#### Group Two

# HEALTH CARE PARTICIPATION

# Skills to Be Taught

- Understanding Your Immune System
- Becoming Knowledgeable about HIV and Hepatitis B and C
- Improving Skills for Establishing and Maintaining a Partnership with Health Care Providers
- Learning Strategies for Improving Adherence to Medical Recommendations



# **COUNSELOR TOOL BOX**

#### Multi-modal Presentation of Material:

Verbal Didactic presentation of material

Questioning Group discussion

Visual presentation of major points using slides

Group responses written on flipchart by counselor Written/Pictorial handouts provided in Client Workbook

written/Pictorial handouts provided in Client Workbook

**Experiential** Medication adherence game

Post-group quiz

Stress management/relaxation technique

**Materials** Flipchart and markers

Overhead projector and slides

Audio tape player and relaxation tape

Clock/timer Pens/pencils

**Prizes** 

"Loaner" Client Workbooks

Handouts:

Group agenda

Group quiz

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)

Prevent Hepatitis B: Get Vaccinated (double-sided)

Hepatitis C Prevention (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.





## Health Care Participation

# AGENDA

# (2-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:		
	Increase Your Patient IQ" (5 mins)		
0:10	Your Immune System (10 mins)		
0:20	HIV Infection and Treatment (15 mins)		
0:35	Hepatitis B and C (10 mins)		
0:45	The Role of STDs and Drug Use on Susceptibility to Infection (10 mins		
0:55	BREAK (10 mins)		
1:05	Review (5 mins)		
1:10	Developing a Partnership with Your Health Care Provider $(5 \mathrm{\ mins})$		
1:15	Patient Communication Skills (5 mins)		
1:20	Adherence Skills (5 mins)		
1:25	Medication Adherence Game (20 mins)		
1:45	Quiz (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

# RESPECT Relaxation (complete quiet...no talking, shuffling of papers, or walking around during relaxation exercise) E ating (No eating during group) Sober (don't come to group high)

Punctuality (come to group on time)

Everyone can't talk at once (no crosstalk)

Confidentiality (what's said in group, stays in group)

Teamwork (group members work together towards recovery)

Show Slide 2.1

- 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)

You are in this program because you are ready to make healthy lifestyle choices. People make better choices in their lives when they are well-informed. In order to maintain or improve your physical health, you need to be well-informed about the effects of drug use and unsafe sexual practices on your health, so that you can make choices that will protect your health. In this group, we will focus on HIV, hepatitis B virus (HBV), and hepatitis C virus (HCV) because they cause illness and death at exceptionally high rates among drug users, their sex partners, and, through mother-to-infant transmission, their children. In other groups, we cover specific strategies for

reducing risk of infection so we will not do that here. What we will be doing today is helping you to become an informed and active participant in your own health care. This entails redefining your role as a "patient" in the health-care system.

Visual

# **PATIENT**

WEBSTER'S DEFINITION OF PATIENT:

(from the Latin)

ONE WHO SUFFERS

HHRP DEFINITION OF PATIENT:

# A "POSITIVE PARTICIPANT" IN HEALTH CARE

Show Slide 2.2

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. As this slide shows, today, rather than talking about how you can be "a good patient"—a passive recipient of health care, suffering in silence, we will use HHRP's definition of patient as someone who is a positive participant in their own health care.

Being a positive participant involves having the courage to take responsibility for your health. You cannot change the negative effect that drug use has already had on your health, but you do have control over whether you live each day from this moment forward 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.

Living a healthy lifestyle entails becoming a positive participant in your health care. So, how do you do that?

#### Visual

# Do you know your Patient IQ?

# Inform & Question

Show Slide 2.3

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.

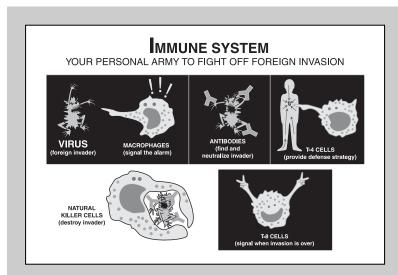
We'll begin with how to inform yourself. In order to actively participate in your health care, you need to become informed about how your body normally responds to infection. We'll go over some of the basics now.

