

# HEALTH CARE PARTICIPATION

## Skills to Be Taught

- Learning to Be a Positive Participant in Health Care
- Increasing Patient “IQ”
- Improving Skills for Establishing and Maintaining a Partnership with Health Care Providers
- Knowing the Consequences of Non-adherence to Medication Regimens
- Improving Strategies for Identifying and Overcoming Obstacles to Adherence
- Learning Memory Aids for Improving Adherence
- Becoming Knowledgeable about HIV and Hepatitis B and C



## COUNSELOR TOOL BOX

### Multi-modal Presentation of Material:

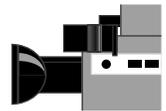
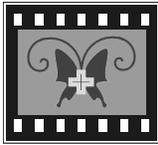
**Verbal** Didactic presentation of material  
Questioning  
Group discussion

**Visual** Visual presentation of major points using slides  
Group responses written on flipchart by counselor  
Written/Pictorial handouts provided in Client Workbook  
Video: "Long-term Survivors"

**Experiential** Demonstration: patient/doctor role-plays  
Medication adherence game  
Post-group quiz  
Stress management/relaxation technique

**Materials** Flipchart and markers  
Overhead projector and slides  
Audio tape player and relaxation tape  
TV, VRC, and video cued to "Long-term Survivors" segment  
Clock/timer  
Pens/pencils  
Prizes  
"Loaner" Client Workbooks  
Handouts:  
Group agenda  
Group quiz  
Characteristics of Long-term Survivors of HIV  
The Decisional Balance Sheet  
Medical Information Sheet (double-sided)  
Medication Adherence Game Worksheet (double-sided)  
Other Infectious Disease Handouts:  
Medical Language Statement  
HIV / AIDS (double-sided)  
Information about Hepatitis (double-sided)  
Prevent Hepatitis B: Get Vaccinated (double-sided)  
Hepatitis C Prevention (double-sided)  
STDs and Infectious Disease (double-sided)  
Endocarditis (double-sided)  
Cirrhosis of the Liver (double-sided)  
Cellulitis (double-sided)  
Osteomyelitis (double-sided)  
Certificate of Achievement (as warranted)

**Reminders** Ensure that all material on quiz is covered well during group.  
Quiz material is indicated by **QUIZ ITEM** in the text.  
Instructions to counselors are provided in **this typeface.**



**AGENDA**

(Two-hour group: Adjust times based on beginning time)

- 0:00 **Begin Group** (5 mins)  
Introductions – Rules – Time keeper assignment
- 0:05 **Introduction to Topic:** “Participating Positively in Your Health Care: Know Your Patient IQ” (5 mins)
- 0:10 **Being Informed about HIV** (5 mins)
- 0:15 **Informing Health Care Provider of Problems and Concerns** (5 mins)
- 0:20 **Asking Questions** (5 mins)
- 0:25 **Developing Communications Skills** (10 mins)
- 0:35 **Demonstration:** Patient/doctor role-plays (5 mins)
- 0:40 **Video:** Long-term survivors (10 mins)
- 0:50 **Discussion** (5 mins)
- 0:55 BREAK** (10 mins)
- 1:05 **Review** (5 mins)
- 1:10 **Consequences of Non-adherence** (5 mins)
- 1:15 **Developing Adherence Skills** (10 mins)
- 1:25 **Medication Adherence Game** (20 mins)
- 1:45 **Quiz and Feedback** (5 mins)
- 1:50 **Relaxation Tape** (10 mins)
- 2:00 **End**

BEGINNING OF EVERY GROUP (5 mins)

- Group members and counselors introduce themselves and welcome new members.
- Group rules are reviewed.

Visual

**HHRP<sup>+</sup>**  
**GROUP RULES RESPECT**

**R***elaxation* (complete quiet...no talking, shuffling of papers, or walking around during relaxation exercise)

**E***ating* (No eating during group)

**S***ober* (don't come to group high)

**P***unctuality* (come to group on time)

**E***veryone can't talk at once* (no crosstalk)

**C***onfidentiality* (what's said in group, stays in group)

**T***eamwork* (group members work together towards recovery)

Show Slide 6.1

- Copy of agenda for today's group is distributed to group members.
- Ask for a volunteer to serve as time-keeper (to keep group on track and on time).
- Announcement of any graduates from the group today.
- Presentation of Certificate of Achievement to those who complete in good standing.

Verbal

Counselor provides introduction to today's topic. (5 mins)

Being told that you are infected with HIV is a life-altering event in many ways. What we will be talking about today is how HIV-infection instantaneously provides you with an additional role to play. It makes you “**a patient**” in the health care system. How you handle this role as “a patient” could affect both the length and quality of your life. Today we are going to talk about this role, but we will redefine it. The word patient comes from the Latin for “one who suffers.” The word brings to mind someone who is helpless, suffering in silence, and passively receiving care from others.

Today, rather than talking about how you can be “a good patient”—a passive recipient of health care, suffering in silence, we will use the **HHRP+** program’s definition of HIV-positive patient as *someone who is a positive participant* in their own health care.

**PATIENT**

WEBSTER'S DEFINITION OF PATIENT:  
*(from the Latin)*  
**ONE WHO SUFFERS**

HHRP+ DEFINITION OF HIV-POSITIVE PATIENT:  
**A "POSITIVE PARTICIPANT"  
IN HEALTH CARE**

Show Slide 6.2

Visual

Being a positive participant involves having the courage to take responsibility for your health. You cannot change the fact that you are infected with HIV. However, you do have control over whether you cope with HIV in a way that improves the quality and quantity of your life, or in a way that both shortens your life and deteriorates the quality of your life and the lives of your loved ones. Being a positive participant in your health care means not only that you are willing to take responsibility for your own health, but also that you are willing and able to form a partnership with your health care provider, such that you participate actively and positively in your treatment plan. So, how do you become a positive participant in your own health care.

