the research provided mostly consist of personal stories from people who swear that they "have been healed" by this product? Though it is tempting to believe these claims, more often than not they are exaggerations.
- Are there nutritional claims made in the pamphlets but not on the product labels or in the advertising? You should know that the government regulates claims made in advertising and on labels but NOT on other printed materials, so these pamphlets can claim *anything*.
- Does the promoter of the product have a financial or personal motive to deceive you?

DON'T DEPRIVE YOURSELF

These nutritional guidelines may seem limiting, but they are just the building blocks for a healthy body. It's very common to feel resistant to giving up things you enjoy and that help you relax. It's important that you still feel freedom to indulge yourself occasionally. The word on the street is to use alcohol and caffeine in moderation. A glass of wine or a cup of coffee may be one of your greatest pleasures and should not be cause for alarm. If you're craving a piece of double chocolate cake for dinner, GO FOR IT; there will always be string beans later. It's critical that you don't feel completely deprived.

"I need 4000 calories a day to keep this marvelous machine (my body) running efficiently. Those calories are my "medications." I take them religiously, daily. I would no more think of skipping an apple than I would think of skipping my anti-retrovirals."

– Brian, HIV positive man

Drugs and Alcohol

It is no big secret that drugs and alcohol are bad for your immune system and your health when used in large quantities. Drinking a lot can suppress the immune system, increase the toxicity of your medications, and damage your liver. Smoking irritates the lungs and can leave you more susceptible to serious lung infections like pneumonia. Uppers like speed, crystal and cocaine can damage the immune system and give a false sense of energy, leaving the body exhausted. And any drug you buy off the streets may be cut with something even more dangerous than the drug itself.

Be sure to tell your health care provider(s) about your drug or alcohol use. Without this information, they could misdiagnose your symptoms or prescribe a drug that could worsen your condition. Of course, your health care provider may encourage you to quit or cut down, but don't let this stop you from getting the medical care you need.

"When I quit drinking totally, when I went to AA, it was like a black veil had been lifted up. After about 3 or 4 days, suddenly I didn't have any kind of little symptoms or headaches that I'd though were probably AIDS related. They all left me"

– Raymond, HIV positive man

CUTTING DOWN OR QUITTING

While stopping the use of alcohol or drugs is usually the best way to maintain or improve your health, abstinence is not a realistic goal for everyone. If this is true for you, then decreasing the amount and frequency of your tobacco, drug, or alcohol consumption is still a positive step toward better health and may be more manageable. Some people have managed alcohol addiction by limiting the number of drinks they allow themselves. The same is true of some heroin users.

Substituting other activities for the use of addictive substances is a way to fill time and experience other things that make you feel good. Think about things you enjoyed doing before you started using drugs - you may still like them. Dancing, running, bicycling, exploring the city, reading, meeting people, cooking and repairing things around the house are a few beginning ideas.

For some people, joining Alcoholics Anonymous (AA), Narcotics Anonymous (NA) or another support group is a way to spend time with others who are not drinking or using while building a spiritual program to help maintain sobriety. In general, if the people around you are supportive of your attempts to quit or cut down, the changes you make will be easier to maintain.

Some people find that getting into a treatment program is the easiest or the only way they can quit. Programs use different methods (methadone maintenance, aversion therapy, etc.) depending on the addiction and the philosophy of the program. Sometimes it takes a while to get into a program, so you may find that some of these other techniques will help you in the meantime. (Pregnant HIV positive women have priority for getting into treatment.)

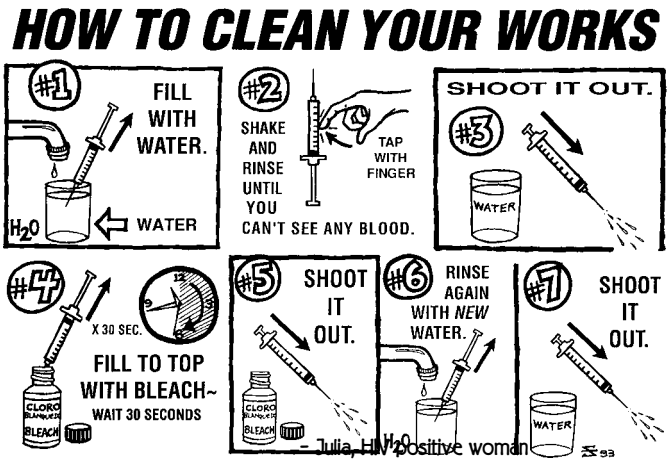
Relapse or "slipping" is a common experience for many people who try to quit or cut down on drinking or using. Rather than view this slip as a slide to doom, look at it as a detour that you can learn from. Relapse can be used to examine what and how certain thoughts, situations and cues may have led you to start using again, and you can choose to avoid these triggers in the future. Relapse can be an opportunity to renew your commitment to change, to seek further help and to remember your prior successes.

SAFER SHOOTING

Sharing a needle is dangerous to you and to your sharing partner. They could contract HIV from you, and you could contract another disease (such as hepatitis) from them. The best option by far is to keep your needles to yourself and get new ones from the needle exchange when you need them. Cotton and cookers can also transmit HIV, and the needle exchange can provide you with these as well.

"My first instinct was to go out, use IV drugs again and just end it. You know, OD. But I had fought so hard up to that point for that year prior that it's really important to me to keep my sobriety and not put anybody else at risk."

– Julia, HIV positive woman



Cleaning your needles with bleach is easy and effective if you can't get a new one. The guidelines for cleaning needles have changed in the last few years to become more effective at killing HIV. Be sure to use these directions when cleaning your needles:

Exercise

Regular exercise will help keep your body healthier and reduce anxiety, tension and depression. Exercise could include walking, jogging, cycling, swimming –

even taking a leisurely stroll. Find an exercise that you enjoy and that gets your heart working, but doesn't leave you exhausted. Start with a 30-minute workout every other day, and gradually increase your time, but keep it under one hour. If you are feeling fatigued, getting sore muscles or have a poor appetite, try cutting your workout back. You're probably working too hard. Work up slowly – exercise should be fun.

If you get a cold or another infection, hold off on exercising until you feel better. Your body will need all its energy to recover. And make sure you eat enough calories to keep your weight up. Energy foods that are also high in vitamins and minerals include bread, potatoes, pasta and rice.

Rest

Fatigue is a very common symptom of HIV infection, and it has a variety of causes. Loss of energy and ambition are often part of the fatigue associated with AIDS, and sometimes it is difficult to know whether the tiredness is caused by the virus or depression. If you are feeling tired, pay attention to what your body is telling you and rest as much as possible. Let your friends or local agencies help you with the cooking, cleaning and child care, and try to find low-energy ways to have fun like playing board games or renting a movie. If the tiredness continues for more than a few days, be sure to tell your health care provider.

Taking Care While Traveling Internationally

Don't overexert yourself – get plenty of rest before, during and after your trip, especially if you travel to a different time zone and experience "jet lag." It is perfectly all right to take naps or spend an evening or day in your hotel room, even if you are in Paris. Save your energy for the things most important to you. If you tire easily, take taxis or public transportation and minimize the walking.

"If you like to travel, can afford it, and feel well enough, then by all means do it. Getting away can be great for your spirits. Of course it is important that you take it easy and prepare well for your trip so that your great time doesn't turn into a rotten time."

– Larry, HIV positive man

Try to avoid stress. This may be the toughest part of all, because traveling involves a change of surroundings and change is usually stressful. Remember that you are seeking change—expect it, and enjoy it. If you're a victim of pickpockets or some other petty crime, don't let it ruin the rest of your trip. It's out of your control. You can replace whatever was taken and get on with your life.

MEDICATIONS

Will your medications be readily available in the countries where you will be traveling? If so, have your health care provider write out a generic prescription for each medication you will take with you, and carry these *separately*, just in

case the medications are lost and you need a replacement. If not, be sure you have enough medication to get you through your trip. You may want to split them up so that if some are lost, you will have others stashed elsewhere.

Don't pack your pills into luggage to be checked aboard an aircraft - keep them on you in their original containers. It is true that in countries with HIV restrictions, this could be a giveaway to customs inspectors that you are HIV positive. However, if they are not in their original containers, they could be confused with illegal drugs by immigration officers. Also, make sure that antimalarial medication and antibiotics commonly used for traveler's diarrhea do not interact with other medications that you are using on a regular basis. Finally, plan ahead how you will keep medications refrigerated if this is required.

If you are traveling far, especially across multiple time zones, consider writing out a timetable for taking your medicines, starting in your current time zone and gradually (over several days) phasing in to your new time zone. Ask your provider or pharmacist to help you construct this table so that you keep taking the medications at their proper intervals: some need to be taken every 24 hours, some every 12 hours, some at 8 hour intervals, and so on. Once you have established your old routine in the new locale, you can carry on as usual, but you will need such a table for the return trip as well.

