

HIV: Day One

By Wynn Wagner

You are reading the right pamphlet if you just found out you have HIV.

Yeah, me too. This is the beginning of your Survival Kit. I'm not a doctor or professional counselor. I'm just a person with HIV, and I've gone through the same thing you're going through.

My plan here is to give you four pointers that I think are Big Deals. Then, I'll show you where you can go get whatever information you are ready for.



This is a reprint of a web page: <http://www.aegis.com/topics/dayone>

AEGiS The largest HIV web site in the world.
<http://www.aegis.com>

Four Pointers For Survival

1 **Use a specialist.** Make sure you find a doctor who *specializes in HIV*. That's a Big Deal. Studies have shown that your survival depends on you being treated by a doctor who deals with HIV on a daily basis.

Your regular doctor may be great, but you don't need general medicine right now. You need a specialist.

Those who get treated by an HIV specialist live longer. Period.

If you can't afford or locate a doctor, find an HIV/AIDS organization that can help you directly, or help you find public assistance.

2 **Be good to yourself.** That means eat right and take vitamins, and it means finding somebody to hug you from time to time.

It also means stop beating yourself up over being HIV-positive. Oh, okay ... do some self-pity for a day or two, if you want ... but remember to snap out of it.

3 **Your best medicines are attitude and knowledge.** Find out all you can and be assertive. It's you versus HIV. Doctors and social workers can help, but eventually it's just you and the virus. Your absolute best weapons are knowledge and attitude. Those of us with HIV have gotten a reputation for being well-informed patients.

It's okay to ask your caregiver (e.g., doctor) questions or to disagree with a treatment strategy. It's okay to be part of the treatment decision process. *You* need to take charge of your own health. Be assertive _or aggressive, if you want _that's okay too, because your doctor is your employee.

4 **Watch for outdated information.**

- Distrust anything you find on the internet that is older than a few months. Major advances in treating HIV have occurred recently. Some web sites haven't reflected those changes.
- The current (1999) recommendation on treating HIV is aggressive:
 1. Start treatment early.
 2. Always use multiple drugs, including a "protease inhibitor." This strategy is called **HAART**, which stands for "**h**ighly **a**ctive **a**nti-**r**etroviral **t**herapy."

Avoid treatment options that are different than this recommendation.

What HIV Is

HIV is a virus. A virus is an organism that has to be inside some other cell in order to multiply.

In the case of HIV, the virus gets inside your *T-cells* —which are part of your immune system.

Technical Notes:

- *The virus gets into more than just T-cells, but T-cells are your biggest concern.*
- *T-cell is sometimes called CD4+. For simplicity, you can treat T-cell and CD4+ as the same thing.*

Monitoring Your Health There are two kinds of tests that see how well you are: "t-cell count" (or "CD4+ count") lets you know how many t-cells you have, and "viral load" shows how much virus is floating around.

You want to get a high t-cell count and a low viral load, but there are treatment options for all combinations of t-cell counts and viral load tests. Doctors *and patient-activist groups* often recommend you get both tests every three or four months.

Treatment Anti-viral treatment attacks the HIV virus in one of two places: (1) keeping the virus out of your healthy t-cells; (2) keeping an infected t-cell from releasing new virus cells.

Other treatment includes boosting your natural immune system so it can fight HIV. This is called "immune modulation." The reason HIV symptoms don't appear for many years is because your immune system does a remarkable job in fighting HIV. Anti-viral drugs are primarily for those whose immune system is overwhelmed by the virus. Other treatment strategies include ways of boosting your immune system's strength, so it can fight HIV longer.

Opportunistic Infections If your t-cells drop too low, your immune system won't be able to fight off diseases. These diseases are called "opportunistic infections."

Those who die of AIDS actually die from one of these opportunistic infections (a.k.a. "O.I."). HIV doesn't kill anybody directly. It just weakens the person's immune system.

There is a battery of weapons your doctor will have to prevent and cure these infections.

Note that I said "**If** your t-cells drop too low...." I did not say "When they drop...." There are things you can do to help keep your t-cell count high. Getting smart about HIV is Step One, and you're already on your way to do that.

It really *isn't* a "death sentence."

Hearing you have HIV is like hearing a death sentence.

It can ruin your day.

It ruined my whole week.

But I've learned about people who are still alive and healthy *and happy* 15 years after being diagnosed. It feels like a death sentence at first, but things will get better. Learning about the disease (like you're doing right now) is your best defense. You are doing exactly what you should be doing.

You tested positive. Your test result is a piece of knowledge, and knowing about the disease is a powerful weapon. Now that you know, you can do something about it.