*Do you know your Patient IQ?*

**Inform &  
Question**

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Visual

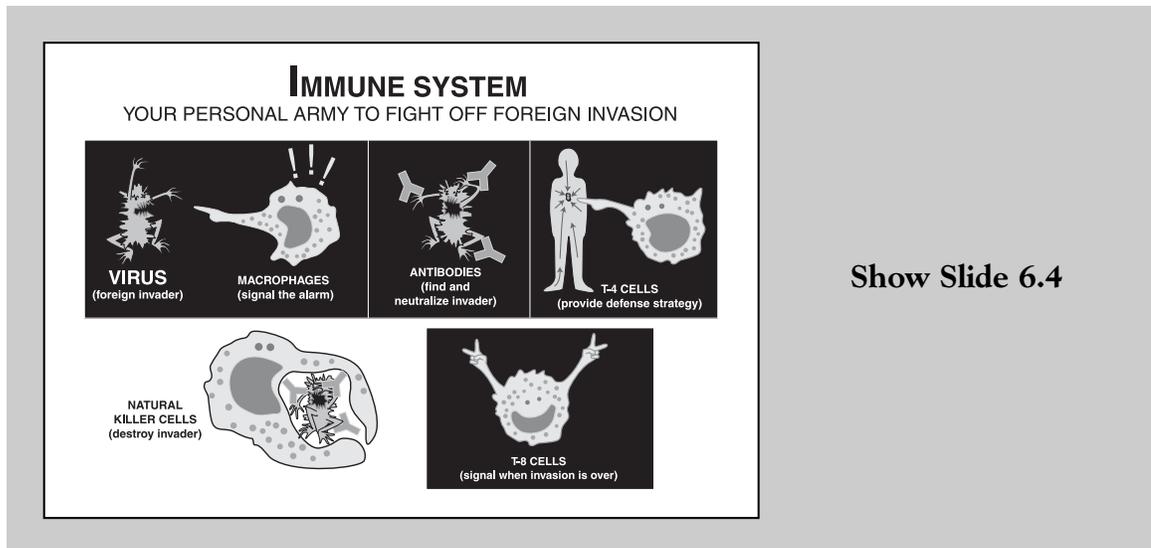
**Answer:** As this slide shows, the first thing you need is a high Patient IQ. IQ here stands for **Inform and Question**. You need to **Inform** yourself and your health care provider and ask **Questions**.

**We'll begin with how to inform yourself:** (5 mins)

In order to actively participate in your health care, you need to understand the basics of HIV and what is going on in your body. Read about your medical condition. There are many books and articles on HIV and addiction. As some of these books and articles are technical, don't hesitate to ask questions about anything you read that you do not understand. We'll go over some of the basics now.

**Be informed about your immune system:**

Visual



Show Slide 6.4

The immune system is extremely complex. This slide presents a highly simplified representation of your immune system, but it provides a way to conceptualize what is going on in your body.

The function of your immune system is to identify and attack invaders, such as HIV. You can think of your immune system as your own private army that protects you against germs—microorganisms and viruses that are around us, and in us, all the time.

**macrophages:** These cells signal the presence of an invader. They also serve as the clean up crew when the battle is over.

**B-cells:** B-cells circulate throughout the body and when they detect the invader they make antibodies to attach to it.

**antibodies:** Antibodies then seek out and attempt to neutralize these foreign substances or microbes. They also signal other components of the immune system into battle.

**T-cells:**

**T-4.** These are commonly called “helper” t-cells. You could think of these cells as the “strategic command or war office.” They orchestrate the actions of the other immune cells and thus play a major role in defending the body against infection. HIV targets T-helper cells, which is why people with AIDS eventually lose their capacity to fight infections and some cancers.

**Natural Killer (NK).** These cells attach to and destroy the invader.

**T-8.** These are commonly called “suppressor” cells. However, not only do they signal that the invasion is over by suppressing other immune cells, they also play a role in attacking and destroying the invader.

So when you were told you are HIV-positive, this means that antibodies were found in your blood that indicated you have been infected with HIV. Once infected, HIV replicates in your body rapidly. Every day it produces ten billion copies of itself; one in every 10,000 of these copies is a mutation, which is a copy of the virus that is not exactly the same as the original. These mutations can lead to the development of different viral strains within the same person. Again, the virus attacks the T-cells—those cells that would normally orchestrate the attack against HIV, but also the attack against other viruses and infections. The higher your viral load (the more copies of the virus you have) the greater the threat to your immune system. The virus so weakens your immune system that it is unable to protect you from other invasions. You’ve probably all had blood tests to determine your CD4 count and your viral load. Your CD4 count is the number of T “helper” cells in your body and indicates the strength of your immune system. Your viral load is the amount of HIV virus you have in your blood. The higher this number the faster you are likely to get sick. The goal of HIV medications is to reduce your viral load to a level that it can no longer be detected in your blood. It is like having two armies at war. You want to keep your defense (immune system) strong and the number of soldiers in this army high, while reducing or eliminating the number of invading soldiers. It is important, however, that you do not judge how well you are doing strictly by your CD4 count, as it can fluctuate. Some patients get very caught up with this number, and can get discouraged if the numbers go down. You should remember that it is just one indicator of a very complex process.

**Be informed about opportunistic infections:**

The term “opportunistic infection” comes from the word “opportunity.” When the immune system is weakened by the presence of HIV, it has difficulty fighting off other infections. This weakened state provides an opportunity for other infections to “move in without a fight.” When a person progresses to AIDS the immune system is so compromised that these opportunistic infections can become life-threatening. Therefore, it is very important for you to keep your medical appointments because there are ways for you to protect yourself against opportunistic infections.

**Be informed about the consequences of continued drug use:**

We’ll focus on cocaine use for purposes of this discussion; however, remember that any illicit drug use has its own set of negative consequences. Cocaine is harmful for everyone, but it is especially harmful for individuals who are HIV positive because cocaine use can speed up progression of HIV.

**QUIZ ITEM**

**Visual**

**BE SMART – STAY HEALTHY – DON'T USE COCAINE**

**COCAINE can:**

- weaken your immune system
- increase your viral load
- reduce blood flow to your brain
- cause cardiac arrest
- increase blood pressure
- lead to weight loss
- interfere with sleep
- change your body temperature and lead to convulsions
- lead to sexual impotency
- damage nasal tissue, lungs, veins, and heart
- increase depression and isolation
- cause hallucinations, paranoia, or coke bugs
- impair your judgment and lead to risky behavior
- **KILL YOU**

**Inform**  
yourself about  
effect of drug use  
on health

**Show Slide 6.5**

As shown in this slide, cocaine use has many serious health consequences:

1. Cocaine weakens the immune system, reducing your CD4 count. As we just discussed, it is imperative that you keep your immune system strong so that it can fight off opportunistic infections.
2. Cocaine may cause HIV to replicate faster. In a test tube, HIV has been found to replicate faster in a solution containing cocaine than it does in a cocaine-free environment.
3. Cocaine reduces blood flow to the brain; this can create all kinds of problems, such as memory problems, problems with attention, anxiety, anger,

and so forth. You may think it is the HIV causing these problems and feel like giving up, when in fact it may be the use of cocaine that is causing these problems or making HIV-related symptoms much worse.