VISAS

Some countries have policies that screen incoming travelers for HIV (especially those planning to stay for an extended period of time), and refuse entry to persons with HIV or AIDS.

If you are planning to visit a foreign country, you should be familiar with the policies and requirements of that particular country. Don't wait until you arrive to find out that you will not be allowed to enter the country. Information on visa policies is available from the local offices of the State Department and the consulates of the individual nations. We suggest you give them a call before making any solid travel plans. This information can be obtained anonymously or under a fake name.

VACCINES FOR TRAVELING

If you grew up in the United States or Western Europe, chances are you received many vaccinations for school. If you are going abroad, however, you may need to get other immunizations or update those you already have. In addition, there is now a vaccine for hepatitis-A, an illness that can result in serious diarrhea

and is common in some countries. Because you are HIV positive, all of these vaccines are especially important.

However some vaccines, such as yellow fever, typhoid and poliomyelitis, contain live viruses that can be harmful to people who have weak immune systems. Talk to your health care provider or the travel clinic at the Health Department to find out about recommended vaccines.

Finally, see your health care provider when you return from your trip. If you develop any health problems after you have been home for a while, be sure to remind your provider of the trip.

Chapter 4

Sex, Love and Relationships

After receiving an HIV positive test result, some people may feel that a fulfilling sex life is threatened, unavailable, or even impossible. For many, it was having sex that resulted in the positive test result, and it can be difficult to return to seeing sex as joyous, playful, emotional and intimate. Your interest in sex may be noticeably lessened, or you may associate feelings of shame and/or regret with it. Some people react by becoming more sexual. Whatever your feelings may be, try to accept them as normal feelings. Testing positive is a big deal—expect that you will go through a lot of emotions. Acknowledging and accepting these feelings can be the first steps in overcoming them and returning to a fulfilling sex life. Your sex drive can be a powerful and inspiring life force; enjoy it and let it help you enjoy life.

The period after learning of your positive test result can be a time to examine the role of sex in your life. What do you want from sex? Fun? Emotional connection? Intimacy? Physical expression? Stress relief? Even if you think you already know, be open to changes in what you want from sex, and allow yourself to want different things at different times. So much of what is discussed in this guide is meant to suggest possibilities or starting points, because there is no single right answer or combination of choices that will work for everyone. Though safer sex is important for everyone to know about, and you may have thought you had it down, there is no getting around the fact that becoming HIV positive makes understanding and sticking with a safer sex plan of even greater importance.

You and Your Partners

No two relationships or sexual situations are the same, so hard and fast rules about safer sex and telling your partners are difficult to come by. As time goes on, you will figure out what you are comfortable with and develop your own style. Keep in mind the moral and ethical importance of informing your partners of your HIV status so that they may make informed decisions. Telling your partners is usually also in your best interests. It can help minimize regrets, as well as future legal problems.

Protecting Yourself

Safer sex is not just for the protection of an HIV negative partner, but also for you as an HIV positive person. Other sexually transmitted diseases (STDs) such as gonorrhea, hepatitis A & B, herpes and human papilloma virus (HPV or genital warts) can endanger your continued good health. STDs are found in blood, semen and vaginal fluids; unprotected sex can expose you to those fluids. Herpes and genital warts are transmitted skin-to-skin, so a condom may not provide complete protection. Hepatitis-A can be transmitted through oral exposure to feces. Consider this with HIV negative and positive partners. Just as with HIV, people can expose you to STDs without knowing it or showing symptoms.

HIV Positive Partners

Health care professionals disagree about the risks associated with repeated exposure to HIV. Some believe that additional exposures to HIV can further harm your immune system. If exposed to another strain of HIV, your immune system could come under new attack, which may hasten disease progression. This is a matter for you and your HIV positive partner(s) to talk over and decide together, what risks are acceptable and whether or not to use condoms. You may find that your priorities when with HIV positive partners are different from those with HIV negative partners. For instance, with positive partners, your main concern may be protecting yourself from re-infection or from exposure to new STDs. With negative partners, on the other hand, you may be most concerned about protecting them from infection (though protecting yourself from other STDs is still a concern). This is another time when you may need to deal with changing feelings. Plan to think about this ahead of time and, that way, you will be better prepared when a sexual situation happens.

Primary Partners

If you have a primary partner at the time you test HIV positive, what and how to tell your partner will likely be one of your first thoughts. For some couples, the test result may have been expected; for others, it can be a surprise that will bring up many difficult issues. If your partner is unprepared for your test result, he/she may have difficulty offering you support and affection at first because of worry over their own HIV status or risk. Though you may need that support more than ever, until your partner has resolved his/her situation, it will be hard for them to respond to you. HIV has happened to both of you, even if your partner tests negative. Do not assume that your partner will have a positive test result even though you may have been having unsafe sex or sharing needles together. Until your partner's HIV status is known, it is essential that you use condoms during sex, avoid needle sharing, avoid sharing razors and toothbrushes, and avoid any other potential blood sharing.

Before telling your partner you have HIV, take some time alone to think about how and when you want to bring up the subject. Do you trust yourself to sense the right moment and just "dive in" or do you prefer to plan an evening when you know there will be no distractions? Choose a moment when you both are as rested, comfortable, and relaxed as possible. If you are feeling tired, hassled or pressured, your reactions to each other are more likely to be defensive, frightened or otherwise hurtful. If there is a history of violence in your relationship, consider your safety first and think about planning the situation with a case manager or counselor.

If your partner is uneasy about sex just after learning you have HIV, it is good for you both to remember the importance of hugging, kissing, and touching. These are ways other than sex for showing affection and support for each other while your relationship adjusts to the changes HIV can bring.

New Partners

Here is where thinking ahead about safer sex can get even more complicated. Before your positive result, maybe you were dating a bit, or perhaps you enjoyed one-time encounters. Now that you have tested positive, think about your "pretest" sex life. Did it satisfy you? Do you want to make any changes? If so, this is a good time to think about those changes because, for many people, a positive test result will call for a new approach. Thinking about the ideas below is important because, as a person with HIV, you may find yourself playing the role of educator when talking about safer sex with new partners.

When telling a casual partner or someone you are dating, you may have a hard time coming up with a definite rule or plan. Each situation is different, because each person is different and because what you want from each encounter may be different. It is still important to think ahead about how you want to go about it.You can always change your approach to telling a (potential) partner that you have HIV—you don't have to stick to one way. One time you may feel fine about being direct and saying, "Before we get together, I want you to know that I have HIV." Another time, you may want to bring it up indirectly ("Let's talk about safer sex…") OR in the context of a general conversation about the importance of safer sex, particularly for people with HIV. If you begin dating someone regularly, you may want to tell him or her about your HIV status before you have sex the first time to avoid hurt feelings. In any case, be sure to protect yourself and your partner.

Remember, your partner could also be wondering, "Is this the right time to say I have HIV?" Rather than expect rejection from any new encounter, search for commonality and connection. You have just as much to offer now as you did before your positive test.

> "In terms of enforcing safer sex guidelines, the first thing I do is don't worry about feeling awkward myself. The second thing is I'm not responsible for them feeling awkward either. I'm responsible for my health and well-being."
> – Monique, HIV positive woman

Problems with Partners

Many people avoid these conversations because they fear rejection, the ending of a sexual relationship, or even violence. These are very real concerns for many people, and you may feel that talking with a friend, a counselor, or a support group will help you to prepare. You may even want a friend or counselor present when you tell your partner. When taking steps to deal with a safer sex problem between you and your partner, remember that you are doing this for yourself and your well being. Anything you do to take better care of yourself is worth doing.

Better Sex

Talking about sex can make it better, though the idea may make you feel uncomfortable or insecure. You may find that the first few times are the hardest, but that the results make up for the initial fear and unease. The discussion need not be just in terms of what you will or won't do, but what you really like to do. If both partners only do those things they are open to and comfortable with, everybody is more relaxed and free to let go of inhibitions. This does not mean doing the same old thing over and over again, but can include experimentation—if openly talked about earlier. Surprising a partner with something you didn't discuss is a risk—saying no in the heat of passion can be difficult. Without talking about sex, you may find yourself hoping your partners will figure out what you want; talk can lead to more satisfaction and less disappointment with sex.

When you decide to tell a partner that you have HIV and you begin to talk about safer sex, you may feel that all the fun and spontaneity goes away. Choosing a moment when the possibility of sex is hours away will give each partner time to take in the discussion and that "clinical" feeling will fade. Rather than talking about what each of you doesn't want to do, talk about the things you like to do. Talking about "yes" things instead of "no" things keeps the conversation sexy and supportive, rather than critical and downbeat. After sex, think about what your partner did for you; there's a good chance they like the same or complementary things. Mirroring those actions can lead to greater feelings of intimacy and empathy.

