

## Getting On With Your Life

Let's face it: Finding out you've been exposed to HIV is no fun. For some people, it's a disaster. They take the news hard and die a little every day. For others, though, it's something else altogether. They take the news as an ultimate challenge to get busy with their lives and the lives of the people they care about—in spite of the way they may feel.

Interestingly, it's this group that contains virtually *all* of the long-term AIDS survivors identified thus far.

It's a special group of people, united by many of the approaches we've discussed and a common theme: That life is more important than a disease that can only take life away.

They know a secret that's as old as time and as timely as tomorrow's headlines: That living without purpose is giving up.

And with AIDS, giving up can be a real killer. ■

### For information on new AIDS treatments, contact:

- ▶ *Project Inform: 1-800-822-7422; in Calif., 1-800-334-7422*
- ▶ *U.S. Food and Drug Administration: 1-800-TRIALS-A*
- ▶ *The National AIDS Hotline 1-800-342-AIDS*



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# Living with HIV Disease



## A Guide for Seropositive People

A Do It Now Foundation Publication by Danielle Hain

## Beyond HIV

News about AIDS—and the human immunodeficiency virus that causes it—has never been particularly good.

In fact, since the disease surfaced in 1981, the HIV story has been mostly discouraging, when it's not absolutely tragic.

Today, that's changing.

New drugs and drug-combination therapies have produced remarkable results—even causing a complete remission of AIDS-related symptoms and HIV viral load measurements below the point of detectability.



*Winning the war? New drug therapies have brightened the picture for seropositive people.*

And while the new drugs aren't a cure—HIV-positive people have to keep taking them indefinitely or they lose their effectiveness—they're great news for seropositive people.

On the other hand, the drugs—a combination of protease inhibitors taken with anti-HIV drugs AZT and 3TC—don't work for everyone. In fact, researchers estimate that they don't work or produce unacceptable side effects in fully 15 percent of HIV-positive people.

But even that news isn't necessarily as tragic as it might seem.

Because others with HIV have survived for years—decades even, almost, at this point—without progressing to full-blown AIDS, and without suffering serious decline in the quality of their lives. And we've learned some things about what works and what doesn't when it comes to living with HIV.

That's why we've put together this pamphlet.

In it, we'll discuss some of the recent advances in HIV research and treatment that are raising the odds of long-term survival for those affected.

We'll outline a three-part program for living with the infection, based on formal research findings and the informal, practical discoveries of long-term survivors from around the world.

We're not even going to try to list all of the treat-

## Even experts aren't sure why some HIV-positive people stay symptom-free for so long...



ments currently being tried and tested against AIDS. But we *will* point out a few directions that are proving helpful for many—and lifesaving for some.

Because while there's still no true cure for AIDS—or a vaccine to block its spread—there *is* hope today for a longer, healthier life for people with HIV.

And that's not only good news—it's great news. And it's *way* overdue.

## The HIV Spectrum

One important thing to keep in mind when discussing HIV is the idea that it is a *spectrum* disease.

That means that everyone infected with HIV is infected by the same virus, but they may have different symptoms at different stages—or, indeed, display no symptoms at all for years after exposure.

The syndrome begins with an initial infection by the virus, which attacks cells in the body's immune system.

Early infection usually lasts one to eight years, and is often symptom-free. So unless they're tested, people in this stage may not even realize they *are* infected.

Initial symptoms—swollen lymph glands, oral thrush (a white coating or spotting in the mouth), and possible memory problems—may appear three to eight years following infection and gradually worsen.

AIDS itself is the final, and most serious, stage of HIV disease. It usually begins 8-12 years after infection, and involves severe immune system breakdown and the onset of rare illnesses, such as *Pneumocystis carinii* pneumonia and Kaposi's sarcoma.



Experts aren't completely sure which factors determine how quickly an infected person passes through the stages or why so many HIV-positive people stay symptom-free for so long, but overall health and exposure to other sexually-transmitted viruses and infections seem to play important roles.

Still, without treatment, the majority of infected people do develop AIDS within 10-12 years.

But researchers have also discovered that progression to AIDS *can* be slowed—perhaps even stopped altogether—by starting treatment as early as possible.

## Step 1: Getting Tested ■

Early diagnosis and treatment are important first steps in containing HIV infection.

It begins with testing. The most common test for HIV is the enzyme-linked immunosorbent assay (ELISA for short), which detects antibodies to HIV in the blood.

Other tests are used to confirm positive results. The tests are usually offered at no charge at public health clinics and, in most states, results are confidential.