4. Cocaine increases your heart rate, and can cause cardiac arrest.
5. Cocaine can increase blood pressure and lead to a stroke.
6. Cocaine can suppress appetite which leads to weight loss. This could be confused with weight loss due to HIV progression.
7. Cocaine interferes with sleep patterns; you may feel as if you have a lot of energy and need little sleep, but that is an illusion, causing your body to work harder, and get weaker at a time when it needs to keep all its strength.
8. Cocaine can change your body temperature and lead to convulsions.
9. Cocaine can make you sexually impotent; although many people report that it makes them more sexual at first, it eventually creates impotence so that you cannot enjoy sexual feelings. You may then misattribute sexual dysfunction as a medication side-effect.
10. If you snort cocaine, you risk damage to nasal tissue and to the lungs; if you smoke cocaine, you damage your lungs, if you inject cocaine, you damage your veins and your heart. There is absolutely no way to use cocaine without truly **devastating consequences** to your health.
11. Cocaine can bring on depression and isolation. These are two things that can lead to more drug use and can worsen HIV-related depression and isolation.
12. Cocaine can cause hallucinations, paranoia, “coke bugs.”
13. Cocaine can impair your judgment and lead to behaviors that place your health and the health of others at risk. When you are using cocaine it is difficult to make good choices about your health. Your focus may be on having a good time in that moment, and not on getting to your medical appointments or on taking your prescribed medications, or on eating or sleeping well. As stated in the beginning, an informed person makes the best choices; however, an informed person can still make poor choices if he or she is using cocaine.

The bottom line is that cocaine can kill you. Be smart. Show that you have a high patient IQ and inform yourself about the danger of drug use. The good news is that if you stop using cocaine, you may not only stop things from getting worse, you may also help things get better. Studies have shown that cognitive abilities (such as memory and concentration) actually improve when you stop using cocaine. Your CD4 count may also increase if you stop

using cocaine. So you do have control—participate positively in your health care, keep yourself informed, and take the appropriate steps to maintain your health.

### **Inform your health care provider:**

To have a high Patient IQ you not only need to be informed about HIV, you also need to inform your health care provider of your problems and concerns as they arise.

## Visual

**I**nform your health care provider of:

- your intention to actively participate in your treatment plan
- symptoms experienced and side effects of medication
- response to treatment
- allergies
- medications prescribed
- street drugs used
- use of alternative/complementary therapies

KEEP YOUR MEDICAL INFORMATION UPDATED  
AND READILY AVAILABLE

Show Slide 6.6

As shown in this slide, you should:

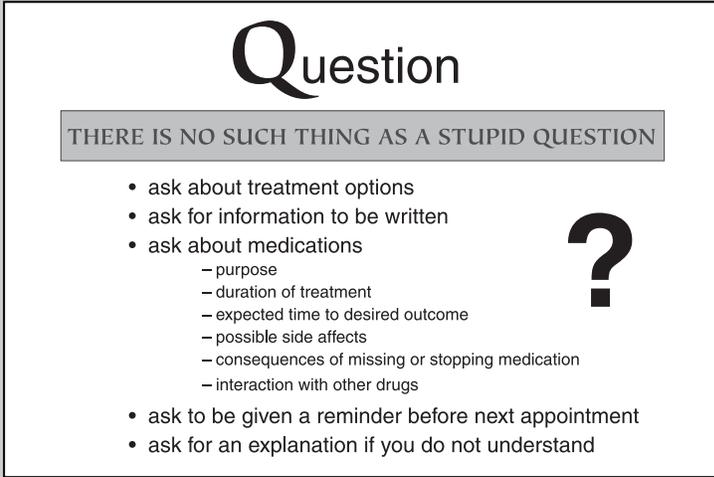
- Inform your health care provider that you plan to actively participate in your treatment plan and that you want to be kept informed of your status and your options at each stage in your treatment.
- Inform your health care provider of symptoms or side-effects of medication. In fact, if you experience any side-effects, the first thing you should do is inform your health care provider. **QUIZ ITEM**
- Inform your health care provider of your response to treatment recommendations—provide your doctor with feedback about how you think the treatment is going.
- Inform your health care provider of allergies.
- Inform your health care provider of any other medications you are taking.
- Inform your health care provider of any street drugs you are using. Because there is the possibility of adverse interactions between different drugs, your health care provider has to know **every** substance you take, including alcohol and street drugs.
- Inform your health care provider of any "alternative" or "complementary" therapies you are getting (such as acupuncture or herbal remedies).

Remember, these are complementary, not “alternative.” That means that if you decide to use them, you should use them in addition to your traditional medical treatment, not in its place, and you should inform your health care providers as to what kinds of “adjunctive” treatments you are engaged in, in case there are any adverse interactions.

Always keep your medical information updated and readily available.

### The Q in Patient IQ stands for QUESTION.

You should never be embarrassed to ask questions. Remember the only stupid question is the one that wasn't asked. You have a right to know what some one else is suggesting you do with your own body.



The slide features the word "Question" in a large, stylized font at the top. Below it, a grey box contains the text "THERE IS NO SUCH THING AS A STUPID QUESTION". To the right of a list of questions is a large black question mark. The list includes: ask about treatment options; ask for information to be written; ask about medications (with sub-points: purpose, duration of treatment, expected time to desired outcome, possible side effects, consequences of missing or stopping medication, interaction with other drugs); ask to be given a reminder before next appointment; and ask for an explanation if you do not understand.