Safer Sex

What is safer sex? The bar graph below and the description following shows the relative riskiness of specific sexual activities. Ultimately, as with all things we do, we must make our own decisions about what is acceptable risk—whether it be having sex, eating ice cream, smoking cigarettes, climbing mountains, or flying in airplanes. However, with sex (except solo masturbation) the risks we take require the participation of other people.

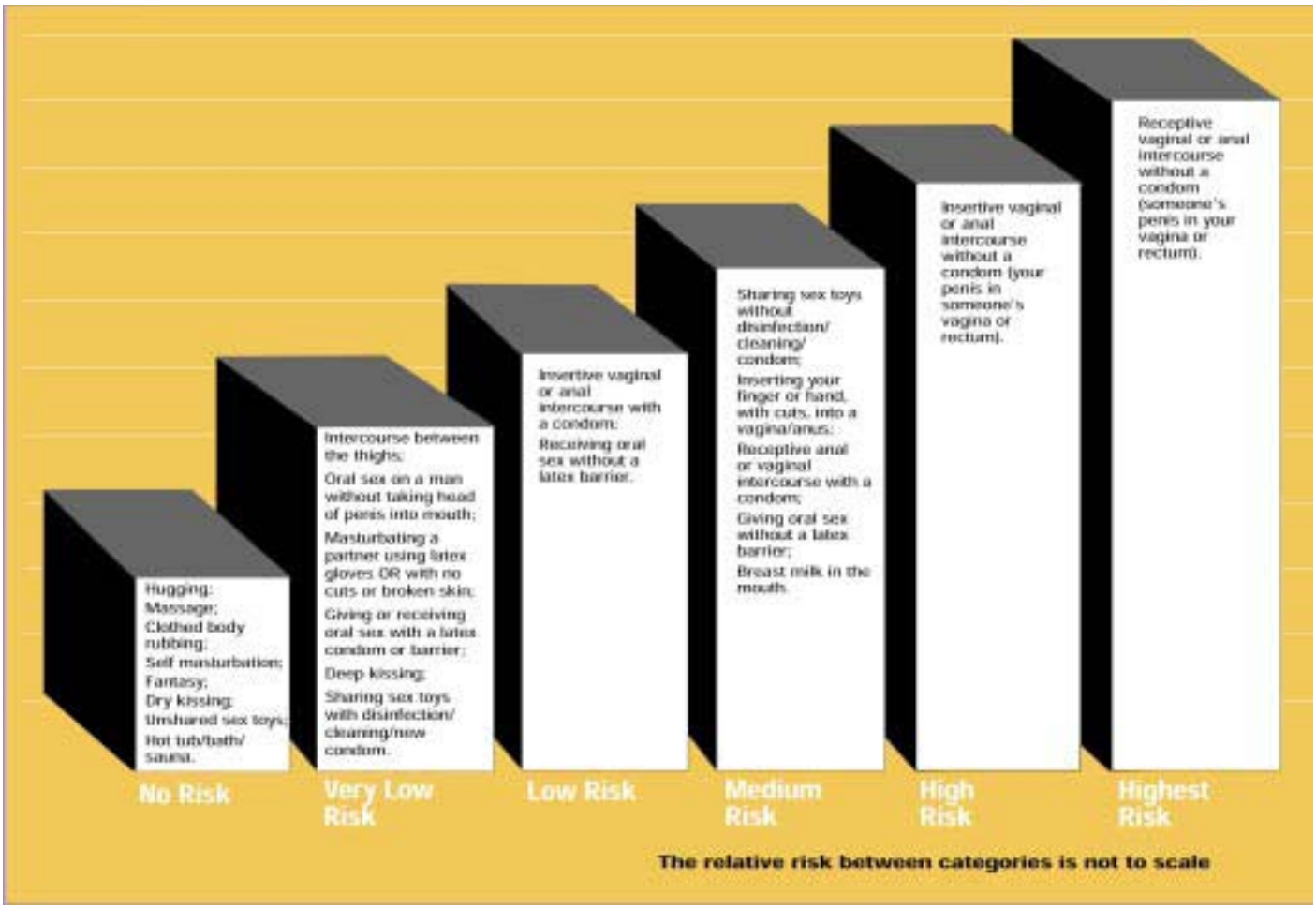
Before your HIV test—before you knew you were positive—there may have been times when you or your partner thought that safer sex talk was unnecessary. Now it is more important than ever to think ahead about what you consider safe, safer, and unsafe. Defining safer sex for yourself before encountering a sexual situation helps prevent the worry or remorse that could follow sexual activity you don't really feel is safe.

Safer Sex Guidelines

The following is the most up-to-date information available to help you in talking with your partners and deciding what to do together.

HIGHEST RISK

- *Receptive anal or vaginal intercourse WITHOUT a condom* (having a man's penis inside your rectum or vagina without the protection of a rubber). This is very risky even if he does not ejaculate (come).



HIGH RISK

- *Insertive anal or vaginal intercourse WITHOUT a condom* (having your penis inside someone's rectum or vagina without the protection of a rubber). This is because body fluids from your partner's rectum or vagina can enter the penis through the urethra or abrasions on your penis.

MEDIUM RISK

- *Receptive anal or vaginal intercourse WITH a condom* (your partner has a rubber on his penis while inside your rectum or vagina). This is because condoms are not 100% fool proof; when condoms fail it is usually because of incorrect usage (see "How to Use a Latex Condom").
- *Oral sex performed on a man NOT wearing a condom* (giving a blowjob). This is risky even if the man does not ejaculate (come) because HIV can be present in the clear fluid called pre-cum.
- *Oral sex on a woman NOT USING a latex barrier* (going down on a woman without a dental dam or plastic wrap). This is to protect against exposure to vaginal fluids or menstrual blood.
- *Sharing uncovered sex toys* (dildos, anal beads, or butt plugs). Again, this is because infected body fluids remaining on the toys could be exchanged.
- Breast milk in the mouth can transmit HIV through small cuts or sores on your gums, tongue or throat.
- Rimming (your mouth in contact with someone's rectum) WITHOUT a latex or plastic barrier is low risk for transmission of HIV, but is a likely way to get giardia or hepatitis-A; be kind to your immune system and avoid exposure to these organisms.

LOW RISK

- *Insertive anal or vaginal intercourse WITH a condom* (your penis with a condom in your partner's rectum or vagina). Some small risk is possible when a condom is not used correctly, or if it breaks.
- *Receiving oral sex WITHOUT a latex barrier* (having someone go down on you). The risk here is because your partner may have blood or sores in his or her mouth, and fluids can get into your urethra. Saliva or spit is not believed to be a risk for HIV.

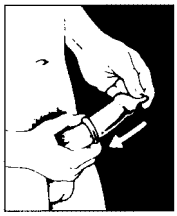
VERY LOW RISK

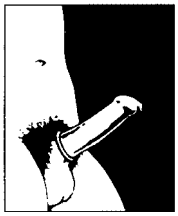
- Finger/hand stimulation of your partner's genitals is very low risk, but can transmit HIV if body fluids come in contact with cuts or rashes on your skin. In addition, fisting (inserting a hand into the rectum or vagina) may create tears and make other activities more risky.
- Intercourse between the thighs, also known as frottage. (Herpes may be transmitted however.)
- Oral sex performed on a man WITHOUT a condom, but NOT taking the head of the penis into your mouth. Give attention to all other parts of the genitals, including the testicles (balls).
- Giving or receiving oral sex WITH a condom.
- Deep kissing (French kissing or tongue kissing).
- Sharing sex toys that have been cleaned, disinfected or covered with a new condom between your use and your partner's use.

NO RISK

- Hugging, massage, clothed body rubbing.
- Self-masturbation, fantasizing, dry kissing, telephone sex, unshared sex toys.

HOW TO USE A CONDOM





1. Use latex or polyurethane condoms. Natural skin/lambskin condoms are much more likely to break or contain small holes, allowing transmission of HIV.
2. Use plenty of water-based lubricant to reduce the friction that can cause breakage. Do not use oil-based lubricants with latex condoms. Massage oils, butter, Crisco, Vaseline, and hand creams all contain oils that cause latex to break down. Water-based lubricants include K-Y jelly, Slippery Stuff, ForPlay, Wet, and most contraceptive gels. With polyurethane condoms, all lubricants are OK.
3. Choose a condom that fits. Condoms come in many sizes, colors, styles, shapes, and flavors. Have a lot of different condoms on hand to suit your mood and your partner. Practice putting condoms on your own penis or on your partner's penis sometime when you are not in the heat of passion. Condoms should be stored loosely in a cool, dry place (not your wallet); check for expiration dates. Keep them where you can easily get them if you decide to have sex.
4. Make sure that the condom package has not been punctured (there should be a pocket of air). Open the package carefully to avoid tearing the condom.
5. Put the condom on after erection but before insertion. Pinch the tip as you unroll the condom for two reasons: (1) it leaves some room for discharged semen (cum), and (2) to prevent air bubbles from being trapped inside the condom—pressure could build up and the condom will pop. Unroll the condom all the way down to the base of the penis. If the penis is uncircumcised, pull back the foreskin before rolling on the condom.
6. After intercourse, withdraw the penis while it is still erect, and hold the base of the condom to prevent it slipping off.
7. Use a condom only once. Tie it off to prevent spillage or wrap it in bathroom tissue and put it in the garbage. Condoms can clog toilets—don't flush them!

