

Building a cooperative patient/doctor relationship

A positive HIV antibody test or an AIDS diagnosis changes many aspects of a person's life, including the kind of relationship they have with their doctor. Many people develop a more assertive attitude about their health and well-being when they find out they have HIV. Because HIV disease and its treatment is complicated, making decisions about when, how and whether to start therapy isn't always easy.

One great step to take is to become an active participant in your health care and treatment decisions. This means that both you and your doctor need to learn how to work and communicate with each other.

This publication's intention is to help both patient and doctor establish reasonable expectations of each other and to set up a climate of cooperation and joint responsibility for healing. Just as there isn't a "one size fits all" approach to HIV care, there's no one doctor-patient relationship that suits everyone.

For the patient ...

SHARE YOUR POINT OF VIEW WITH YOUR DOCTOR

Share your point of view. If something is or isn't working for you, it's important to let your doctor know. Being honest about your viewpoint is especially important if you want to enroll in a study or use experimental treatments.

Explain why you're considering a particular decision and listen to what your doctor has to say. Many doctors are willing to work with and support patients who have clearly put some thought and time into their decisions.

Whether or not agreement is reached on particular treatments,

properly monitoring through exams and lab tests should be routine. In turn, you should agree to heed reasonable warnings suggested by this process.

If you want certain prescriptions, asking in a friendly tone is likely to work best. If the doctor opposes it, you're entitled to know why, in clear terms. His or her concerns and knowledge should be given due respect, whether or not you agree with them.



CHOOSE A RELATIONSHIP STYLE

Choose a relationship style and discuss it with your doctor. People have different styles of relating to doctors, and those styles may change at different times or for different illnesses. In the "traditional" doctor-patient relationship, the doctor leads and the patient follows. For some, this is effective because they feel secure and cared for.

Others may view their relationship as more of a partnership, where both contribute to the decision-making process. Some prefer to make decisions and use a doctor primarily as a consultant. This style requires diplomacy by the patient as many doctors have not adjusted to the role of consultant.

None of these styles is right or wrong, but they all make different demands upon the relationship. It's important that you let your doctor know which style you prefer. As you become more familiar with HIV and



FACING NEW DECISIONS? WONDERING WHAT'S THE NEXT STEP?

National HIV Treatment Hotline: 1-800-822-7422 (toll-free)
10a-4p, Monday-Friday, Pacific Time

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For the patient, continued ...

experience different health challenges, the doctor-patient relationship style that works best for you may change.

LEARN THE INFORMATION

Knowledge makes a world of difference. Generally, the more you know before a medical appointment, the more you can benefit from each visit. Obtaining information on your own doesn't need to be difficult or over-whelming. In fact, the education process can begin right at home.

Many websites, hotlines and community organizations are dedicated to answering questions about HIV. Realize that you can't learn everything at once, so concentrate on the information that's most important to your health right now. While self-learning is great, it should not substitute using your doctor as a source of information.

PREPARE FOR APPOINTMENTS

You can benefit most when a visit is well-planned. It takes only a few minutes to write down key questions ahead of time. Get in the habit of writing down items in a journal about side effects you've experienced, missed doses, or any questions that come up between visits. Use it to update your doctor at the start of the visit.

Use the limited time in your doctor's office to focus on the most critical issues, rather than everything that comes to mind. Maybe bring along treatment literature to discuss in the visit. This allows your doctor to know your sources of information and how to evaluate them.



GETTING EMOTIONAL NEWS

Be prepared for the emotional content of the visit. Most doctors are sensitive, caring people who respond emotionally to their patients. Still, there's only so much support a doctor can give in the short time allotted for most visits. Plan in advance to make use of other support resources.

If you prefer a more straightforward approach, let your doctor know. But don't expect him or her to also serve as your therapist if news is unusually hard to hear. By choosing a more direct approach, you also choose a path that requires greater inner support.

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For the doctor ...