## ▶ Step 1.5: Getting Help

**T**he critical first step in any plan for living with HIV is to find a knowledgeable doctor or clinic that you feel comfortable with and confidence in.

Start with your family doctor, if you have one, or contact an AIDS helpline for referral to a specialist in your area.

After that, get serious about getting on top of your life *and* your infection.

HIV isn't a winning ticket in life's lottery, but it's not an automatic death sentence, either. Thousands of people have lived with HIV for years, and some say they didn't really *start* living until they got their test results back and decided to begin right then and there.

What they also started doing, then and there—or shortly after—was to take care of themselves.

You should, too. Have your doctor show you how. ■



Who should get tested? **You** should if you've:

- ▶ had sex with someone who's HIV-positive
- ▶ had sex with multiple partners
- ▶ used needles to shoot drugs
- ▶ had sex with an IV drug user or a sexual partner of an IV drug user

Because people with early-stage AIDS feel healthy and often show few signs of being sick, the only way to be certain if you have it or not is to be tested.

## Step 2: Getting Treated ■

If you're positive that you're positive, your prospects are better than you might imagine. Because treatment today is light-years ahead of where it began.

The best news is the expanding arsenal of new drugs that have been approved for treating AIDS-related symptoms—and to prevent their onset.

In combination with long-time anti-HIV veterans AZT (Retrovir®) and 3TC, several protease inhibitors—including saquinavir, zidovudine, zalcitabine, and didanosine—are being used to slow the disease process and shore up immune system response.

The drugs are expensive (up to \$20,000 a year) and don't work for everyone, and they have to be taken on a precise daily schedule, or HIV cells can develop immunity to them. But they dramatically improve the health and long-term prospects of most seropositive people.

And while many of the anti-HIV drugs *are* toxic, dosage can be adjusted to combine the efficacy of high-dose treatment without intolerable side effects.

Since the new drug therapies are so new, our understanding of them—and our awareness of potential problems associated with them—is expanding almost daily.



*Daily doses. Protease inhibitors have to be taken on schedule or could lose their effectiveness.*

# **e**mergence of AIDS symptoms can be slowed—and perhaps even stopped altogether—by treating HIV infection as early as possible.

That's why it's important to get treated early and closely follow the treatment regimen laid out for you by your doctor.

What else can *you* do?

Keep yourself healthy. Along with your medical care plan, start a self-care plan aimed at shoring up your immune system and preventing further damage.

## Step 3: Getting Healthy ■

That self-care plan should involve making any lifestyle changes you need to make to promote overall health and well-being: making sure you have a balanced diet, plenty of rest, and regular exercise and relaxation.

Avoid doing the sorts of things that put a strain on your immune system—acquiring other sexually-transmitted diseases, for example, or using recreational drugs.

If you're hooked on drugs, get yourself into a detox or methadone program.

If you only consider yourself a “recreational” drug user, consider doing something else for recreation.

Alcohol, heroin, cocaine, and other chemicals inflict their own forms of havoc, even among the healthy, and may speed up the progression to AIDS.

If you haven't done it already, make sobriety a cornerstone of your healthy-living, HIV-survival strategy.

Your immune system is balanced too precariously to take any unnecessary tilting.

## ■ Help Yourself: Doing It With Diet

**D**iet plays a main role in any HIV survival plan. That's because people with AIDS are vulnerable to food-borne microorganisms. And food-related infections can be life-threatening.

According to the U.S. Centers for Disease Control, people with AIDS are 20 times more likely to contract *salmonella*, a contaminant of under-cooked poultry and eggs, and 200-300 times more likely to develop *listeria* infections from poultry, meat, and raw fish. Since animal foods—including cheese, milk, and eggs—are a main source of food infections, experts offer the following advice:

- ▶ **Eat meats well-done.** Use a thermometer to insure that poultry, fish, and other meats are well-done, and pre-cook grilled meats. Avoid sushi, shrimp, and other raw meats.
- ▶ **Cook eggs thoroughly.** Avoid dishes containing raw eggs, including Hollandaise sauce, egg nog, and Caesar salad.
- ▶ **Drink pasteurized milk.** Raw, unpasteurized dairy products can also be a problem. Better keep your distance.
- ▶ **Clean utensils after handling raw meat.** Infectious organisms can spread to other foods and dishes, and to uncovered cuts or sores on the hands.

Also, you may want to consider soy and vegetable protein substitutes for meat, milk, and cheese that are available at health food and grocery stores.

For more information, contact the National AIDS Clearinghouse at 1-800-458-5231. ■



*Super strategy: Following HIV dietary guidelines is as easy as, well, ABC.*