

# Being Diagnosed Late in the Course of HIV Disease

By Mark Katz, M.D.

It's hard to find out you're **HIV+** under any circumstances, but some people don't find out until they wind up in the emergency room. This can be devastating. Even if you have been **diagnosed late** (with fewer than 200 CD4 cells or an opportunistic infection) there are still things you can do to **improve your health and prolong your life!** Follow this list:

## 1. Find a doctor who specializes in HIV care.

Studies show patients of doctors who have larger HIV practices did better than patients of doctors who only saw a small number of HIV+ patients. Check with a local AIDS service agency to find a specialist in your area.

## 2. Accept the need for treatment.

It is likely that you will be placed on treatment for HIV immediately, probably three HIV drugs to start. Study after study has shown the benefit of treatment in advanced stages of HIV disease.

## 3. Accept the possible need to change HIV drugs.

If your viral load (amount of HIV in your blood) does not drop enough or you experience side effects, your doctor may need to change your treatment. Don't be discouraged if this happens; there are about 20 HIV medications. It is likely that a combination will be found that works well for you!

## 4. Keep your CD4 cells afloat.

With the help of your medications (taken on schedule), maintain a CD4 cell count of more than 50. Almost no one dies from complications of AIDS today with CD4 cells above 50.

## 5. Prevent other infections.

If you have low CD4 cells, you may need to take medications to prevent you from getting HIV-related illnesses (opportunistic infections). These medications can help your immune system fight off infections until the HIV drugs work to increase your CD4 cell count.

## 6. Make friends with your pharmacist.

Go over your medication regimen carefully with your pharmacist to check for drug interactions. Report side effects to both your doctor and pharmacist.

## 7. Be aware that anxiety and depression tend to increase as CD4 cells decline.

Depression can be successfully treated with medication and/or therapy.

## 8. Report your symptoms.

Several HIV-related conditions occur more commonly in later-stage disease. These include neuropathy (tingling of the hands or feet), loss of sexual drive and fatigue. All are potentially treatable, so be sure to mention them to your provider.

## 9. Play it safe.

Even though you already have HIV, you can become re-infected with another, worse strain of the virus. Being HIV+ is not a reason to give up safer sex and needle guidelines. You also do not want to pick up an additional sexually-transmitted disease or infect anyone else.

## 10. Find support.

Being diagnosed late means you need extra support to deal with often overwhelming feelings of fear and anger. Find a group of friends, relatives, coworkers or healthcare team members who care about you and who know about your condition. Consider joining a support group at a local AIDS service agency.

## 11. Meet with a social worker or lawyer.

Take steps to plan for your future and the

care of your children, including drawing up legal documents such as medical directives and wills.


## 12. Be as healthy as you can be.

The better your health is overall, the better you can deal with HIV. Get regular medical and dental checkups and treatment for conditions like diabetes, hepatitis, high blood pressure or high cholesterol. Avoid smoking, drinking too much alcohol and recreational drugs.

## 13. Learn all you can about HIV.

Educate yourself so you will understand how you got infected, basic facts about HIV and treatment options. Find a local AIDS service agency, speak to a treatment educator, attend workshops, search the Internet and read newsletters and fact sheets.

### Some resources are:

- National AIDS Hotline: 1-800-342-2437
- Project Inform Treatment Information Hotline: 1-800-822-7422
- New Mexico AIDS Infonet: [www.aidsinfonet.org](http://www.aidsinfonet.org)
- GMHC Hotline: 1-800-AIDS-NYC
- The Body: [www.thebody.com](http://www.thebody.com)
- Positively Aware: [www.tpan.com](http://www.tpan.com) 

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