

MAKING DECISIONS ABOUT THERAPIES



issues to consider when developing your personal treatment plan

Making decisions about treating HIV can sometimes feel overwhelming. Developing a personal plan to help you think about, plan for and make treatment decisions can help. Whether considering pharmaceutical drugs or complementary therapies, it's important that your plan is one you're comfortable with and feel empowered by. This discussion paper focuses on issues to consider when developing your treatment decision-making plan.



A PUBLICATION FROM

PROJECT
inform

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

MAY 2004

WHAT'S INSIDE

The basis for making a decision: 2; Choosing a doctor: 3; Learn about HIV disease and your treatment options: 4-5; Information, consider the source: 5; Once you've made a treatment decision, consider ... : 6-7; Choosing the best time to start: 6; The power of the mind: 7; Some final words on making decisions: 8.

the basis for making decisions

Regardless of the therapy you consider, the same basic principals for making decisions can be used, including:

■ **CHOOSE AN EXPERIENCED PROVIDER.**

Choose a healthcare provider or doctor who is experienced with the treatment of HIV disease and with the types of therapy you are interested in pursuing.

■ **DEVELOP THE RIGHT RELATIONSHIP.**

Learn about the different types of doctor/patient relationships; determine how you want to interact with your doctor and develop the right relationship. Discuss your decision-making process style of relationship with your healthcare provider.



■ **GET INFORMED!** Learn about your health condition(s) and possible treatment options:

- What does the research show? Consider sources of information that give you objective information about various treatments and strategies. Project Inform offers this kind of information free-of-charge through a toll-free hotline, printed documents, public meetings and website.
- Explore, examine and challenge your beliefs about therapy.
- What has been the experience of friends and people you trust?
- Does your healthcare provider or doctor have opinions about particular drugs, combinations, or strategies? What does your provider recommend and why?

■ **TALK BEFORE YOU START.** Talk to your doctor before you start therapy (regardless of what that therapy is) and come to mutual agreements about:

- When to start therapy.
- What overall treatment strategy you will pursue.
- How to monitor whether or not a therapy is working.
- How to monitor (and manage) for side effects of therapy.
- When to switch therapy and how you plan to sequence the available therapies.
- Under what conditions you might choose to stop therapy.

Choosing a doctor

Finding a doctor who has experience treating people living with HIV is very important. Studies have shown that people with HIV who see doctors experienced in treating people with HIV are more likely to be long-term survivors than those with inexperienced doctors.

According to these studies, an HIV-experienced doctor is someone who has five or more people in their practice who are living with HIV, though in general, the more experience and patients the physician has, the better. Consider five a minimum. Experienced doctors will usually have more skill in prescribing and monitoring anti-HIV drugs wisely, and are also more likely to wisely prescribed preventative therapies. Because women face unique gynecological and pregnancy concerns, choosing an experienced gynecologist and/or obstetrician is also important.

In some cases, choosing a highly HIV-experienced doctor is not possible. This is especially true in rural settings where HIV-positive people may be more isolated than in major cities. This does not mean that one need receive less than optimal care.

Even in the most rural settings, there is usually at least one healthcare provider who has worked with HIV-positive people. Some experience is better than none. However, it may mean that the patient and doctor need to be more diligent in learning about HIV, keeping up to date on the latest in treatment information and finding appropriate resources. Developing

an open and comfortable relationship will help this ongoing process.

Often, people living with HIV in such situations play an important role in keeping their doctors up to date by bringing them new information, reports from medical conferences and resources available from groups like Project Inform. While doctors may sometimes at first be inclined to reject information from anyone other than doctors, they often get over this prejudice when they realize that, at least in HIV disease, community groups and resources often have better access to information, and more time for reviewing it, than they do. Many physicians come to welcome the input their patients can bring them.

Finally, the general principal of choosing an HIV-experienced doctor applies to practitioners of alternative systems of healing as well, like tradi-



tional Chinese medicine, herbalists, acupuncturists and other holistic healers. If you have an interest in complimentary or alternative therapies, the healthcare provider should have experience in their use in HIV-positive people, not just experience with therapies themselves.

Some herbs and supplements, for example, can affect the way commonly used anti-HIV drugs are absorbed in the body, so knowledge of both types of therapy is critical. A doctor or healing practitioner who keeps up to date on literature about new discoveries in our understanding of HIV disease and who has experience treating people living with HIV is an important partner in your healthcare.

developing a relationship with your doctor

Working with your provider to develop a relationship that you both feel comfortable with is the next step. It's important to trust your own reactions when deciding whether this doctor is the right one for you. But you also may want to give the relationship some time to develop. It takes more than one visit for you and your doctor to get to know each other. For more information on developing a relationship with a doctor, call Project Inform's Hotline and request *Doctor/Patient Relationship*.