SUPPORT YOUR PATIENT'S INTERESTS IN THEIR HEALTH CARE

Support your patient's interest in monitoring and treatment. While not every treatment is appropriate, every patient's opinions and health are. The more uncertainties a given treatment raises, the more important it is that you monitor its use. Patients may be willing to follow your recommendations if you're willing to monitor your patient's other choices simultaneously.

When someone asks to be monitored in a course of treatment, it doesn't imply you agree with it—only support for your patient's well-being. There are no legal precedents in AIDS in which a doctor has been accused of malpractice for taking blood counts while a patient used a drug against his or her recommendation.

BE FLEXIBLE WITH YOUR RESPONSES

Recognize that the uncertainties of the epidemic demand a flexible response. The expectation that patients will passively follow orders simply doesn't work with everyone, certainly not when doctors may not have answers for every question.

HIV has changed forever the way many people relate to their doctors. The new assertiveness and knowledge won't go away. To cope effectively, doctors must learn how each person wants to be treated, particularly in regards to degree and form of collaboration in their healing process.

DESCRIBE BOTH SIDES OF THE ISSUES

Doctors have always known that there are two or more viewpoints on most issues. Be prepared to describe the

many sides of medical issues that confront patients, and do not feel insulted if your patient chooses something you don't recommend.

Today, many people take a strong role in the decision-making process. Of course, that empowerment doesn't automatically make your patient right. Doctors should help persuade patients to do what makes sense. Use of well-phrased questions, reasoning, shared information, respect and patience on both sides best achieve mutually satisfying choices.

RESPOND MEDICALLY

Patients may use a treatment anyway if they're determined to and you may not be able to sway them against it. Refusing to monitor diminishes your patient's confidence and may increase the risk of harm.

Respond in a medical fashion to the uncertainties of unapproved treatments or strategies. Perhaps this means more frequent visits, other diagnostic tests, or more cautious reading of lab markers. Added expense may be the price and the patient must be prepared to heed the outcome of the monitoring process.

DON'T PUSH YOUR PATIENT

Don't push patients to begin treatment before s/he is ready to commit. Starting a regimen is a big step and will change many things in a patient's life.

For example, taking pills every day is a constant reminder of HIV. Disclosure is often an issue: your patient may be reluctant to begin therapy that must be taken around their family or at work.

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If disagreements occur ...

When disagreements occur, it's difficult to know what to do. When an active disease appears, such as a bout of PCP, the doctor's expertise must lead the way because its treatment is better known. Exceptions may occur in institutions or areas of the country where expertise with HIV is not at a state-of-the-art level, or when bureaucratic procedures may hamper the quality of care. Then, a second opin-

ion should be sought from doctors in leading AIDS hospitals, or doctors could call the WARMline at 1-800-933-3413.

Disagreements about how to treat HIV may occur. When patients have as much information as the doctor about some therapies, each may arrive at different conclusions based on similar data. This presents a challenge for both.

A doctor must feel that s/he is practicing sound medicine, while patients may feel they cannot compromise on treatments they consider essential to their health. Both must strive to listen and understand the other's views. Sometimes, it's possible to find new options that neither party had expected before the discussion began.

The patient might ask:

"What will it take for you to feel comfortable with what I want to do? More careful monitoring? Reviewing the decision in a month or two? More review of available data? Discussion with other doctors? A statement releasing you from liability?"



The doctor might ask:

"What can I do to help you better understand the risks and why I'm concerned with what you want to do?" or "What other options, if any, have you considered?" or "Will you wait while I review the matter more carefully?"

However, patients can't expect their doctors to heartily support remedies for which there's no supporting evidence. Nor can patients realistically expect their doctors to give the same credence to highly experimental drugs as they would to better proven therapies. And doctors shouldn't ex-

pect patients to "wait and see" indefinitely while the research proceeds.

Sometimes doctors and patients must question whether it's possible to continue their relationship. It's possible to maintain the relationship while disagreeing and continuing to communicate over the differences.

Changing doctors should be reached only as a last resort, and only when it's clear that you both cannot accept the other's part in the relationship. Each of us must ultimately find the combination of patient + doctor + approach that makes a cooperative relationship possible.