**Visual**

**Show Slide 6.7**

So, as the slide shows, to have a high Patient IQ, you should:

1. Ask about treatment options.
2. Ask for information to be written. **QUIZ ITEM** It is easy to forget what you are told in a doctor's office. If you have it written down you will be able to read it over later.
3. If you are being prescribed medications, ask:
  - What is the specific purpose of the medication?
  - How long will I need to continue taking the medication? Sometimes you may feel just fine, but still need to take the full-course of treatment. For example, if you test positive for TB, you will probably be prescribed a medication that must be taken for a full year. In the “addict” role, you are probably used to self-medicating—stopping and

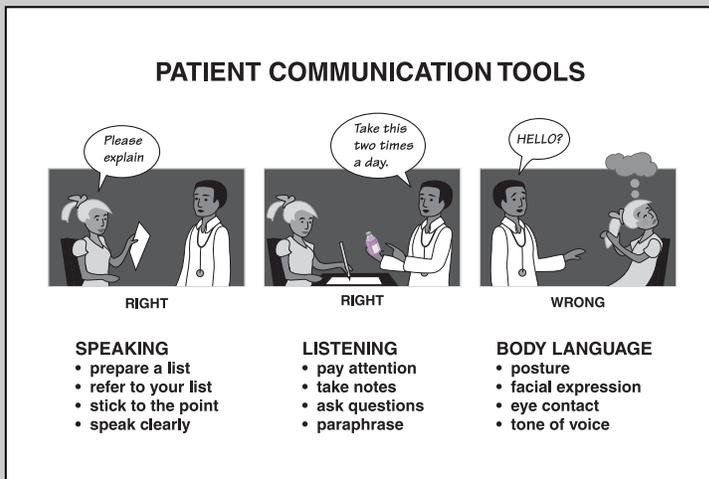
starting drugs based on the immediate effect. The medications that you will be prescribed by your doctor cannot be used that way. In your role as “patient,” you need to take all your prescribed medications at the prescribed dose and for the recommended length of time. We’ll talk more about this after the break.

- How long before I can expect to see some positive benefit? Knowing this may motivate you to continue and may decrease your chances of becoming discouraged.
  - Are there any side-effects; how long might they last? Some side-effects diminish over time.
  - What are the consequences of missing doses or stopping the medication prematurely? Some medications cannot be missed or stopped abruptly.
  - Does the prescribed medication interact with any other drug, or food, nutritional supplement, or alcohol?
4. Ask to be provided with a reminder telephone call or card before your next appointment. When you do not show up for appointments and do not call to reschedule, the message you give to others is that you don't care about your own health or about your health care provider's time.
  5. Ask for an explanation for anything you do not understand.

**Verbal**

**Patient communication skills. (10 mins)**

It is clear that being a positive participant in your health care requires attending your health care appointments and demonstrating a high patient IQ—the ability to inform and question—both of which require good communication skills. Because interactions with your health care provider are time limited, you need a special set of communication skills to get your needs met in the allotted period of time, which is often quite short.



Show Slide 6.8

**1. When speaking:**

- Organize ahead of time what you want to say and prepare a list of issues you wish to raise and questions you wish to ask. **QUIZ ITEM**
- Refer to your list often while speaking to the health care provider.
- Stick to the point; time is very limited; don't digress.
- Speak clearly and sufficiently loudly.

**2. Listening well entails:**

- paying close attention.
- taking notes so that you don't forget, or asking for information to be written for you. **QUIZ ITEM**
- asking for clarification or for something to be repeated.
- paraphrasing what was said to make sure you understood correctly.

**3. Body language refers to:**

- your posture (sit up straight, facing the doctor/nurse).
- your facial expression (do you appear unconcerned, inattentive). **QUIZ ITEM**
- eye contact (do you maintain good eye contact).
- tone of voice (is your tone of voice one of concern, assertive but respectful).

Counselors role-play a patient/doctor interaction two different ways. Role-play #1 demonstrates a patient who is not participating in his health care. Role-play #2 demonstrates a patient who does participate. (5 mins)

**Script for role-play #1 (demonstrating poor communication skills):**

- Doctor: Good morning. How are you today?
- Patient: (slouched, not appearing attentive, not making good eye contact, mumbling)  
Okay, I guess.
- Doctor: I notice from your chart that you've lost weight. It's important you keep your weight up. However, before I prescribe appetite stimulants, I'd like you to try a nutritional supplement. Start drinking one can of Ensure three times a day and we'll see how you do. Also results of blood tests indicate that it is time for you to begin anti-retroviral therapy. (Doctor writes the prescriptions).
- Patient: (still mumbling) I don't much like taking medicine.
- Doctor: I understand, but it's important to take these medications to reduce your viral load. You need to take them exactly as instructed on the containers. There may be serious consequences if you don't. Do you have any questions?
- Patient: Nope.
- Doctor: Okay, then I'll see you again in a month.

**Script for role-play #2 (demonstrating good communication skills):**

- Doctor: Good morning. How are you today?
- Patient: (Patient has a list and refers to it; posture straight; attentive; good eye contact, clear voice).  
Actually, I've been trying to keep a record of how I'm doing (points to list), and I do seem to get tired more easily than I used to; I've also lost weight.
- Doctor: Your fatigue and weight loss could be related. How's your appetite?
- Patient: Not too good.
- Doctor: Any insomnia?
- Patient: No, I seem to sleep okay, just feel run down.
- Doctor: It's important we keep your weight up. However, before I prescribe appetite stimulants, I'd like you to try a nutritional supplement. Let's start by having you drink one can of Ensure three times a day.
- Patient: Will you write down the name of that supplement for me?
- Doctor: Yes, of course. I also wanted to talk to you about your blood tests. Changes in your CD4 count and viral load indicate that it's time to start you on antiretroviral therapy. Okay? I'll write out the prescriptions; all the instructions will be on the containers. When you take these medications it is important that you not miss any doses. There may be serious consequences if you do. Do you have any questions?