Get informed! Learn about HIV disease and ...

A key to participating in treatment decision making is to get informed about HIV disease, treatment options and overall strategies sooner rather than later. If a person waits too long before seeking medical care and has already come down with an opportunistic infection, there may be little time to learn about options since immediate treatment may be needed.

Whenever possible, people should get informed about treatment strategies and option well before it's time to start treatment. For more information about monitoring HIV disease, call Project Inform's Hotline and ask for *Day One*.

If you're healthy and not feeling like you need or want to start therapy immediately, it's still a good idea to learn about your treatment options and strategies and begin talking with your doctor about what to do and when to do it. Making those decisions before the problem is critical can diminish some of the fear that is often associated with starting any kind of therapy for the first time. Starting these discussions with your doctor is perhaps the best form of "early intervention" and will greatly increase the chances that you will avoid starting therapy either too early or too late.

What does the research show?

Getting informed and learning about HIV and your options and strategies may seem overwhelming at first. It's not easy for anyone. Sometimes it's hard to read about HIV disease and the information may sometimes seem like it's written in a foreign language ... at first!

One of the missions of Project Inform is to provide understandable information to people living with HIV. The staff at Project Inform spends hundreds of hours annually in medical libraries, attending medical conferences and analyzing studies to learn about the latest advances and what they mean. We try our best to put that information together in a way that people who aren't scientists or doctors can understand it.

Some people think of Project Inform as a sort of *Consumer Reports* on HIV treatments. Though we do everything we can to make it the best source, Project Inform is not the only place to get information about HIV treatments and strategies, however. There are several newsletters and sources of HIV information, each with its own special benefits.

For a list of references, call Project Inform's Hotline and ask for *Guide to HIV/AIDS Related Resources*. The Project Inform Hotline operates Monday through Saturday and volunteers are available to talk to you about treatment questions you might have and mail you information, free of charge.

Explore, examine and challenge your beliefs about therapy.

Most people have concerns and fears about starting therapies, be they anti-HIV therapies or complementary herbal therapies. Learning about that therapy can sometimes lessen your concerns and help you decide whether it's right for you. Consider how it might impact your lifestyle and whether any dietary restrictions may be a problem. Learn about potential side effects and prepare for them, should they occur.

In exploring your beliefs about a therapy, you might find that you have come to a conclusion based on personal fears or rumors. Grounding yourself in knowledge, rather than fears, and challenging where possibly unfounded beliefs might be clouding decision-making is critical. Challenging your beliefs and seeking their roots is important. Personal experience and knowledge about a given therapy is far better information to inform decision-making than fears or conjecture.

With that said, however, if you truly believe that a particular approach may be more harmful to you than its potential benefits, you might be better off considering another option. You can always revisit that decision at a later time. Don't reject what you believe about therapy when it comes to making your decision—it should weigh in with other considerations but those beliefs should be explored, examined and challenged.

your treatment options!

What has been the experience of friends and people you trust?

Learning about other people's experience with a particular therapy or treatment-decision plan can help inform your own decisions. Talk to friends, people in support groups and others who are experiencing similar health conditions. Ask them about what kinds of treatments they're using. Why did they choose those treatments and what have their experiences been?

But great caution should also be exercised when using the experiences of others as a source of information. The fewer people you ask, the less reliable that information will be. Remember, what works for one person won't always work for you. Just because someone you know had a bad experience—or a good one—with a particular therapy doesn't mean that you will.

There are many factors beyond our control that affect how each of us responds to a particular treatment strategy. The personal experiences of others should be only a piece of the pie as you gather information. The most reliable picture of a therapy's actions will usually come from well-designed studies, but even these cannot predict how you will respond.

Does your healthcare provider have an opinion about the therapy option or strategy you're considering? If so, what is it and what is it based on? Ask your doctor about his or her experience with or opinions about the therapies and strategies you are considering. Does the doctor have advice about whether a particular therapy might be helpful for you? Has the doctor followed other people using the same approach? Talk to your doctor about the different options you are hearing about and the information reported in sources such as newsletters.

If you find that your doctor likes to put everyone on the same treatment, ask why. HIV treatment information and guidelines are not meant to be a cookbook, to be used the same way with everyone. Ask how you might develop a treatment strategy that takes your personal needs and concerns in mind. For more information on developing a relationship with your doctor, call Project Inform's Hotline and ask for *Building a Doctor/Patient Relationship*.

You can't make an informed decision about treatments—regardless of what type of treatment you're considering—if you're not informed about all your options. Get as much information as possible, from a variety of credible sources that you trust. Learn about HIV and treatment options. It's better to make an informed decision that you feel very comfortable with than a hasty one.