The Reality Condom

The Reality "female condom" is available in stores. This is a large condom made of polyurethane and fitted with two rings that help keep it inside the vagina. Users report some awkwardness in placing it, but many feel it is worth the effort. Because it is made of polyurethane, any lubricant can be used without damaging the condom. The Reality condom has been approved by the Food & Drug Administration (FDA) for use in the prevention of HIV and STDs during vaginal intercourse. It should be used in place of, not with, the male condom.

Some users report success and satisfaction with the Reality condom for anal intercourse, despite some initial awkwardness and minor discomfort. The

condom contains small plastic rings to help hold it in place; removing the inner ring makes insertion easier. Using a dildo or plug for initial insertion has worked for some people. However, it should be noted that the FDA has NOT approved the Reality condom as a means of preventing transmission of HIV and STDs through anal intercourse. NOTE: all condoms can be purchased with medical coupons and some clinics and prevention agencies provide free condoms.

Polyurethane Condoms

Polyurethane condoms for men are also now available, though they are more expensive than latex. If you or your partner is allergic to latex, polyurethane condoms may be a solution.

BIRTH CONTROL

As you know, latex and polyurethane condoms are the only forms of birth control that are also effective in reducing transmission of HIV and STDs such as gonorrhea, chlamydia, and syphilis. Some HIV positive women use an additional birth control method to increase their protection against pregnancy, but condoms must also be used.

The *diaphragm* and *tubal ligation* (getting your tubes "tied") are both safe forms of birth control for HIV positive women. Another option is for the man to get a *vasectomy*.

There are three hormonal birth control methods: *birth control pills, Depo-Provera,* and *Norplant*. These methods are often safe for HIV positive women, but they may interact with other medications you are taking. If you are interested in one of the methods, discuss it with your health care provider.

The *intra-uterine device (IUD)* is NOT recommended for women with HIV because the presence of this foreign object in your body may cause irritation and infection, something you want to avoid.

COMMON QUESTIONS ASKED BY PEOPLE WITH HIV

1. Is it OK for someone to give me a blowjob if they stop before I come?

HIV is found in ejaculate (cum) and pre-cum and there is a growing body of evidence that HIV can be transmitted through oral sex. To reduce risk, many do not insert the head of the penis into their mouth to avoid contact with pre-cum. The amount of pre-cum varies from man to man; similarly, the amount of HIV found in pre-cum varies. Generally, people are most infectious in the weeks following infection, just before getting sick, and when they have other STDs, but it is difficult to know when these times occur. The risk is low but real, and condoms or abstinence are the best prevention.

2. Should I have sex only with other HIV positive people?

This is a choice made by some people with HIV—they see it as a way of reducing both the chance of rejection for having HIV, and the chance of infecting someone else. They may also feel that they simply have more in common with other HIV positive people. But don't forget that new partners can have STDs that are new to you. Only you can decide if this approach is a good one for you.

3. If I tell someone I have HIV and they still want to have unsafe sex, what should I do?

This is a question you definitely want to think about in advance, to avoid being caught off guard. Though your partner may seem to be making an informed decision, be sure that drugs, alcohol or passion have not clouded their thinking. One thing to consider is how you would feel if he or she became infected, or if you became infected with another STD. A partner who consents to unsafe sex now may feel very differently in the future, and you could be contributing to the ongoing spread of HIV.

4. I worry about kissing my children and other family members—is it OK?

Don't worry about showing affection for your children, aunts, uncles, friends—anyone. Holding, touching, or kissing others is safe because no body fluids are exposed or transferred. Deep kissing with sexual partners is very low risk, and dry kissing, as you would do with family and friends, is not a risk.

5. If I am jerking off with someone and I get cum on their skin, will they get HIV from me?

Intact skin (healthy skin without rashes, chapping or cuts) is a good and strong barrier to disease. Body fluids should be kept away from injured skin, rashes, and sores, because breaks in the skin are a potential opening to the bloodstream. HIV can get through mucous membranes (inside of eye, nose, mouth, vagina, penis and anus) so avoid getting body fluids near these areas. Use condoms.

6. Can HIV be transmitted through oral sex on a woman?

Yes—HIV positive women may have HIV in their vaginal fluids or menstrual blood. If these fluids get into a partner's mouth, the virus may be transmitted. One way to reduce this risk is to use a barrier between the mouth and the vagina. The easiest thing to use is regular household plastic wrap; you can also use a dental dam or a split condom. A small amount of water-based lubricant on the side touching the genitals will increase the sensation. Be sure to use a large enough piece to cover the entire labia, clitoris and vagina. Do not turn the barrier over during use and do not reuse any barrier.

If you have additional questions, please call one of the information lines listed in "Getting Good Services."

infectious disease specialist. In addition, a regular doctor or other provider is important for routine growth and development evaluations, immunization, and routine pediatric care. The specialty provider and case manager can assist in finding a primary provider for your baby.

Your infant needs immunizations. It is important for infants born to HIV positive women to have all childhood immunizations. However, the injectable polio vaccine (a dead virus) should be used in place of oral polio vaccine (live virus). Be sure your provider does not give the oral polio vaccine.

Your infant may need special treatment. There is a kind of pneumonia called PCP that is highly dangerous to HIV infected babies during the first few months of life. Because there is a preventive treatment for that pneumonia, many babies born to HIV positive women are treated before it is known if the infants are actually infected. When a baby is known to be infected, many different

Chapter 5

Parenting and Pregnancy

Parenting

If you have children, it is important to think about the many ways in which their lives could be affected by your HIV diagnosis. This can be a painful process, but planning for the future is also a loving and responsible act that may bring your family closer. Even if you are completely healthy it is best to plan early, and whenever possible and appropriate, involve the children in the discussion. Case managers who work with parents and families are available for support and referrals to resources. They can assist with everything from finances to housing to helping you map out your plan for your children's future. Talking with other parents in similar situations can also help.

It is best to have in place a plan for respite care (when you need a rest), emergencies (such as going into the hospital suddenly), and long term care (who would raise your children if you were to die). Possible caregivers for your children include the rest of your family at home, other family, friends, foster care, and adoption. Many people turn first to the help that is closest to them among their family and friends. This will normally be the best choice for the children as it reduces the disruption and change in their lives. However, do not be afraid to approach state resources for foster care or adoption if necessary. Your children will not be taken away from you because you have HIV, and these resources can be valuable in providing short or long term care.

Planning ahead and thinking about the needs of your children in the long run gives you the opportunity to get advice, help, and legal assistance, and gives your children time to develop a strong relationship with any additional caregivers. This will help them in feeling less frightened of the future, though it may be hard for them—and you—at first.

Pregnancy

If you are pregnant or are thinking about becoming pregnant, you may encounter attitudes suggesting this is wrong; however, the choice of whether or not to have children is an individual one and should always be made by the woman (and her partner). This is no less true now that you have HIV.

Having a child is a life-changing decision, whether or not you have HIV. So take time to think about all the advantages and disadvantages. In addition, you will need to consider whether you have the support, strength, and resources to care for a child.

Minimizing the Risk

Babies born to HIV positive mothers have a small but real chance of being HIV infected during pregnancy, birth, and breastfeeding. The risk of transmission is between 1 in 4 and 1 in 12, depending on the status of your disease and the

level of care you receive throughout your pregnancy. If you have been ill, your CD4 count is low, or your viral load is high, the risk of transmission is greater. In addition it is possible, though unlikely given current evidence, that pregnancy may damage your health and immune system.

It is important to learn about all treatment options available for you and your baby, so consult with your provider even before trying to become pregnant. You may be asked to join a clinical trial; if so, you have the right to be informed of all risks and benefits in order to make the right decision for you and your baby.

Good prenatal care: Your child will be healthier in every way if you get good, consistent prenatal care. Get good care and accurate information about being HIV positive and pregnant by finding an obstetrician (a doctor who works specifically with pregnant women) or other health care provider as early as possible, and choose one who has specific knowledge about HIV and pregnancy. Prenatal care includes checking for diseases such as hepatitis, herpes, and anemia, any of which could affect your infant's health if not treated. It also includes nutritional counseling and extra food, so that your baby will grow and develop fully, as well as monitoring your immune status, treating any HIV-related illnesses, identifying early any problems with your pregnancy, and a variety of other services. This care is vital to encourage the healthy development of all babies, whether the mother has HIV or not. Prenatal care is available to you even if you have no income and no insurance.