## Health Care Participation

- Patient: Yes. Actually, I don't really understand why I need medication right now or what you expect these medications to do.
- Doctor: The purpose of the medications is to reduce your viral load— that's the amount of virus in your body. As your viral load increases, your body's ability to fight infection decreases, and the faster you will develop symptoms. Since your last visit, your viral load has increased and your CD4 count has decreased. That's why I'd like to start you on a regimen of three medications, and we'll see how you respond.
- Patient: I see. Are there any side-effects?
- Doctor: Nausea or diarrhea are reported by some patients. So you should take some of these medications before you eat. Because of your weight loss it is important that we don't decrease your appetite further, so follow the instructions to the letter. Some patients also experience headaches or rash, so you should let me know if that happens.
- Patient: Are there any other drugs I'm not supposed to take at the same time.
- Doctor: You've told me that you aren't being prescribed any other medications by any other doctor, except your daily methadone, and I'll work with your methadone clinic to monitor your blood levels to make sure there are no unexpected interactions with the methadone. But it's important that you let me know if you take anything else, whether prescribed or street drugs. Okay?
- Patient: I used to use cocaine, but I'm clean right now. I don't intend to use again, but I'll let you know if I slip. How long will I need to take these medications and what will happen if I decide not take them?
- Doctor: If you decide not to begin antiretroviral therapy, you'll probably get sick faster. These medications will give you a fighting chance to get your viral load down and manage this disease. You will probably need to take this medication or others like it indefinitely. New medication regimens are being developed all the time, so I can't tell you exactly what treatments will be recommended a year from now. Once you begin it is important to take all medications exactly as prescribed, otherwise you increase your risk for developing resistance to the virus. So you really need to be committed to seeing it through.
- Patient: I am committed. It sounds like it's important to begin, and if I don't follow-through, I could mess up my chances for treatment in the future. Are all the instructions written down for me?
- Doctor: Yes, here you go. I'll see you again in a month.
- Patient: But I should contact you in the meantime if I have any problems, right?

## Health Care Participation

Doctor: Absolutely. Here's the telephone number to call.

Patient: Thanks, doc. I plan to be very involved in my treatment and I'd appreciate you keeping me informed of my status and options as we go along.

### Discussion

Counselor leads discussion on differences between the two doctor/patient role-plays, asking group members for comments and questions. (5 mins)

We are now going to show a ten minute segment from a video entitled "Living with HIV" (Copyright 1992 Glaxo-Wellcome, reproduced with permission). In this segment you will see and hear a discussion among long-term survivors of HIV.

### Visual

Show Video "Living with HIV"

At the conclusion of the video, counselor directs groups members to the handout "Characteristics of Long-Term Survivors" in their Client Workbooks.

You will find this list of characteristics of long-term survivors in your Client Workbook. Notice that the first two characteristics of long-term survivors are—a sense of personal responsibility for their health and a sense that they can influence their own health outcome. Something to think about!

### Break

(10 mins)

### Review

Counselor reviews material covered before the break. (5 mins)

Before the break we discussed the importance of being a positive participant in your health care. That means showing up for your medical appointments and having a high Patient "IQ"—being informed, providing information, and asking relevant questions. We reviewed the basics of HIV and the immune system, and the effects of drug use on your health. Then we covered the communication skills required to demonstrate your high patient IQ during a time-limited appointment with your health care provider. This includes

writing down problems and questions prior to your appointment, speaking clearly and concisely, listening attentively, asking for clarification when necessary, and using appropriate body language. You also learned that one characteristic long-term survivors of HIV have in common is that they take personal responsibility for their health. That’s what this group today is all about. We are going to move on to discuss the importance of taking your medications exactly as prescribed.

HIV medications and medication adherence. (10 mins)

Verbal/  
Didactic

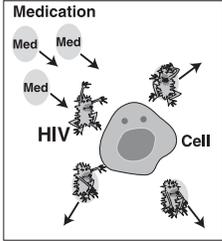
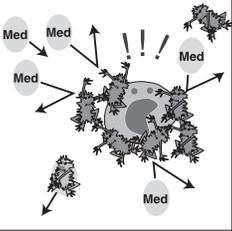
*(Note to Counselors: Approaches to the treatment of HIV change rapidly. This section should therefore be updated and revised as appropriate).*

Many of you may already be taking one or more antiretroviral medications. You may be taking a number of different medications, which your doctor may refer to as HAART—which stands for “highly active antiretroviral therapy.” These medication “cocktails” of different antiretroviral medications are capable of reducing your viral load to undetectable levels. What this means is that the amount of virus in your blood is so low that it cannot be detected by currently available blood tests, which in turn means that you can stay strong and healthy much longer. It does not mean that you can no longer transmit the virus or that you no longer have the virus. **QUIZ ITEM**

The availability of these medications, although not a cure, represents a major advance in the treatment of patients who are infected with HIV, allowing them to live longer, healthier lives. However, these medications must be taken exactly as prescribed, otherwise there may be serious consequences.

**Medication-resistant HIV.**

**POTENTIAL CONSEQUENCES OF MISSED MEDICATION**  
MEDICATION RESISTANCE

		
<p>Medication suppresses viral replication reducing opportunity for resistant mutations to emerge</p>	<p>Missed medication leads to viral replication and opportunity for resistant mutations to emerge, multiply and grow stronger</p>	<p>Medication not effective against this new form of virus</p>

**Show Slide 6.9**

Visual

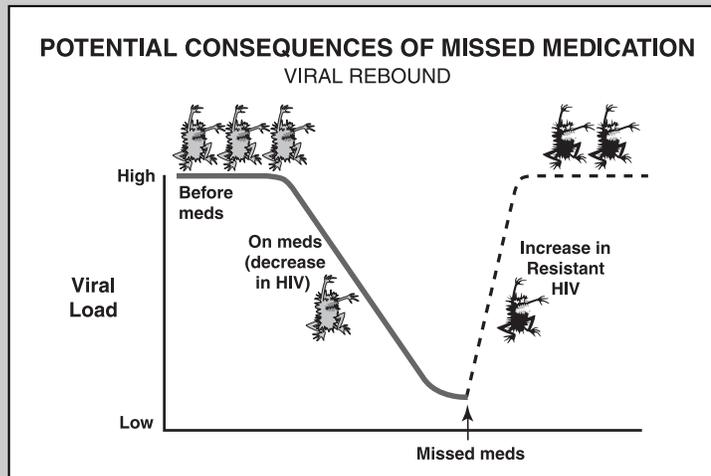
As shown in this slide, one of the potential consequences of not taking your medication exactly as prescribed is development of medication resistant virus.

Before the break, we talked about how HIV replicates rapidly, and mutates, meaning it has changed. Some of these mutations may not respond well to medication. When you take your medication as prescribed you are reducing your viral load and thus reducing the rate of replication and the chance of producing medication resistant mutations. However, when you miss a dose or don't take the medication exactly as prescribed, replication of HIV resumes, and you have now provided a window of opportunity for medication-resistant mutations to take hold and get stronger. Once this happens:

- the medications you are currently taking will no longer be effective in reducing your viral load.
- alternative medications may also be ineffective against this form of the virus.