Information: consider the source

As you're learning about HIV and possible treatment approaches, be aware of false and misleading medical information and claims about therapies. When you're reading about HIV and HIV treatments, consider the source of the information.

Pharmaceutical companies that market HIV therapies have an interest in selling products and may not always provide a balanced view of their products. Pharmaceutical company advertising should be viewed with skepticism.

Increasingly, community and physician

forums and educational materials are being paid for with pharmaceutical money. Just because a pharmaceutical company supports an educational forum doesn't automatically mean that the information isn't useful; but you have a right to ask questions about the speaker's involvement with the company—like whether or not they received money from the company. Consider how that might influence their ability to provide unbiased information.

There are many people who, under the guise of alternative/complementary ther-

apies, propose to have "cures" for HIV, cancer and many other life-threatening diseases. Often they will claim that they have a therapy that is being suppressed, shrouded in controversy and government conspiracy. In reality the vast majority of all such claims are outright fraud. In nearly all cases, individuals prey on the vulnerability and hopes of people who are frightened and make a pretty penny in doing so. For more information, read Project Inform's *How To Identify AIDS Fraud*.



Once you've made a treatment decision, consider ...

When to start?

Starting any therapy can cause anxiety.

There is no one proven "right" time to start anti-HIV therapy, for example, for everyone. There are differing opinions about starting therapy early in the course of HIV infection vs. later. Either choice has possible long-term consequences.

In general, current thinking in the US and Europe is leaning in favor of delaying treatment until there has been a significant decline on CD4+ cell counts. The most recent research shows that this loss can usually be recovered when people start treatment.

In contrast, starting treatment very early, before significant decline of CD4+

cell counts, can force people to begin using up the limited time that each drug will work, earlier than necessary. It may also lead to an earlier risk of developing both drug side effects and drug resistance. These cannot always be corrected so easily. (For more information, call Project Inform's Hotline and ask for *Anti-HIV Therapy Strategies*).

While there are instances where using anti-HIV therapies have clearly been shown to be beneficial, when to start therapy remains an individual decision. Most important, it doesn't make sense to start therapy until you are ready and committed to it.

Making a decision about what criteria you will use as a basis for starting therapy (of any kind, anti-HIV therapy, herbal therapy, etc.) puts the

decision and control over using therapy in your hands. Making decisions about complementary therapies are often more difficult and complex because there's a lack of information from studies to help guide decision-making. (Read Project Inform's publication entitled *Herbs, Supplements and HIV*.)

For example, you might decide to start an herbal therapy right now, regardless of your CD4+ cell count, your viral load and your overall general health. Or, you might decide to start anti-HIV therapy if your CD4+ cell count has a decreasing trend to below 350 and/or your viral load continues to rise above 50,000 and/or you begin to experience symptoms associated with HIV disease. Deciding on your own criteria, with the guidance of your doctor, lets you be in control of your treatment decisions.

How to monitor whether therapy is working for you?

Before you start any kind of therapy, it's important to have realistic expectations around what the therapy will do and to determine how you will monitor to decide if it is working. In terms of anti-HIV therapy, typically you will look for decreases in viral levels (HIV RNA), increases in measure of immune health (CD4+ cell counts) and improvements in your overall general health.

Determining whether a complementary therapy is working, when it doesn't have any direct anti-HIV activity, can be difficult. How will you decide if that therapy is working for you? How will you determine if it's worth your money and the risk of potential side effects? (Remember, just because something is available over-the-counter doesn't mean that there are no risks associated with using it!)

choosing the best time to start

The following factors can help you and your provider when choosing the best time for *YOU* to start therapy:

- **CD4+ TREND** CD4+ cell count trends (consistently decreasing CD4+ cell counts, over time, indicate immune health is declining); the most recent guidelines suggest that anti-HIV treatment should be encouraged when the counts fall consistently below 350 (some guidelines recommend waiting until 200);
- **VIRAL LOAD TREND** Trends in viral load (consistently increasing HIV RNA levels, overtime, indicate that the virus is becoming more active; this may either cause more damage to the immune system or might be a signal that the immune system is failing already);
- **GENERAL HEALTH** Overall general health and the presence or absence of minor symptoms; and
- **YOUR READINESS TO START:** You should begin treatment when you're ready for the demands of treatment. Without a strong basic commitment, you're likely develop poor adherence to your therapy.

Talk to your doctor and work together to develop realistic ways of determining if the therapy you want to start is working. If after some agreed upon period of time you are not achieving your goals, agree to revisit the use of the therapy approach you are trying. Have these discussions before you start taking the therapy.

How to monitor for (and manage) potential side effects?