## Verbal

Counselor provides basic information about the workings of the immune system (10 mins)

Your body's defense against infection is your immune system. 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.

## Visual



Show Slide 2.4

The function of your immune system is to identify and attack invaders, such as HIV and hepatitis. 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. For example, tests for HIV tell you whether or not your immune system has created antibodies in an attempt to neutralize HIV. If it has, this means you have been infected.

#### **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 and destroys T-helper cells, which is why people infected with HIV who have progressed to AIDS 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.

Let's talk now specifically how your immune system responds when it has been exposed to HIV. **Sources:** *Centers for Disease Control and Prevention (CDC)* and *National Institute on Drug Abuse*, NIH Publication Number 00-4812, Printed September 2000.

Counselor provides information about HIV transmission, testing, and treatment (15 mins)

Verbal

#### Transmission (5 mins)

**QUESTION:** Which body fluids spread HIV **QUIZ ITEM**?

Counselor writes group members' responses on the board.

Note: Only the four listed below should be written on the board.

**Answer:** HIV is not spread by casual contact or insect bites. Only these body fluids have been proven to spread HIV:

Semen QUIZ ITEM
Vaginal fluid QUIZ ITEM
Breast milk QUIZ ITEM

The human immunodeficiency virus (HIV) is passed from one person to another through blood-to-blood and sexual contact. In addition, infected pregnant women can pass HIV to their babies during pregnancy or delivery, as well as through breast feeding. HIV causes AIDS and most people with HIV infection will develop AIDS as a result of their HIV infection. AIDS is life-threatening because the immune system of someone with AIDS has lost the ability to defend itself against life-threatening cancers and other infections. More than one-third of all AIDS cases reported in the United States are directly or indirectly associated with drug use. It is estimated that between 650,000 to 900,000 people in this country are now infected with HIV and approximately 40,000 new infections occur every year. Being well-informed about HIV is therefore crucial for maintaining your health and the health of your loved ones.

#### Getting tested (5 mins)

The blood tests commonly used to detect HIV infection actually determine whether antibodies have been produced by your body to fight HIV. Remember that antibodies are produced in response to infection, so you would only have these particular HIV antibodies if in fact you had been infected. The period of time between when you were infected with HIV and when antibodies can be detected is called the "window period." During this window period, your HIV test result may be negative when in fact you are actually HIV-positive. Most people will develop detectable antibodies within 3 months after infection. The average window period is about three weeks. In rare cases, it can take up to 6 months. It is therefore recommended that you get tested 6 months after the last possible exposure (unprotected vagi-

nal, anal, or oral sex or sharing needles). It is very important to get tested regularly and to learn your test results because medications are now available that may keep you healthier longer. The less time that HIV has to multiply in your body, the better your chances for managing the disease and the more likely you can prevent transmission of HIV to your drug and sexual partners and to your partner's children.

**QUESTION:** How do you protect yourself from exposure to HIV?

Counselor writes answers on the board and ensures that the following are discussed

#### **Answer:**

- No penetrative sex without latex protection
- No direct needle sharing (using another person's syringe after he or she has used it)
- No sharing drugs from the same syringe (e.g., through frontloading or backloading)
- No indirect sharing (mixing fluids without actually sharing a syringe), for example:
  - Do not put syringes in the same container of water or drug solution
  - Do not use a plunger from a previously used syringe to mix the drug solution
  - Do not use a used syringe to distribute or return the drug
  - Do not draw drug from a shared cotton filter
  - Do not return the drug to a shared cooker
  - Do not "Beat the cotton" or "scrape the cooker"
  - Do not rinse your syringe in other people's water

Do not confuse HIV testing with prevention. Some people who are **not** well-informed think that they do not need to change their behavior if they continue to test negative for HIV.

#### This is not true.

If you engage in any of the behaviors we just discussed with someone who has been infected, you are at risk for infection. There is no way to prevent transmission except through your own behavior. You are in control.