AZT during pregnancy: Research first demonstrated in 1994 that taking AZT (an antiviral medication) during pregnancy and giving AZT to the infant for the first six weeks of its life can significantly reduce (by 66%) the risk of the baby becoming infected with HIV. So far, there is no evidence that the drug causes abnormalities if taken during pregnancy; babies born to the general population had the same rate of birth defects as that found in children born of mothers with HIV. More recent evidence suggests that combining AZT with delivery by C-section may even further reduce the risk that the child will be born with HIV.

C-Section: Once pregnant, do discuss the option of a Cesarean section with your medical provider. Recent studies have shown that a C-section, before labor begins and membranes rupture, may decrease the risk of mother-to-child HIV transmission. However, this may be of little benefit if your viral load is low or well-controlled on anti-retroviral medications. The final decision about how you deliver should be made by you and your provider only after careful consideration of your pregnancy history, the status of your HIV infection, and the possible increased risk to your own health should there be complications after such an operation.

Breastfeeding: There is a risk of transmitting HIV through breastfeeding, so this should be avoided. Formula feeding will provide all the nutrients your baby needs.

Becoming pregnant safely: Much is still unknown about HIV and pregnancy, and HIV positive people must make many decisions in the face of uncertainty. Find counseling, support, and as much information as you can. Always know that the decision about whether to get pregnant or have a child is yours to make. If you want to conceive a child with a male partner who is HIV negative, one option is artificial insemination: getting your partner to produce some sperm which you then insert. This protects the father from possible HIV infection. If you are an HIV positive man wishing to father a child and your partner is negative, you could consider artificial insemination by an HIV negative male donor. It is recommended that you seek the advice of an obstetrician (pregnancy doctor) knowledgeable about HIV to discuss the options before you conceive.

When the baby is born

Your infant will need testing for HIV. A fetus may become infected with HIV at any point in the pregnancy, but transmission is thought to occur more commonly during labor and delivery. All babies born to HIV positive mothers, even those who are not truly infected, will test positive for HIV antibodies at birth and for many months afterward. Providers who know a lot about HIV and pregnancy can do special tests to determine whether the virus is in the infant's blood. Still, it often takes at least three months to find out whether the baby is actually infected with HIV. It is important for an HIV positive baby to be examined by a pediatric infectious disease specialist at birth, and then frequently throughout the first year of life. Examinations should continue yearly until age 3, even if it is determined that a child does not have HIV infection.

Your infant needs a special doctor. Because of the special knowledge required, a baby born to an HIV positive woman should be seen frequently by a pediatric infectious disease specialist. In addition, a regular doctor or other provider is important for routine growth and development evaluations, immunization, and routine pediatric care. The specialty provider and case manager can assist in finding a primary provider for your baby.

Your infant needs immunizations. It is important for infants born to HIV positive women to have all childhood immunizations. However, the injectable polio vaccine (a dead virus) should be used in place of oral polio vaccine (live virus). Be sure your provider does not give the oral polio vaccine.

Your infant needs special treatments. AZT during the first six weeks of life, in addition to the mother taking AZT during pregnancy and delivery, greatly reduces the chances an infant will become HIV infected. As well, there is a kind of pneumonia called PCP that is highly dangerous to HIV-infected babies during the first few months of life; many babies born to HIV positive women are treated preventatively for PCP before it is known if the infants are actually infected. When a baby is known to be infected, many other treatments are available. Your baby's doctor can prescribe the best ones for your child.

Caring for HIV Positive Children

In addition to having a medical provider who specializes in HIV and can monitor their health and development, HIV positive children need to grow up in an ordinary but enriching environment. They can attend childcare and school; they can participate in games and sports; they can make friends and learn from their peers. A caution: these interactions can expose HIV positive children to childhood illnesses that may prove taxing to their health. Even so, the benefits of interacting with their world outweigh this drawback. In a childcare/school setting, the employees and teachers will likely have been trained in the use of universal precautions to prevent HIV transmission.

Get Resources

There are lots of resources for HIV positive women and women with children. These resources include support groups with other HIV positive mothers, food, housing assistance, drug treatment, medical care and case management. Services are often free, and lack of money should never keep you from getting the best care and services. See "Getting Good Services," the last chapter in this guide.

Chapter 6

Legal Issues for HIV Positive People

Despite all the jokes about lawyers, there are times when we need their services. If you encounter discrimination in housing or employment, if you want a final opinion on your will, or if you run into problems with your health or life insurance, a good lawyer can be really helpful. In such a situation, there is a local service in Seattle that finds attorneys for people with legal needs and problems related to AIDS or HIV. These attorneys charge a reduced fee (or sometimes no fee). Check the chapter "Getting Good Services" to find this and other legal resources. However, before you embark on a legal course of action, it is best to discuss your concerns with someone objective (a case manager if you have one) to get an unbiased perspective. There may be a solution that does not involve a lawyer at all.

Putting Your Affairs in Order

Few of us enjoy the thought of writing our will, drawing up a power-of-attorney, or making funeral arrangements. It is easy to think that if we ignore these things, they will magically be taken care of or become unnecessary. Unfortunately, this is not true for anyone. If you don't make preparations now, the people who care about you will have to do so after you are gone, at a time that will already be stressful and difficult for them. As with many unpleasant but necessary tasks, completing these things will leave you feeling relieved and proud of yourself, and will assure that you have a voice in the future.

There are four legal tools you ought to consider, even if you feel completely well now: (1) a Living Will, (2) a Power-of-Attorney, (3) a Last Will and Testament, and (4) a Living Trust.

LIVING WILL

The living will directs your medical provider to withdraw or not begin any "artificial" means that may extend your life when there is no hope for recovery. In other words, it tells your provider to let nature take its course. The living will gives you the choice and removes that responsibility from your doctor or loved ones. You must be at least 18 years old and of "sound mind" to make a living will. A living will has nothing to do with euthanasia (mercy killing). It simply means that if it is clear there is no hope of recovery, the medical staff tending to your care will not connect you to tubes and machines that support body functions but cannot make you well. You can revoke a living will at any time by tearing it up and telling your doctor and loved ones that it is no longer in effect.

A living will is strictly a matter of choice—you are not required to have one. If you do not prepare a living will, your next of kin will be asked to decide for you if end-of-life decisions must be made at a time when you're not able to speak for yourself. Be clear about what you really value when you make this choice. The issues you are looking at are tough ones, but they are issues we will all face. Be gentle with yourself and take some time to think things through.

You don't need a lawyer to make a living will. You can write it up yourself, or ask for help from your medical provider or a case manager. Examples of living wills are easy to come by; ask for a copy at the hospital you visit or call the public library. The document does not need to be notarized (though some lawyers recommend it). However, two people must sign as witnesses to your signature. The witnesses cannot be related to you, cannot include the providers of your medical care, and cannot be anyone entitled to part of your estate or with a claim against your estate. The living will is not used until the situation(s) described in it actually arise during care. There is one exception: if you are pregnant, the document will be invalid and you may be kept alive even if it is against your wishes. Your health care provider must have a copy of the signed living will, and hospital staff should be alerted that it exists whenever you are admitted to the hospital.

POWER-OF-ATTORNEY

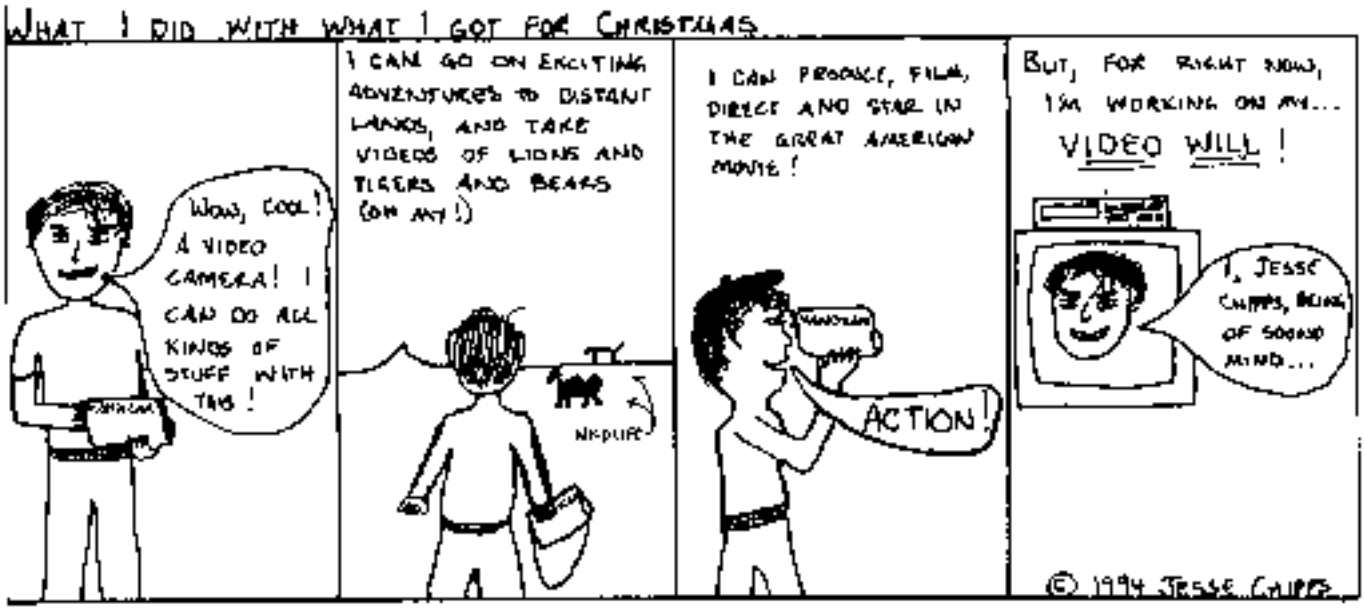
A power-of-attorney is a legal document that simply allows somebody else to act for you in legal matters. In the power-of-attorney, you name a trusted person to act for you and spell out exactly what that person is empowered to do. That person becomes your "agent" and you become the "principal."