Before you start a given therapy, learn about potential side effects, how to monitor for them and how to manage them. Recognize that there is almost no such thing as a drug that doesn't have side effects. Even aspirin can have potentially fatal side effects if used constantly. Moreover, despite the claims of advertisers, many herbs and supplements can have side effects, some of them serious.

Many people who start or switch to a new anti-HIV therapy will experience some side effects or symptoms. These may include headache, nausea, diarrhea and tension. Often these types of effects go away within four to six weeks. It's unclear how much of these types of side effects are associated with the therapies and the body adjusting to the medication and how much they are due to stress and anxiety associated with being on therapy.

Not everyone experiences these effects. Some therapies have potentially life-threatening side effects that occur very rarely. Being aware of early signs of these side effects and what to do if they arise is important. Moreover, if you have a very clear understanding of what the potential side effects of a given therapy are, you can prepare to manage them should they arise. (Read Project Inform's *Drug Side Effects Chart*.)

Talking with your doctor about side effect before you start a therapy allows you to have realistic expectations and come up with criteria around when you might consider stopping or switching therapies based on side effects concerns. You will be able to more fully participate in monitoring for side effects and identifying early signs of side effects and possibly intervene before they become a problem.

When to switch therapy and what you might switch to (if necessary)? In developing a long-term strategy for treating HIV disease and managing your health, it's a good idea to think ahead and be prepared. Fortunately, many people are making strategic decisions about therapy that look years into the future instead of days or weeks. To do this, it requires a person to think even more seriously about how the therapies they start today will affect the options available to them later.

Consider what you might do in terms of treatment if your first option doesn't work, causes too many side effects or for other reasons doesn't fit with your lifestyle. Again, being prepared and thinking about this before

the need for a change arises gives you time to learn even more about your next choice and takes some of the anxiety away from facing a situation where you might need to consider switching to a new therapy regimen.

When to stop?

For the same reasons that it's important to decide when to start therapy, it's also important to consider when or if it's ever appropriate for you to stop, for any length of time. How do you determine when a given therapy or approach just isn't working for you? At what point do you say that the cost or potential risks associated with using the therapy isn't worth the potential benefits of staying on it? Working with your doctor before you start therapy to develop some criteria around this, that you both feel comfortable with, is important.

In all of these areas you might come to decisions and agreements that change overtime. Your expectations of a given therapy may change as you learn more about it and as new information becomes available. Changing your mind and re-thinking your strategies and approach is a healthy and normal part of evolving a decision-making process.

the power of the mind

Studies show that more than one-third of people who receive a placebo (a sugar pill with no medicinal value) receive some of the benefits as people taking a real drug. This is because they believe that what they are taking is good for them.

If you believe that a particular therapy is "poison," chances are greater that you'll experience side effects and won't do as well on that therapy. If you believe that something you're doing is good for you, chances are greater that you'll experience benefit and have an overall better experience with the therapy (like fewer side effects). Do not underestimate the power of the mind in health and healing. It can really make a difference!

some final words on making decisions

For most people, the idea of having a decision-making process around healthcare is a new concept. The vast majority of us have done as we we're told when it comes to healthcare decisions. If the doctor prescribed a pill, we simply took it. (Or we didn't, but we probably didn't tell the doctor!)

Participating with your doctor—in choosing therapies and monitoring for side effects and the effectiveness of a therapy—is a new experience for most people. It's not something that all doctors feel comfortable with nor is it something that many people immediately feel comfortable with either.

Studies have shown, however, that people who participate in their healthcare decisions and form a partnership with an HIV-experienced doctor, tend to do better.

While information about HIV and the various options for managing HIV disease can at times seem overwhelming, developing a decision-making process around treatment is not a mystery. In fact, the general principals of decision-making around your health and treatment choices are the same principals that you probably already apply in many areas of your life.

In essence,

- consider how you feel (ultimately how do I feel about all this?);
- consult people that you trust (what do my friends think about it?); and
- consider the facts (what does the research show?).

Once you've decided what you want to do, next decide:

- when you're going to do it (when to start),
- how you're going to know if it's the right thing (how to monitor for benefit), and
- how you're going to know if it's hurting you (how to monitor for side effects).

Moreover, plan ahead:

- think about what you might do if it doesn't work out (when to switch), and
 - under what circumstances you might just decide not to do it anymore (when to stop).
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This type of decision-making process can be applied to any kind of therapy approach, be it pharmaceutical drugs, complementary therapy or alternative systems of healing. Participating as a full partner in your treatment decisions offers many

benefits, but it also takes effort on your part. The likelihood of benefiting from therapy increases and the likelihood of experiencing serious side effects from therapy decreases when you're involved in decision-making and monitoring.