Time

If you are like me, there are several topics you are not ready for —sex, for example.

After I tested positive, I couldn't even think about friendships, relationships, and sex — but I was sure that I would never have a friend again.

If you start worrying about this stuff in the next few weeks, just remember what I said. It's just your brain playing mind games.

File this away for later: you can make friends again; you can have relationships again; and I am living witness that safe sex can be really hot.

Death and Dying

This is one thing we have in common with those who don't have HIV. Everybody gets to die some day. But...

You don't have to die today.

That is the one phrase that snapped me out of my HIV-blues.

I've learned to pay attention to today. Things are better when I concentrate on today. When I get wrapped up in yesterday, it's usually a feeling of regret. When I go off ` ` on tomorrow, it's almost always fear.

Picture yourself with one foot on yesterday the other foot on tomorrow.

What's left for today? With one foot on yesterday and the other foot on tomorrow, the only thing you can do about today is piss on it.

Topics

When I first hit the internet after getting my HIV test result, my head was swimming. I didn't know where to turn. I started reading everything I could.

The ÆGIS web (where "Day One" is available online) is huge. It is the largest HIV web site in the world. This place is great for researchers, and it'll be good for you when you want to find in-depth information.

In addition to the resources at ÆGIS, there is a great deal of information at other web sites. Here are some places I found handy —

[Telling others](http://www.thebody.com/learning.html) - <http://www.thebody.com/learning.html>

I told everybody about my HIV status, but you may choose another route. *The Body* has several web pages on topics related to telling others about your HIV status. *The Body* is a wonderful web site, and I think you will find lots of information there.

[All About Treatment](http://www.aegis.com/topics/treatment/strategy.html) – <http://www.aegis.com/topics/treatment/strategy.html>

Here is a truckload of information on treatment strategies —when to start anti-HIV drugs, when to change to different drugs, how to know they are working. Almost all HIV Specialists will want to hit the virus hard and early, unless they have strong evidence such an approach would be dangerous to you.

[Topics at ÆGIS](http://www.aegis.com/topics) – <http://www.aegis.com/topics>

This is a good starting point for you to explore the huge resources available here at ÆGIS. Subjects include opportunistic infections, traveling with HIV, and drugs.

[Glossary of HIV/AIDS Terms](http://www.aegis.com/ni/topics/glossary/) <http://www.aegis.com/ni/topics/glossary/>

Bookmark this for a rainy day. There are lots of "AIDS glossaries" on the network, but this one is the most comprehensive glossary on the planet.

[Politics and Activism](http://www.actupny.org/) - <http://www.actupny.org/>

No HIV group has gotten more media attention than ACT UP (AIDS Coalition To Unleash Power). People with HIV have a reputation for being aggressive patients. You may or may not like the approach ACT UP takes, but that's the group which has brought the most changes in the U.S. government —particularly at the FDA (the agency that okays new drugs). Pressure from ACT UP forced the FDA to slash the amount of time it takes for new drugs to be available.



[Yahoo's HIV/AIDS list](http://www.yahoo.com/Health/Diseases_and_Conditions/AIDS_HIV/) - http://www.yahoo.com/Health/Diseases_and_Conditions/AIDS_HIV/

Yahoo has an extensive collection of other links. Here's where you will find access to regional services.

[Search For Another Topic](http://www.aegis.com/search) – <http://www.aegis.com/search>

You are already at the right web site to find in-depth material. ÆGIS is the mother lode of HIV articles, journals, and news stories. If I didn't cover something you want to know about now, try the ÆGIS search engine.

That's it. I hope it helps.

If you got anything out of this web page, I hope you got this: there are proven ways for you to stay healthy so you can be here for the cure.

I saw a piece in the newspaper recently about a doctor having to tell a patient that he was getting so much better that he was going to have to get off disability.

"Go back to work?" gasped the patient.

Many of us with HIV got used to planning for short-term goals. Now, we are thinking about retirement plans again. What a difference a few scientific discoveries can make.

The bottom line: HIV is a real bummer. But if you had to get the disease, you couldn't have picked a better time to do it.

Play safe. Stay well. Blessed be.

— Wynn Wagner

<http://www.global.org/wynn>

"Day One" is also available in French, German, Italian, and Spanish.

In mid-1999, it is scheduled to be available on video tape in American Sign Language.

For more information on non-English versions, see the AEGIS web site:

<http://www.aegis.com/topics/dayone>

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This document was last updated in early 1999. Watch for outdated material!

This information is designed to support, not replace, the relationship that exists between you and your doctor.