This legal relationship allows your affairs to continue when you can't do business yourself if, for instance, you are hospitalized. It allows a lover, a spouse, a special friend or family member to do things in your name, such as buying or selling, banking, investing, entering into contracts, managing your business or your general affairs. It can also give your agent the authority to make medical decisions on your behalf. Finally, in the power-of-attorney, you can name the person you would like to be your legal guardian, should it become necessary to appoint one. You must be very sure that you can trust your agent because they may be able to take all your money out of the bank or sell your investments.

Sometimes AIDS causes a loss of mental function. It's a brutal fact that must be accepted now while you are well. The power-of-attorney can be the solution to management of your affairs if you lose the mental competence to do business yourself. It's possible to write a document that either retains your agent or makes someone your agent only in the event you are no longer competent. This document can only be written while you are legally competent. It must specifically empower your agent to act on your behalf if you become incompetent.

This is not a fun subject. We all shudder to think of losing our mental abilities. Always remember, though, that planning for the possibility of some dreaded event does not make it happen. It does not mean you are giving up or giving in. It means you are in charge. It means you know how to work the system to stay in charge even in the worst possible scenario. And, while we are talking about worst possible scenarios, get this—if you become incompetent and have no agent with durable power-of-attorney, the court could appoint a guardian to act for you, and you will have no control over that choice.

We advise you to consult a lawyer before you begin a power-of-attorney document, though you can write one yourself. Most case managers have access to generic forms where you need only fill in the blanks. It is generally advisable to have both your signature and witnesses' signatures notarized. If your agent



will be dealing with any real estate or certain other transactions, the power-of-attorney may have to be both notarized and recorded in the county office where deeds are recorded. Considering the far-reaching, meaningful effects of power-of-attorney, do ask a lawyer to at least study any document before you sign it. Frankly, you are better off having the attorney write the document as well.

LAST WILL AND TESTAMENT

A will assures that after your death, the people you want to give things to will actually get them. It may also designate guardians for your children. Your will must go through probate court before your estate can be distributed. Any property you hold jointly with someone else will automatically pass to the surviving party. Without a will your estate goes to relatives; unmarried partners, lovers, and friends have no right to inherit anything even though a relationship may have been long-standing.

You do not need a lawyer or notary to execute a will, but you do need two witnesses (who are not named in your will) to sign it. You can write your own document, buy a software program or buy a generic version of a will at a stationery or office supply store. Do be careful. You should consider doing it yourself only if your estate is uncomplicated, you are able to pay off any debts, and no one is going to challenge your intent or your wishes.

If your estate amounts to very much, if you have large debts, if you have a legal spouse, if you have legal dependents, if you have a community property agreement, or if you think your estate may be in dispute for any reason—get a lawyer. Not only will you want good legal advice in ordering your affairs, you will want to assure that your wishes are honored. Wills can also spell out your wishes regarding such things as burial, cremation, etc.

Remember that a power-of-attorney ends at death and then the will takes over. If such is the case, you must state in your will that you want your power-of-attorney agent (or some other person) to become the executor of your estate (the person who will carry out the terms of your will). Choose the executor thoughtfully; he or she will have the power to make any decisions that are not spelled out in your will. If you do not choose an executor, the court will appoint someone (probably a relative). A well written will in the safekeeping of your attorney makes it easier to establish that it is indeed your last will and is therefore valid. A will also resolves potential questions and lowers everyone's stress during what is, of course, a very difficult time.

LIVING TRUST

A trust is a legal arrangement in which one person (grantor) transfers property

to a second person (trustee), for the benefit of a third person (beneficiary). With a revocable living trust, the grantor places property in trust but reserves the right to revoke the trust. In either case, upon the death of the grantor, the property goes to the named beneficiary.

Placing property in the trust is referred to as "funding the trust." Personal property is transferred by a bill of sale, real estate by a deed, stocks and bonds must be put in the trust through a transfer agent. Assets such as personal bank accounts or those subject to taxes upon transfer (e.g., retirement accounts) are best left outside the trust and covered with a will instead.

Advantages of a living trust include the following: 1) it avoids probate, which can take months and be costly, and 2) a living trust is a private document (probate records are public) and thus may be harder to contest than a will. You may purchase a living trust kit, or have a lawyer draw up a document.

Child Custody

If you are your children's only legal guardian, it is best to make formal arrangements for someone to take care of your children in the event of your illness or death. This is a powerful act of love and caring for your children. In the short term you may want to organize a support network of people who can assist you with child care if you become too ill. For the long term, you should try to locate a friend or family member who would be willing to raise your children. This can be a family member or someone unrelated but who would be a good care provider for your children. Allow your children to spend time with this person; this will make the transition easier should such a circumstance arise. Finally, contact a lawyer and ask her or him to represent you in drawing up the necessary legal papers.

Sometimes people with HIV fear that courts or ex-spouses will attempt to take custody of their children. The law does not allow discrimination based on HIV status when determining custody questions, and your ex-spouse may not prohibit visitation because he/she fears the spread of AIDS. If you experience this discrimination, contact an attorney who handles family law.

Fighting Discrimination

The Americans with Disabilities Act (ADA) is a civil rights law, which protects people with disabilities from discrimination in private settings such as employment, education, and business services. Businesses with more than 15 employees are prohibited from discriminating against people with HIV disease. Under the ADA, an employer cannot fire you, refuse to hire you, or refuse to promote you simply because you have HIV. Employers must also make a reasonable effort to make it possible for you to continue working even if you become sick or physically disabled. This may include allowing you to work part-time, transferring you to a different job, or granting a leave of absence.

Also under the ADA, businesses and service providers are prohibited from denying you service because of your HIV status. This includes doctors, dentists, pharmacists, health care providers, hotels, restaurants, movie theaters, and stores. People with HIV are also protected from discrimination by laws in Seattle, King County, and Washington State.

Proving discrimination is not easy. There are strict time limitations on how long you can wait to charge discrimination, so seek out legal advice at the earliest possible time. You also cannot expect the employer or business to admit discrimination. You must be prepared to locate witnesses and documents to support your story.

Debt and Bankruptcy

Sometimes HIV disease leads to job loss and a sudden decrease in income, making it hard to pay outstanding debts. If this happens to you, your best bet is to consult a case manager or an attorney to get some advice and help. With whatever money you have, make rent and utility payments such as heat and water first; you don't want to be evicted or have basic services shut off. Some people in this position decide to file for bankruptcy in order to make a fresh start; you may want to consider this option. However, it is not without risks and may not be necessary.

According to the law, debt collectors cannot contact you outside of regular hours (8:00 AM to 9:00 PM), cannot contact you at work if they know your employer disapproves, and cannot contact anyone aside from you or your lawyer with reference to the debt. If the debt collector violates these laws, you can sue for damages.

Immigration

Unfortunately, immigration to the United States is difficult for people with HIV. Applications for lawful permanent residence require an HIV test; the results of this test will be given to you in a sealed envelope that must be submitted with your application. You will be allowed to obtain residency if you can show that you are enrolled in a recognized program of treatment for your medical condition, that you will not be a danger to others, and that you are not likely to need welfare, Medicaid, or other public assistance.

If you are in the United States illegally, you should know that the United States Constitution gives all people on U.S. soil the right to remain silent when approached by government officials. When the Immigration and Naturalization Services (INS) deports someone, it is usually on the basis of statements made voluntarily by the immigrant; remain silent and INS officials may be unable to formally charge you. If the INS charges you as a deportee, you have the right to a hearing before an immigration judge. Consult with a lawyer to determine your options before giving up that right or agreeing to leave the United States. For instance, if you are ill it is possible that your deportation could be postponed or suspended. Resources are listed in the 'Getting Good Services' section of this guide.

chapter 3

Getting Good Services

Seattle and King County have a wide range of services geared to HIV positive people. These services include support groups, legal assistance, free meals delivered to your home, medical services, referrals to health care providers who have experience with HIV, free massage, drug and alcohol counseling, and more. Some services are open to all people with HIV, others are for specific groups such as women or people with hemophilia or those who have been diagnosed with AIDS. Some organizations use mainly volunteers; others have paid staff. In addition to services for people with HIV, there are also support services for partners, families and friends. All of the services listed in this directory are government or non-profit agencies, and most provide services at low or no cost, depending on your income level and your ability to pay.

