REASONS FOR HOPE

Doctor, who?

The fast-changing knowledge involved in HIV treatment makes it crucial to have a reliable health care provider

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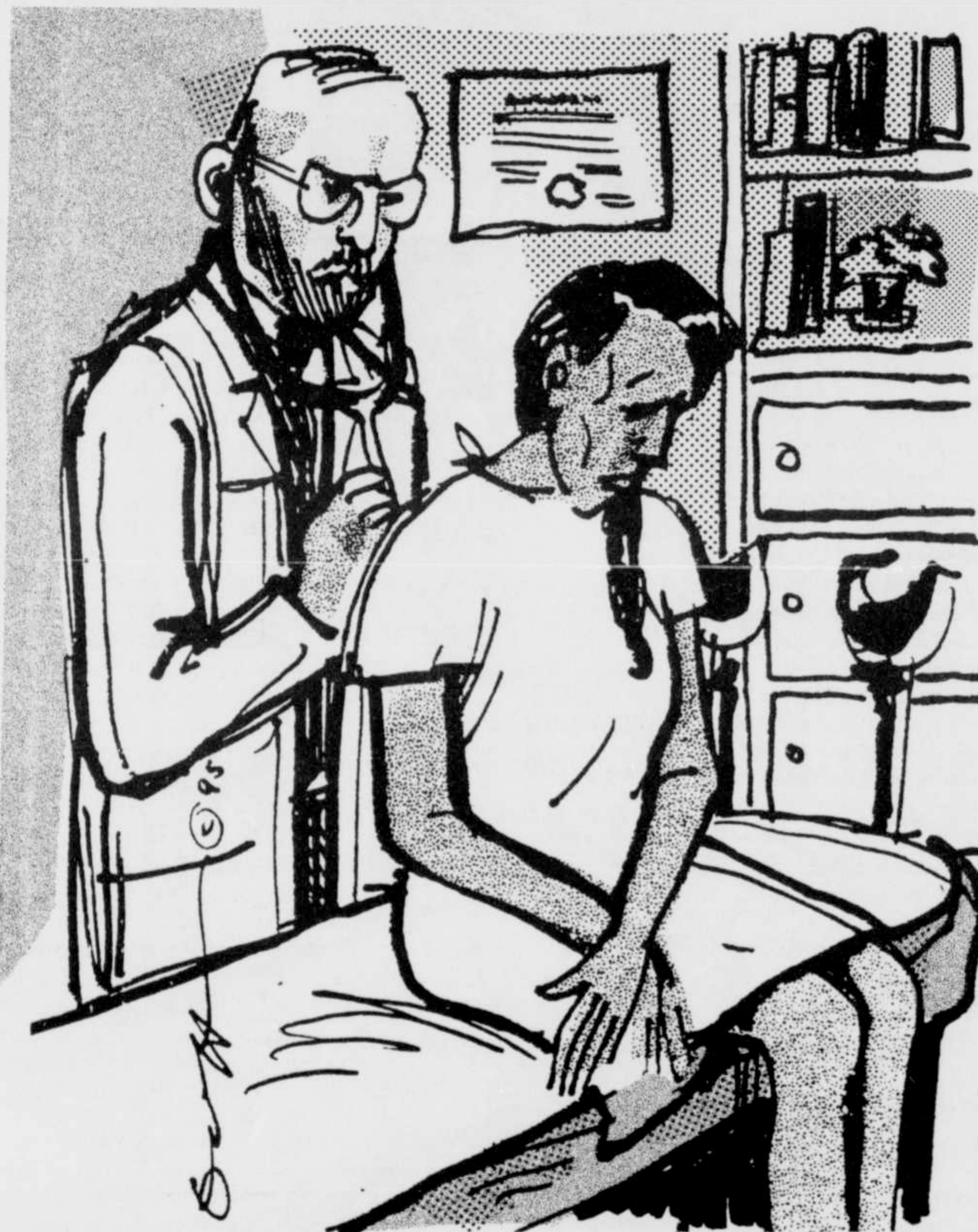
by the Boston AIDS Writers Group

Choosing a physician may be the most important decision a person with HIV disease makes regarding treatment. A recent study showed that those who have doctors with many patients with HIV live twice as long as those who don't. New treatments for HIV are being developed so fast, and management of the disease has become so specialized, that people with HIV need to find a competent doctor who can provide individualized care.

Many people prefer doctors and nurses who explain what is going on, and with whom they can be honest and feel comfortable. There is a lot of prejudice surrounding this disease, so it is critical that a medical provider be nonjudgmental. Talking to friends about the care they receive, what they think of their doctor, and comparing that to what you want in a doctor might be the best way to decide on a health care provider. A good provider is comfortable when a patient presents outside information regarding treatments. Ideally, a medical team should listen, answer questions and have time for you. If you feel you are being rushed, important information may not be communicated. While a busy doctor is often a good one, waiting a month or more for an appointment may allow time for serious problems to arise.

HIV is becoming a specialized field. Knowledge about HIV is changing so fast that a doctor needs to keep up on the latest findings and understand details about recently available drugs. Many treatments are still experimental, so a provider should know how to get these treatments, whether through clinical trails or compassionate-use programs. Across the country there are AIDS Education and Training Centers set up to provide training to doctors in HIV treatment. You can encourage your provider to access this information.

A good doctor does not try to do everything, and will often refer patients to specialists. Sometimes experts understand HIV well enough that they do not follow the prevailing wisdom in particular circumstances, and have good reasons for doing so. Nevertheless, the following are eight points to look for that tell you your provider is well versed in HIV treatment.