So, one of the serious consequences of not taking your medications as prescribed is that you may ruin your chance of being able to take a medication that could make it possible for you to live a longer and healthier life. So, never take a “drug holiday” (a break from antiretrovirals) unless instructed to do so by your doctor.

## Visual



Show Slide 6.10

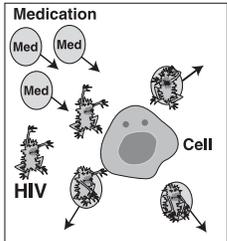
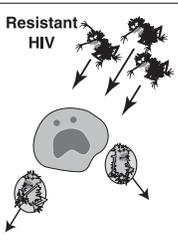
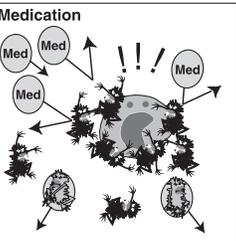
### **Viral Rebound.**

As shown in this slide, medication may reduce your viral load, but if you stop taking it against the advice of your doctor...

- Your viral load may rebound; that is, increase to very high levels that won't respond to treatment.
- Your CD4 count may decrease leading to life-threatening opportunistic infections.
- HIV may reseed in previously uninfected cells, making treatment more difficult.

**Super-infection.**

**POTENTIAL CONSEQUENCES OF RISKY BEHAVIOR**  
SUPER-INFECTION

 <p style="text-align: center;">Medication reduces your viral load</p>	 <p style="text-align: center;">Share needle or have unsafe sex. Get infected with drug-resistant HIV</p>	 <p style="text-align: center;">Medication not effective against this new virus</p>
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**Show Slide 6.11**

**Visual**

As shown in this slide, you may be taking antiretroviral medication and responding well. Your viral load is being successfully reduced to almost undetectable levels. But then you engage in a risky behavior (such as sharing needles or having unsafe sex). If your partner has developed a different strain of the virus—for example one that does not respond to medication—you could potentially become reinfected and get this medication resistant strain of the virus in addition to the virus you already have because you engaged in risky behavior. **QUIZ ITEM**

There are two take home messages here:

1. when you don't take your medications as prescribed you can develop a medication-resistant strain of HIV. **QUIZ ITEM** This will not only hurt you, it could cause harm to others if you engage in risky behavior and transmit this medication-resistant virus to your partners.
2. even if you do take your medications exactly as prescribed, you could potentially become re-infected with a medication-resistant form of the virus if you continue to engage in high risk behavior (such as needle sharing and unsafe sex). **QUIZ ITEM**

So, the consequences of your behavior could have adverse effects both for yourself and for others. Remember, your behavior is under your control.

These skills are applicable regardless of the type of infection a person lives with; be it HIV or hepatitis. The way that you take control is by staying informed and asking questions. There is also some information about hepatitis in your Client Workbook. For those who did not bring their Client Workbook, we can make copies of the handouts at the end of the group. Are there any questions before we discuss medication adherence skills?

### Developing Medication Adherence Skills. (10 mins)

Just as you need a high Patient IQ and skills to form a partnership with your health care provider, you also need skills to adhere to what can be rather complicated medication regimens.

1. The first thing to do is to conduct a cost-benefit analysis of adhering to your medication regimen:

## Visual

**HHRP<sup>+</sup>**      **The Decisional Balance Sheet**  
 (a cost-benefit analysis for medication adherence)  
*(example)*

Perceived Costs	Importance Rating (0-10)	Perceived Benefits	Importance Rating (0-10)
Side-effects	8	Reduced Viral load	9
Inconvenience	4	Increased T-cell	9
Confidentiality	4	Longer Life	10
No cocaine use	6	See kids graduate	10
Worry about missing a dose	3	Less hopelessness	6
Financial	6	Less fear	6
Diet restrictions	2	Quality of Life	10
Difficulty swallowing	2	Less sickness or pain	10
<b>TOTAL costs</b>	<b>35</b>	<b>TOTAL benefits</b>	<b>70</b>

**Cost:Benefit Ratio = 1:2**

Show Slide 6.12

In your Client Workbook you will find a blank Cost-Benefit Analysis Sheet, like the example shown in the slide, for you to complete at home. On the slide, you can see examples of some of the costs and benefits of taking and not taking medications as prescribed for a hypothetical patient we'll call Pat. A cost-benefit analysis for medication adherence is very personal; what you perceive as the costs and benefits of taking medication is likely to differ for each of you. For Patient Pat shown on the slide, the perceived costs of taking medication include concern about side-effects, inconvenience, concern about confidentiality, concern about

interaction with cocaine, concern about what will happen if a dose is missed, financial concerns, diet restrictions, and difficulty swallowing pills. Next to each of these “costs” is a rating of personal importance from zero to ten, not at all important to the highest level of personal importance. Then in the next column are the benefits that Pat perceives will occur from taking medication as prescribed. As you can see the benefits to Pat have pretty high ratings, like living longer and seeing kids graduate. When you add up the costs and benefits, you can see if the benefits outweigh the costs. In our example, Patient Pat has learned that the benefits outweigh the costs two to one. This is a good tool to use when you are initially considering starting a medication regimen. It can also help keep you motivated if you are already taking medications and find strict adherence difficult.

2. Another skill is being able to develop a social support system to help you take your medications.

A “medication buddy” is someone who can help you adhere to your medication regimen. Care needs to be taken in selecting this “medication buddy.”

**HELP WANTED: MEDICATION BUDDY**

**QUALIFICATIONS:**

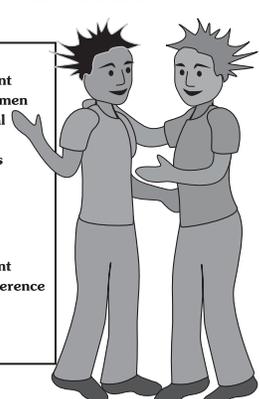
- Non-drug using friend or family member of patient
- Willing to help patient adhere to medication regimen
- Able to keep patient's HIV-serostatus confidential
- Willing to maintain daily contact with patient
- Willing to receive training about HIV medications
- Willing to make a firm commitment

**DUTIES:**

- May be asked to dispense medications to patient
- Will help develop system of memory aids
- Will provide written or verbal reminders to patient
- Will provide support and encouragement for adherence

**COMPENSATION:**

- Patient's undying gratitude and improved health



**Show Slide 6.13**

Visual

As shown in the slide, a “medication buddy” should be:

- a) A non-drug-using friend or family member who is willing to help you with your medications.
- b) A person with whom you are willing to disclose your HIV-serostatus.
- c) A person who can maintain daily contact with you.
- d) A person who can attend at least one medical appointment with you

to be educated about your medications.

