

BUILDING A COOPERATIVE DOCTOR/PATIENT RELATIONSHIP



issues you may face when building the relationship you want with your doctor



A positive HIV-antibody test or an AIDS diagnosis changes many aspects of a person's life, including the kind of relationship they may choose to 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 treatment is complicated, making decisions about when, how and whether to start anti-HIV therapy isn't always easy.

One great step to take is to become an active participant in your healthcare and treatment decisions.

This means that both patients and doctors need to learn how to work and communicate respectfully and thoughtfully with each other.

Project Inform suggests the following guidelines for discussion between patient and doctor. Our intention is to help both parties 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 treatment and care, there's no one doctor-patient relationship that suits everyone.

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PROJECT
inform

Information,
Inspiration and
Advocacy for People
Living With HIV/AIDS

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for the patient ...

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ISSUE

sharing your point of view with your doctor

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

Explain why you are considering a particular decision and listen to what your doctor has to say. While some doctors feel uncomfortable recommending certain studies or unapproved medications, many 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 the use of a particular treatment, cooperation in the form of proper monitoring through examinations and lab tests should be secured. In turn, you should agree to heed reasonable warnings suggested by the monitoring process.

When requesting prescriptions for existing approved medications, a friendly and firm request is likely to work best. If the doctor is opposed, you are entitled to know why, in clear terms. The doctor's concerns and knowledge should be given due respect, whether or not you agree with them.



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ISSUE

choosing 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 the doctor-patient relationship as more of a partnership, where both doctor and patient contribute to the decision-making process. Some prefer to make decisions and use a doctor primarily as a consultant. This relationship style will require diplomacy on the part of the patient; many doctors have not adjusted to the role of consultant.

None of these relationship styles is right or wrong, but they are all different choices that make different demands upon the relationship. It is important that you let your doctor know which style you prefer. Realize that as time passes and you become more familiar with HIV/AIDS and as you experience different health challenges, the doctor-patient relationship style that works best for you may change.

ISSUE

3

learning
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 overwhelming. In fact, the education process can begin right at home. Many websites, hotlines and community organizations are dedicated to answering questions about HIV/AIDS—from transmission to treatment.

If you're comfortable with some of the basics of HIV disease and treatment, you will be better able to ask your doctor specific questions during your visit. Do realize that you can't learn everything at once, so concentrate on the information that is most important to your health right now. Remember that while self-learning is great, it should not be a substitute for using your doctor as a source of information.

ISSUE

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preparing for
appointments

Come prepared for appointments. Both the patient and doctor benefit 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 symptoms and side effects you've been experiencing, the changes in meds (including complementary therapies), the missed doses, and any questions that come up between visits in a medical journal. Use this record to update your doctor at the start of the visit.

The limited time in the doctor's office should be used to focus on the most critical issues, rather than everything that comes to mind. Preparation might include bringing along treatment literature to be discussed in the visit. This allows the doctor to know your sources of information and how to evaluate them.

Show your written list of questions to your doctor at the beginning of the visit, so they can be incorporated into the overall visit. Don't wait until the end of the visit to ask questions, as there may not be enough time to address them all.

ISSUE

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getting
emotional news

Be prepared for the emotional content of the visit. Most doctors are sensitive, caring people who respond emotionally to their patients. They have seen an enormous amount of suffering. When fear is written all over a patient's face, no one should fault the doctor for using the "kid gloves" gentle treatment, perhaps even shielding the patients temporarily from the harshest implications.

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.

In any case, there is only so much emotional support a doctor can give in the short time allotted for most visits. Plan in advance to make use of other support resources.

for the doctor ...

Just as there are things patients can do to make the relationship more cooperative, there are things the doctor can do as well. The following suggestions are intended to help doctors deal with patients whose expectations may have been changed by the epidemic

or personal education about treatments. Despite the dedication most doctors feel, nothing has fully prepared either doctor or patient for the crisis they now face together. Here are a few helpful hints.