What to Look For: Viral Load

The first three points to look for come from the new understanding that viral load tests are the most important way to decide if your HIV is under control and if your medicine is working for you. Viral load tests measure how much virus is floating around in your bloodstream, and accurately predict how much damage is being done to your immune system. There are several tests available, which are more or less equal.

1. After you test positive, if your health care provider wants you to get viral load tests as well as T-cell counts before any therapy, it's a good sign that your provider is up on the latest. Such a provider would use a test able to measure viral loads as low as 500 copies per milliliter, or even lower.

Reason: Viral load tests are the best way to tell if a therapy is needed. If you've never had a viral load test done before, the doctor may suggest getting two done, several weeks apart, to make sure that your starting point is correctly determined.

2. In general, if your doctor says it is time to begin antiviral therapy when you have a high viral load, or low or rapidly declining T-cell levels, you should keep him or her.

Reason: Viral load and T-cell counts are the best predictors of how quickly the disease will progress. For people with few or falling T cells or a high viral load, waiting to begin treatment could be a mistake.

3. If your provider uses viral load tests and other blood work to see how a change in your therapy is doing within about four to six weeks of starting a new therapy, your provider is a winner. A provider who is up on the latest understands that, to be successful, combination therapy with a protease inhibitor should lead to undetectable amounts of virus after 12 to 16 weeks.

Reason: You need to know right away if a therapy works or needs to be changed. It is not only a waste of time, money and drugs to continue with a therapy that doesn't work—it means you are less likely to benefit from any of those drugs later. In particular, combinations that use a protease inhibitor may fail unless they get viral load down to undetectable levels.

What to Look For: Antiviral Therapy

The next three areas to check come from understanding how drugs fail over time and how to avoid this. This is important, because there is no point to taking complicated and expensive therapies in a way likely to lead to failure.

4. If your clinician tells you not to start any of the antiviral drugs presently available alone, as a single drug therapy, that's a good sign.

Reason: Over time, every drug studied thus far leads to viral mutations that ignore it—that become "resistant" to the therapy. This means that any drug used alone may quickly become useless, and will make it very unlikely that the drug you use can be used later in a combination more likely to get viral load down to zero. Even the most powerful drugs, such as the protease inhibitor indinavir, have a limited success rate when used alone. Yet the very same drug when used together with AZT and 3TC is successful at getting viral load down, and keeping it down to undetectable levels, over 90 percent of the time.

5. If your provider refuses just to add a protease inhibitor to your current regimen, that clinician is generally correct.

Reason: It is now understood that simply adding one more drug to an already failed or failing regimen is similar, although not identical in effect, to using one drug at a time. It is now known that using one drug alone (called monotherapy) will not work for very long.

6. If your health care team discusses with you the likely success of a new therapy based upon your entire medical history (including what antivirals you have already taken), and considers how the recommended regimen might limit future treatment options, you can feel comfortable about your care.

Reason: Antiviral therapy should be individualized. If you've failed some drugs in the past, it is less likely that combinations including them will be effective now. Ignoring your medical history and just mechanically prescribing a therapy is not a good idea. A good provider will pick therapies that are most likely to get your viral load down to undetectable levels based on an understanding of what combinations will work given your antiviral history. That provider will also look at your medical history to be sure that you are going to do well with a therapy, as some people have conditions which make it less likely that they will succeed on a particular drug. This means that a physician often has different patients taking different therapies.

Other Things to Look For

Given the new therapies for HIV disease, it is now crucial that people take their medications on time. It is also important to have backup plans on what to do if, for some reason, the first therapy picked doesn't work out.

7. If your T-cell count remains below 200 for some time, and your doctor tells you to start taking drugs to prevent opportunistic infections (or OIs), thank that provider. She or he may have you stay on these prevention drugs even if a new antiviral treatment sends your T-cell count back up, and may add more prevention drugs should your T cells continue to fall.

Reason: A T cell's job is to help protect the body from a particular disease, anything from flu to pneumonia to cancer. As one's T-cell count goes down, the cells trained to fight certain diseases may disappear. It's a lot easier to take Bactrim or another preventative drug to stop PCP (*Pneumocystis carinii* pneumonia) before you get it, than it is to treat it afterwards. A doctor may want a patient whose T-cell count goes back over 200 to stay on these drugs because a significant increase in T cells is not a guarantee of a strengthened immune system.

8. If your provider discusses with you the most common side effects and drug interactions that you might get from a treatment, what the real chances of getting them are, and what to do if you start having them, he or she is doing a good job. Should the doctor have a backup therapy plan that is ready to go if the side effects cannot be successfully dealt with, thanks are in order.

Reason: The most common reasons for a person's lack of success with the new combination therapies are the inability to endure the drugs' side effects and the failure to take them regularly. The new therapies don't work unless they are used properly. A good doctor will warn a person about possible side effects and has a plan on how to reduce them, and a backup plan for a quick change of therapy if this does not work. Side effects are not to be taken lightly, as some of them can last a lifetime. A good provider is also aware of the risks and effects of mixing drugs.

In Conclusion

The good news is now that we have so many therapies that work, a person with HIV has real options. The days of going on AZT and waiting to get sick are over. The bad news is that given the explosion in the understanding of HIV management many providers cannot keep up unless they have a practice with many HIV-infected people. It makes more sense than ever to pick a health care provider who is keeping up with the latest treatments, because finally there are treatments that actually help. The eight points above may help you decide on a physician, but remember that they are not absolute. If your provider seems to be doing some things differently from what is suggested here, find out why. There may be a very good reason. (Psst…and if you have a good doctor, pass the word!)

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