It is important to know your rights as a service user. You have the right to expect and receive services which are respectful, competent and confidential. No organization should disclose information about you to anyone else without your permission. Many organizations report statistical information to their funding sponsor, but any of your personal data should be stripped of identifying information before it is reported. It may be a good idea to ask organizations for their policy on confidentiality if you want to use their services.

There is also a lot of published information available on HIV and AIDS. We have included a short list of some of the most helpful books, newsletters, and electronic resources on AIDS to get you started.

For a more extensive list of King County resources ask your service provider about the HIV/AIDS Resource Manual or download it from the HIV/AIDS Program homepage (at http://www.metrokc.gov./health/apu). If you have any further questions on any AIDS or safer sex topic, call the HIV/STD Hotline at (206) 205-7837 or in Western Washington toll free at 1-800-678-1595, TTY (206) 296-4843.

King County Resources

ALTERNATIVE MEDICINE

Bastyr University Natural Health Clinic - (206) 632-0354. Primary care naturopathic clinic providing naturopathic medicine, acupuncture, Oriental herbs, nutrition counseling and psychological counseling.

In Touch - (206) 633-2419. Massage therapy for people with AIDS.

Kang Wen Clinic - (206) 322-6945. Acupuncture, Chinese herbal medicine, acupressure and naturopathic medicine for all people who are HIV positive.

Northwest Institute of Acupuncture and Oriental Medicine - (206) 633-5581. Acupuncture, Chinese herbal medicine and naturopathic medicine for all people who are HIV positive.

CASE MANAGEMENT

Northwest AIDS Foundation (NWAF) - (206) 329-6923. Information, referral, financial assistance, housing and case management for people with AIDS.

Northwest Family Center (Health Department) - (206) 731-3066. Case management, medical and child care services for HIV positive women, children and their families.

CAREGIVERS

AIDS Caregiver Support Network - (206) 937-3368. Emotional support and training for family, friends and caregivers of people with AIDS.

American Red Cross - (206) 323-2345. Training for caregivers of people with AIDS.

Professional Registry of Nursing - (425) 656-9031. 10-hour, intensive hands-on training for caregivers of people with AIDS.

CHILDREN AND TEENAGERS

Children's Hospital and Medical Center - (206) 526-2116. Comprehensive medical care for HIV infected children and adolescents.

Northwest Family Center (Health Department) - (206) 731-3066. Case management, medical and child care services for HIV positive women, children and their families.

Project P.I.E. - (206) 694-4508, x1259. Case management services for street involved, homeless and sexual minority youth; free, anonymous or confidential HIV testing, ages 14-25.

Rise n' Shine - (206) 628-8949. Emotional support services for children and teens affected by HIV/AIDS.

UW/Harborview Teen HIV Clinic - (206) 731-5100. Medical services for 12-20 year olds.

CHORE SERVICES (FOOD, TRANSPORTATION, PET CARE)

Chicken Soup Brigade - (206) 328-8979. Meals, groceries, transportation and home care services to people with AIDS.

Pet Support Network - (206) 270-1015. In home care for pets of persons with HIV, including pet bathing, grooming, flea control, limited financial help with veterinary care.

CLINICAL TRIALS

AIDS Clinical Trials Information Services - 1-800-TRIALS-A. Nationwide referrals for clinical trials.

AIDS Clinical Trials Unit (ACTU) - (206) 731-3184. Local clinical studies and treatment studies for people who test positive for HIV or have AIDS.

Bastyr University AIDS Research Center - 1-800-475-0135. Research investigating the use of alternative medicine and complementary therapies for HIV/AIDS.

Primary Infection Clinic - (206) 720-4340. Early HIV testing for those with possible symptoms; subsequent enrollment in treatment studies with free medical services.

DRUG/ALCOHOL SERVICES

Central Seattle Recovery Center - (206) 322-2970. Substance abuse counseling and education w/ services for Spanish-speaking.

Needle Exchange - (206) 205-7837. Exchange used needles for new needles (one for one, no limit). Also provides cottons and cookers. Call for times and locations.

Alcohol/Drug 24 - Hour Help Line (206) 722-3700. Referrals and information on drug and alcohol treatment.

Stonewall Recovery Services - (206) 461-4546. Drug and alcohol counseling and education primarily serving gays and lesbians.

Street Outreach Services (SOS) - (206) 625-0854. Drop-in center for homeless and those using street drugs, support groups for HIV prevention.

HEALTH CARE INSURANCE AND PROVIDERS

ACAP (AIDS Care Access Project) - (206) 284-9277. Referrals to medical and dental health care providers for people with HIV. Call to find out about state-funded insurance, HIP (HIV Intervention Program) and APDP (AIDS Prescription Drug Program.)

45th Street Community Clinic - (206) 633-3350. Medical, dental care for HIV+ individuals and their families with services for youth and Spanish-speaking.

Country Doctor Community Clinic - (206) 461-4503. Primary care for HIV+ individuals and their families.

Madison Clinic (Harborview) - (206) 731-5100. Primary care and case management for HIV+ individuals.

Sea-Mar Community Clinic - (206) 762-3730. Primary care for Spanish-speaking HIV+ people.

Seattle Indian Health Board - (206) 324-9360. Primary care for HIV+ individuals, families with emphasis on native and Spanish-speaking people.

HOUSING/HOME HEALTH CARE

Bailey-Boushay House - (206) 322-5300. Residential health care and adult day care facility for people living with AIDS.

Hospice Northwest - (206) 368-1793. Specializing in providing hospice services in an in-patient setting.

Fremont Homecare - (206) 634-3605. Home care for people with AIDS. Sliding fee scale.

Lyon Bldg. - (206) 341-9575. Permanent housing for adults with disabilities, including HIV/AIDS, chronic mental illness and substance abuse.

Northwest AIDS Foundation (NWAF) - (206) 329-6923. Centralized housing referral service.

LEGAL RESOURCES

Neighborhood Legal Clinics - (206) 340-2593. Free legal consultation offered in 14 locations in King County.

Northwest Immigrant Rights Project - (206) 587-4009. Community education, advocacy, legal services for immigrants and refugees, information and referral for homeless.

Volunteer Attorneys for People with AIDS (VAPWA) - (206) 340-2584. Legal services for people with HIV/AIDS.

MENTAL HEALTH RESOURCES

Asian Counseling and Referral Services (ACRS) - (206) 695-7600. Mental health services for HIV+ people of Asian descent.

Consejo Counseling and Referral Service - (206) 461-4880. Mental health, domestic violence and substance abuse services for Spanish-speaking HIV+ people.

Mental Health Access Project - (206) 731-5100. Counseling referral agency for people with HIV/AIDS in King County; assists in finding appropriate counseling resources in either the private or public sector.

Seattle Counseling Service - (206) 323-1768. Counseling, therapy and psychiatric medication management for gay and lesbian people and other sexual minorities.

SUPPORT GROUPS

Asian Pacific AIDS Council (APAC) - (206) 467-0884. A "buddy" program for people with HIV of Asian decent.

BABES Network - (206) 720-5566. Support for women living with HIV/AIDS; social gatherings, one-on-one support, educational forums and advocacy. Child care provided.

Crisis Clinic - (206) 461-3222 or 1-800-244-5767. Emergency emotional support and referral 24 hours a day.

Rise n' Shine - (206) 628-8949. Emotional support services for children and teens affected by HIV/AIDS.

Seattle AIDS Support Group (SASG) - (206) 322-2437. Support groups and drop-in center for people with or affected by HIV/AIDS.

Shanti - (206) 322-0279. Free one-on-one emotional support for people with HIV/AIDS and their loved ones.

TELLING PARTNERS

HIV/AIDS Program, Seattle King County Department of Public Health- (206) 205-7837. Health Department workers can tell your sexual or needle sharing partners of their possible exposure without giving your name, and with your safety in mind.

TREATMENT INFORMATION

HIV/AIDS Treatment Information Service (ATIS) - 1-800-448-0440. Information about federally approved treatment options and resources.

Project Inform - 1-800-822-7422. Information on treatments for HIV/AIDS.

Seattle Treatment Education Project (STEP) - (206) 329-4857 or 1-800-469-7837. Information on alternative and experimental treatments for people with HIV.