- e) A person who is willing to make a firm commitment to working with you on your plan for adherence.

Your “medication buddy” can help you adhere to your medication regimen in several ways:

- a) If your “medication buddy” is someone who lives with you, he or she could actually dispense your medications to you.
  - b) Your “buddy” could help you develop a system of memory aids. We’ll talk more about that in a moment.
  - c) Your “buddy” could provide you with verbal or written reminders.
  - d) And last but not least, your buddy can provide you with encouragement and support.
3. Another skill you need is understanding how to use memory aids to help you remember to take your medications as prescribed.

**Visual**

**MEMORY AIDS**

- ★ *Daily Planner / Appointment Book*
- ★ *Computerized reminders*
- ★ *Alarm clock, beepers*
- ★ *Post-It Notes in places you will notice*
- ★ *Cues - reminders in daily routines*
- ★ *Location - medication placement*
- ★ *Pill organizer*

**Show Slide 6.14**

As shown in the slide, these can include:

- a) Using a daily planner/appointment book and referring to it daily.
- b) Using computerized reminders that provide an alarm or signal when medication is due.
- c) Using alarm clocks, and beepers.
- d) Placing post-it notes in conspicuous places (e.g., refrigerator, bathroom mirror).
- e) Identifying cues in daily life that can serve as reminders (e.g., meal times, favorite TV shows).

- f) Location—medication placement (e.g., keeping medications next to something in your house that you know you will see at the time the medication is to be taken. Such as next to the bed if medication to be taken upon awakening or retiring).
  - g) Using pill organizers that contain all the pills that need to be taken at any given time. If you don't use a pill organizer, you should get into the habit of taking your medications in a specific order and setting the container aside, so that you know which ones you have already taken.
5. Another important skill is to be able to problem solve with your health care providers. Use your patient IQ and inform your health care provider of any potential obstacles to adherence that you may face, and don't hesitate to ask about alternatives. Your doctor may be able to make modifications to the medication regimen in a way that will not jeopardize your health. **Never, ever, try to modify it yourself.**
6. Finally, you need to develop a specific plan with your health care provider concerning how you will adhere to your medications, and **make a personal commitment to this plan.** With your provider's help, you should write down the name, dose, and special instructions for each of your medications, the names, addresses, and telephone numbers of your care providers, the name of your "medication buddy," and the specific strategies you are going to use to help you remember to take each medication. In your Client Workbook, you will find a blank Patient Information Sheet.

Counselor refers group members to Patient Information Sheet in their Client Workbook.

Fill out this sheet with your health care provider. Keep it updated and readily available.

Medication Adherence Game. (20 mins)

Experiential/  
Game

**Materials required:**

Worksheet  
Pens/pencils

Timer.

Prizes (e.g., medication organizer, daily planner, post-it notes).

**Therapeutic goals:**

- Identify potential obstacles to adherence
- Develop medication adherence skills
- Improve communication skills
- Encourage teamwork and appropriate social interaction

**Instructions:**

1. I'm going to divide the group into pairs and provide each pair with a Medication Adherence Worksheet.

Counselor distributes worksheets.

On the worksheet is a hypothetical medication regimen for Patient Pat whose cost-benefit analysis you saw earlier. I'll review this with you now. Pat is being prescribed four different medications, labeled on your worksheet as A, B, C, and D. Don't worry about the actual names of the medications right now. The instructions to Pat are to take two A tablets twice a day 30 minutes before a full meal; one B tablet twice a day; three C tablets three times a day with a meal; and one D tablet four times a day at least two hours before or two hours after a meal. The worksheet also tells you a little about Pat's daily routine. Pat usually gets up at around 6:00 in the morning and goes to the clinic for methadone at 6:30. Pat returns from the methadone clinic by 7:30, eats breakfast, and gets ready for work. At 8:30 Pat leaves the apartment to catch the bus. Pat then works as a retail clerk from 9:00 am to 5:00 pm. Sometimes, Pat goes out in the evening with a friend; occasionally they use cocaine together. Two nights a week Pat bowls on a league from 8:00 pm to 10 pm. Pat goes to bed at around midnight.

Your task will be to propose a medication schedule that Pat can follow (a blank schedule is provided on Page 2 of the Worksheet). As you and your partner attempt to create this schedule for Pat, you will identify potential obstacles that Pat might face due to Pat's normal daily schedule. Write down these obstacles in the space provided and propose solutions (such as changes in Pat's schedule, not changes in the medication regimen). Finally, you will recommend memory aids that Pat can use on a daily basis. You and your partner will earn one point for each medica-

tion entered correctly on the schedule. If no mistakes are made you can earn 11 points in this category. If you enter any incorrectly, you lose a point. You will also earn one point for each potential obstacle you identify, one point for each appropriate solution, and one point for each memory aid. The team with the schedule that is most convenient for Pat will earn an additional point. In the event of a tie, a point will be awarded to the pair with highest level of participation.

2. You will have ten minutes to collaborate with your partner on an appropriate medication schedule. Then one member of each pair will come to the front and write the proposed schedule on the board so that it can be checked for accuracy by counselors and remaining group members. The other partner will then read to the group the potential obstacles, proposed solutions, and memory aids that you have recommended for Pat. I'll keep score and the pair with the most points wins the game and a prize.

Counselor allows 10 mins for completion of the assignment. During this initial 10 minutes, counselor draws a blank daily schedule on the board so that group members can present their proposed schedule to the entire group. Counselor also writes scoring criteria on board.

### **Scoring:**

#### Categories:

- Scheduling of medications = 11 points possible.  
One point is subtracted for each medication not appropriately scheduled (e.g., scheduling medication C without food).
- Potential obstacles (one point awarded for each)
- Potential solutions (one point awarded for each)
- Recommended memory aids (one point awarded for each)
- Bonus point awarded to team that presents the schedule that is most convenient for Patient Pat.
- In the event of a tie: One point awarded to team with highest level of participation.