1 supporting your patients' interests in their healthcare

Support patient interest in monitoring and treatment. While not every potential treatment is worthy of support, every patient's opinions and health are. The more uncertainties a given treatment raises, the more important it is that the doctor monitor its use. Patients will often be willing to follow a doctor's best-supported recommendations if the doctor is willing to monitor the patient's other choices simultaneously.

Some doctors express fear that monitoring implies agreement. When someone asks to be monitored in a

course of treatment, it doesn't imply agreement—only support for the patient's general 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. It is not common, after all, for a doctor to deny care to a patient involved in recreational drug use or abuse, so there's no basis for refusing to monitor use of a drug taken in the interests of healing.

2 being flexible with your responses

Recognize that the uncertainties of the epidemic demand a flexible response. The expectation that patients will passively follow orders simply won't work with everyone, certainly not when doctors have no hard answers for many questions.

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 the healing process.

TOPIC

3

describing both sides of the issues

Be prepared to describe both sides of the medical issues that confront patients, and do not feel insulted if the patient chooses a different option than you recommend. Doctors have always known that there are two or more viewpoints on most issues. In the past, after making their own synthesis of the pros and cons, doctors were often quick to recommend their preferred solutions for their patients.

Today, many people take a strong role in the decision-making process. Of course, such empowerment doesn't automatically make the 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.

TOPIC

4

responding medically

In most instances, patients will use a treatment anyway if determined to do so and the doctor is unable to sway them against it. Refusal to monitor diminishes a patient's confidence and may increase the risk of harm.

Respond in a medical fashion to the uncertainties of unapproved treatment or treatment strategy. Perhaps this means more frequent visits, additional diagnostic tests, or more cautious reading of laboratory markers. Added expense may be the price required of the patient. Often, the doctor can take the lead in this regard, and the patient must be prepared to heed the outcome of the monitoring process.

TOPIC

5

not pushing your patient

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

For example, taking pills several times a day is a constant reminder of HIV. Disclosure is often an issue: if the patient's supervisor and co-workers are unaware of his/her HIV status, the patient may be reluctant to begin a treatment that must be taken during work.

if disagreements occur ...

When disagreements occur despite a cooperative relationship, it's difficult to know what to do. In consideration of active disease states, such as a bout of PCP, the doctor's expertise must lead the way because the course of treatment is better known and, in many instances, there is a degree of medical consensus. 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. In these cases, a second opinion should always be

sought from doctors in the leading AIDS hospitals, and doctors can be referred to the WARMLine.

When considering treatment of HIV infection and immune deficiency, disagreements about treatments often occur in a very different context. When patients may 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 he or she is practicing sound medicine, yet

the patient may feel s/he cannot compromise on a treatment option s/he considers essential to his or her health or survival. In this instance, both must strive to listen and understand the other's views. Rather than butting heads, both must seek to find ways to satisfy the other's needs and concerns. Both must begin by acknowledging a common goal of keeping the patient alive and maintaining health. Sometimes, it's possible to find new alternatives 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?"



Similarly, 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?"

While this type of dialogue is very productive, it won't overcome every obstacle. Patients cannot expect doctors to heartily support the use of remedies for which there is no supporting evidence of any kind. Nor can patients realistically expect doctors to give the same credence to highly experimental approaches as they would to better proven therapies. And doctors can't realistically expect patients to "wait and see" indefinitely while the research proceeds.

At the very least, both parties must take the time to fully understand each other's beliefs and the reasoning behind them. Simple confrontation over opposing conclusions is unproductive for both.

If, in the final analysis, the doctor cannot feel comfortable cooperating with unapproved or unorthodox treatment strategies, and the patient is equally firm in his or her convictions, then doctors and patient must question whether it's possible to con-

tinue having a mutually acceptable relationship. In many instances, it is possible to maintain the relationship while disagreeing and continuing to communicate over the differences. The option of changing doctors should be reached only as a last resort, and only when it is clear that the parties cannot accept each other's approach to the relationship. Each of us must ultimately find the combination of patient + doctor + approach that makes a cooperative relationship possible.