ELECTRONIC RESOURCES

The Internet has a great deal of AIDS information. Here are four sites that can serve as excellent starting points for electronic information retrieval:

Aegis. Sister Mary Elizabeth brings the world's largest database to the Web. (http://www.aegis.com)

The HIV/AIDS Program Page (King County Health Department). Local resources, statistics, fact sheets and links to more information. (http://www.metrokc.gov/health/apu)

Marty Howard's Home Page. Put together by an HIV positive individual, this site contains information on almost every aspect of HIV/AIDS. (http://www.smartlink.net/~martinjh/)

ARIC PWA's Resource Guide. Excellent listing of both on-line and print resources. (http://www.critpath.org/aric/)

BOOKS

AIDS (year): A Year in Review. Philadelphia: Current Science. 1988—Present (annual Publication). Reviews all major developments in AIDS research during the preceding year. Includes virology, epidemiology, vaccines, immunology, clinical treatment, social and political aspects and global statistics.

Goldstein, Eleanor, editor. The AIDS Crisis. Boca Raton, FL: Social Issues Resources Series, Inc., 1983-present. A continuously updated collection of magazine and newspaper articles on AIDS, available in loose-leaf format and also on compact disk. Articles are reprinted in full text.

Magazines and Newsletters
(plus their websites where applicable)

AIDS Treatment News. (John James, P.O. Box 411256, San Francisco, CA 94141. (800) 873-2812). The best of coverage of HIV/AIDS treatment; includes standard and experimental information. (http://www.immunet.org/immunet/home.nsf/page/homepage/)

Alive & Kicking! The Monthly newsletter of We The People Living with AIDS/HIV of the Delaware Valley. (http://www.critpath.org/wtp/alive.html)

Being Alive Newsletter. (Being Alive, People With HIV/AIDS Coalition, 3626 Sunset Blvd., Los Angeles, CA 90026). Written by and for the diverse populations of people living with HIV, this wide ranging newsletter is written primarily in English but does include, in each issue, a Spanish language section discussing the medical aspects of HIV. (http://www.critpath.org/newsletters/ba/ba.htm)

BETA. (P.O. Box 426182, San Francisco, CA 94142 Subscriber services: 1-800-833-0159 Telephone: (415) 487-8060 E-mail: beta@sfaf.org). San Francisco AIDS Foundation's quarterly with in-depth feature articles on new treatments and drug studies, and interviews with clinicians about the medical management of AIDS. (http://www.sfaf.org/beta.html)

Body Positive. (Body Positive 19 Fulton Street, Suite 308B, New York, NY. (212) 566-7333 E-mail: bodypos@aol.com http://www.thebody.com/bp/bp.html)

Diseased Pariah News. (c/o Men's Support Center, P.O. Box 30564, Oakland, CA 94604. Four-issue subscriptions are $10 from DPN.) An allegedly quarterly, though its ten issues to date have appeared at increasingly wide intervals over the last six years. (As one issue pointed out, what do you expect? It's desktop-published by sick people.) A humorous publication for persons with HIV/AIDS featuring sarcastic articles. DPN publishers describe their work as being "free of teddy bears, magic rocks and seronegative guilt." Not for the faint of heart.

Gay Men's Health Crisis Treatment Issues. (119 West 24th Street, New York, NY 10011. (212) 807-6664 http://www.thebody.com/gmhc/gmhcix.html#issues)

Positively Aware. (Test Positive Aware Network, Inc. Positively Aware , 1258 West Belmont Ave., Chicago, IL 60657. (312) 472-6397). A good source of basic information, very well-presented. Free to all.

POZ. (1279 Ol Chelsea Station, NY, NY 10113. (212) 242-1900) A lifestyle publication for people affected by HIV.

PI Perspectives. A quarterly of Project Inform that covers both conventional and alternative therapies, conducts town meeting (treatment forums), and publishes fact sheets on regiments, drugs and treatments. Also features information on underground and experimental treatments, with some in depth coverage on pathogenesis and news on expanded access advocacy. Also, information in Spanish. (http://www.critpath.org/newsletters/pi/pi.htm)

SIDAahora. (Coalicion de Personas con SIDA Nueva York, 50 West 17th St., 8th Floor, New York, NY 10011 (800) 828-3280). A bi-monthly Spanish/English magazine written by and for Latinos affected by AIDS/HIV.

STEP Perspective Newsletter. (127 Broadway East, 3rd Floor, Seattle, WA (206) 329-4857) The Seattle Treatment Education publishes a newsletter that contains the most current medical treatment information. (http://www.thebody.com/step/stepix.html)

Women Alive Newsletter. (1566 Burnside Ave. Los Angeles, CA 90019. Telephone: (213) 965-1565. Website: http://www.women-alive.org/ info@women-alive.org) "Women Alive: Involvement is Power, Awareness is Life" is a quarterly publication by and for women with HIV/AIDS. A task force of women infected with and affected by HIV/AIDS continues to act as an advisory board and editorial team for the newsletter. The quarterly newsletter is focused entirely on women's issues. It is unique in that it is focused on current medical, research and nutritional information, and political updates. (http://www.thebody.com/wa/wapage.html)

WORLD, Women Organized to Respond to Life-Threatening Diseases. (WORLD, P.O. Box 11535, Oakland, CA 94611. (510) 658-6930) A newsletter for HIV-affected women.

Glossary

acupuncture - an alternative type of therapy using needles applied to certain points in the body to relieve various illnesses and pain.

anemia - means there is less than the normal amount of red blood cells in body; symptoms include headache, shortness of breath and fatigue.

antiretroviral - a substance which stops or slows retrovirus reproduction or activity.

asymptomatic - a term for people who have a medical condition (such as HIV infection) but no actual symptoms.

bequest - to leave something to someone through a will.

botulism - an extremely dangerous food poisoning; symptoms include vomiting, stomach pain, muscle weakness, problems seeing.

chiropractic - a system of therapy that says disease is the result of nervous system problems; treatment focuses on massage or manipulation of the spinal column.

chronic - a condition that is ongoing or returns frequently.

circumcision- minor surgery often done on male infants to remove the foreskin on the penis.

cryptosporidiosis - a parasitic infection causing diarrhea, weight loss and weakness in the immune-compromised.

dementia - a progressive, organic mental disorder characterized by chronic confusion, disorientation, stupor, deterioration of intellectual capacity and function, impairment of memory, judgement and control of impulses.

diagnosis - a medical conclusion based on history, physical examination, and laboratory findings.

fecal/feces - another word for stool, or “shit”.

gonorrhea - an infectious bacterial disease of the genitals or throat.

hemophilia - an inherited disease that prevents blood from clotting normally.

hepatitis - inflammation of the liver caused by a number of viruses and by toxins (like alcohol).

herpes - the generic name for viruses causing cold sores and blisters around the lips, mouth, eyes, genitals, or other parts of the body.

homeopathy - a system of medical treatment using very small doses of medicine that in large doses produce the same symptoms as the illness being treated.

human papilloma virus (HPV) - causes warts and nipple-like bumps near the genitals and anus.

hydration - replacing water lost through sweat, hyperventilation, and urination.

mental competence - a person in good mental health and deemed able to make legal, financial and other personal decisions.

mycobacterium avium complex - MAC (also often called MAI) is an infection which can lead to weight loss, fever, fatigue and enlarged spleen.

naturopathy - a therapy using only “natural” remedies, such as a combination of sunlight, diet, herbs, vitamins, and massage.

neuropathy - inflammation or degeneration of the peripheral nerves (the motor and sensory nerves outside the brain and spinal cord), resulting in loss of movement and sensation in affected areas of the body.

notary/notarized - a person with legal power to witness and certify documents and signatures, and take affidavits and depositions.

parasite - an organism that lives by using another organism for food and protection.

placebo - a substance (such as a sugar pill) that has no medicinal effect on the body; placebos are used as standards against which to judge the effectiveness of new drugs.

pneumocystis carinii pneumonia (PCP) - inflammation of the lungs and disease in other organs in immuno-compromised persons.

prenatal - care received while a woman is pregnant—to ensure the health of both her and the baby.

prophylaxis - treatment meant to prevent disease from developing in the first place, or from returning after a previous occurrence.

protease inhibitors - a new class of antiretroviral drugs that make it difficult for HIV to create copies of itself that can then spread the infection to new cells in the body.

salmonella - bacteria causing a type of food poisoning that results in diarrhea, sometimes severe, particularly in people with damaged immune systems.

toxoplasmosis - a parasite that causes abscesses and surrounding swelling in the brain; the heart, lungs, glands, and testicles can also be affected, and there may be fever and severe headache.

tuberculosis - a bacterial infection usually affecting the lungs which is transmitted through coughing by persons with active disease.

vaccination - a shot or series of shots to prevent a disease; usually made from dead or weakened virus particles that activate the body’s defense system and prepares it for contact with the actual disease.

vasectomy - a form of male birth control using surgery to close or remove a part of the duct that carries sperm to the penis.

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