During the next 10 minutes, while team members present to the group, Counselor records each team's scores on the board, with input from remaining group members. After all teams have presented, Counselor reviews any potential obstacles, solutions, and memory aids not covered by the group members' presentations. For this purpose, an example of a completed worksheet is provided below to be used by the Counselor as needed.

**Examples of potential obstacles faced by Pat (one point awarded for each):**

1. Pat gets up at 6:00 and eats at 7:30, but has to take a pill two hours before a full meal.
2. Pat eats only two meals a day, yet has to take one medication with meals three times a day.
3. Because some medications are to be taken during working hours, Pat may be concerned about confidentiality.
4. Pat may want to have a snack between meals, especially when socializing in the evenings, yet one medication cannot be taken within two hours of any food.
5. Pat may be concerned about interactions with methadone and with occasional use of cocaine.
6. Pat's routine may change on weekends.

**Examples of potential solutions (one point awarded for each):**

1. Change breakfast time. Get ready for work before breakfast and eat breakfast at 8:00 instead of at 7:30.
2. Take a light lunch to work.
3. Take short breaks at work in order to take the mid-morning and mid-afternoon medication doses. If asked about medications, Pat is not obliged to disclose HIV status.
4. In order for Pat to be able to snack when socializing with friends in the evening, Pat could take medication D before going to bed rather than mid-evening, but Pat cannot eat after 10:00 pm if taking medication D at midnight.

5. Pat should discuss these concerns with health care provider, but should also attempt to see non-drug using friends and family members in the evening.
6. Every Friday night create a schedule for the weekend identifying when each medication will be taken during weekend; place this schedule in a prominent place (e.g., on refrigerator) and refer to it often. Ask family member (“medication buddy”) to call daily to remind Pat to look at weekend schedule.

**Examples of memory aids (one point awarded for each):**

1. Use pill organizer and/or keep detailed daily planner.
2. As Medication D is taken upon arising and upon retiring, keep medication D next to bed. In addition, upon arising and retiring use the bathroom as a cue and place a post-it note on bathroom mirror which says “Did you take your D medication yet?”
3. Use return from methadone clinic as cue to take medications A and B. Leave A and B near those items that are always needed to get ready for work.
4. Leave note on outside of lunch box to remind Pat to include two D tablets and three C tablets when making daily lunch; also leave a note inside the lunch box as reminder to take three C tablets with lunch.
5. Establish a routine of taking short “water cooler” or restroom breaks at 10:30 and 3:30 to take the D tablet. Identify something that happens at work at that time to serve as a cue. Keep a clock nearby. If personal telephone calls are permitted at work, ask a family member to call Pat at 10:30 and 3:30.
6. Medication buddy: Ask friend at work to remind Pat to take breaks; ask family member to call daily with reminders.
7. Use a beeper, timer, or alarm at home or work.
8. Keep Medication C (which must be taken with meals) next to the refrigerator or with dishes. Place note on refrigerator as reminder to take medication C with meals.
9. On bowling night, use end time (i.e., 10 pm) as cue that no more food is permitted if medication D is to be taken at midnight. On other nights, ask non-drug using friend or family member to remind Pat not to eat

## Health Care Participation

past 10 pm (alternatively, set an alarm; put “don’t eat past 10” post-it note on refrigerator).

Example of a correctly completed Worksheet:

<b>Time</b>	<b>Medication (A,B,C,D)</b>	<b>Quantity</b>
6:00 am	D (upon getting out of bed)	D=1
6:30 am	Methadone clinic	
7:30 am	A and B (upon return from clinic) then get ready for work (30mins earlier than usual)	A=2; B=1
8.00 am	C with breakfast (eat breakfast 30 minutes later than usual)	C=3
8:30 am	Leave for work	
9:00 am	Begin work	
10:30 am	D (take break; no food)	D=1
1:00 pm	C (Take a light lunch to work)	C=3
3:30 pm	D (take break; no food)	D=1
5:00 pm	Leave work	
6:00 pm	A and B (30 mins before dinner)	A=2; B=1
6:30 pm	C with dinner	C=3
8:00 pm	Bowling or out with friends	
10:00 pm	End bowling (no more food)	
Midnight	D (before bed)	D=1

Following review and discussion, Counselor awards prizes to winning team.

## Quiz

### QUIZ WITH IMMEDIATE FEEDBACK (5 mins)

As you know, we end each group with a quiz and a ten minute relaxation exercise. I’m going to pass around the quiz now.

Counselor distributes the quiz (attached), and reads the items aloud, providing sufficient time for group members to mark their answers.

**Detailed feedback:**

Counselor re-reads each item aloud to the group, providing the correct answer after reading each item.

1. Is the statement about cocaine true or false? The answer is **(a)** true, cocaine use can speed progression of HIV.
2. Which of the items listed are communication skills? The answer is **(d)** all of the above; you should prepare a list of issues to discuss, ask for information to be written down for you, and make sure your body language shows that you are an active partner in your health care.
3. What is the first thing you should do if you develop side-effects to medications? The answer is **(c)**—immediately inform your health care provider; don't tinker with your dose and don't self-medicate.
4. Which of the statements provided is true? The answer is **(a)**—medication resistance can develop if you don't take medications as prescribed. The other statements are false. You can be reinfected with a different strain of HIV, you can also infect someone else even if your viral load is reduced to an undetectable level.
5. Which of the items listed is a memory aid? The answer is **(d)**—all of the above; pill organizers, alarms, and post-it notes can all help you remember to take your medications as prescribed.

**STRESS MANAGEMENT/RELAXATION EXERCISE (10 mins)**

**Stress Management**

We are going to conclude by doing a brief relaxation exercise. I'll be dimming the lights and playing an audiotape. I'd like you to get comfortable in your chair, uncross your legs, and sit quietly with your eyes closed and just follow along with the tape as it asks you to imagine various relaxing scenes. Remember that learning to relax is a skill that takes practice, so if you feel restless at first, just remind yourself that this is a ten minute gift of quiet time that you give to yourself and to the other members of the group. With practice, you can use this technique in many areas of your life, including helping you to cope better with HIV and to participate more fully in your health care.

Counselor dims the lights, says "quiet please," and begins the tape.

**END SESSION**