#### Interpreting your test results

If you test negative:

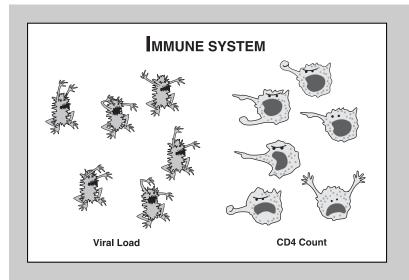
If you test negative, don't forget the "window period." You may in fact be HIV-positive, but your immune system has not yet developed detectible antibodies. However, if you still test negative six months after the last time you engaged in any high risk behavior, then you can feel assured that you have not been infected. Do not assume that because you tested negative, that your partner is also negative. Because HIV is not necessarily transmitted every time there is exposure, your partner could in fact be infected but did not yet infect you. Therefore, if you engage in high risk behavior again with this person you could still be at risk unless your partner also tested negative 6 months after his or her most recent high risk behavior.

#### If you test positive:

If you are told you are HIV-positive, this means that antibodies were found in your blood that indicated you have been infected with HIV. Depending on how much of the virus you have and the strength of your immune system, your doctor may prescribe some medications that will help you to stay healthy longer. There is no cure. If you engaged in high risk behavior any time after you were infected, you could have infected your partners. That's why it is so important for everyone to get tested.

The sooner you know that you have been infected, the sooner you can begin treatment, and the sooner you can stop the spread of HIV to others.

## **Visual**



Show Slide 2.5

This slide shows what happens in your body once you are infected with HIV. Once infected, the virus attacks the T-helper cells (also called CD4 cells) remember that these are the cells that would normally orchestrate the attack against viruses and infections. One measure of the strength of your immune system is your CD4 count; a high number indicates that your defense against foreign invaders is strong. Your CD4 count gets lower and lower as the amount of HIV in your body increases. Your viral load is the amount (number of copies) of the HIV virus you have in your blood. The higher your viral load (the more copies of the virus you have) the greater the threat to your immune system. If you are HIV-positive, you may have hundreds of thousands of copies of the virus in every drop of your blood. This is because every day the original virus that infected you produces about 10 billion copies of itself. The more copies of the virus you have, the weaker your defenses have become, and the faster you are likely to get sick. Also, the more of the virus you have, the more likely you are to infect other people. Having HIV 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. In the last few years a number of medications have been developed that reduce viral load and therefore slow down the destruction of the immune system. While the development of these medications represents a major advancement in the management of HIV disease, it is very important to remember that there is **no cure.** If you are less concerned about becoming infected now than you were in the past because you believe that HIV can now be cured by taking medication, you are sadly misinformed.

The truth is that, in the year 2001, despite medical advances, HIV remains a serious and usually fatal disease that requires complex, costly, and difficult treatment regimens.

We'll talk about these treatments now.

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

**Verbal** 

Individuals who are infected with HIV may have to take a number of different medications, referred to as HAART—which stands for "highly active anti-retroviral therapy." These medication "cocktails" of different antiretroviral medications are capable of reducing HIV viral load to undetectable levels.

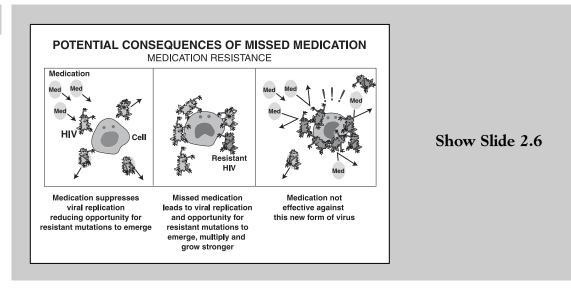
However, these treatments don't work for everyone. Sometimes when they do work, they have unpleasant or intolerable side effects. Some people can't take them because the interaction with their other drugs causes serious problems. Still others find it extremely difficult to maintain the drug treatment schedules. Remember that if you protect yourself from getting infected in the first place you will not need to follow these difficult and costly medication regimens. If you are already infected, remember that you **must** take these medications **exactly** as prescribed in order for them to be effective.

These medications can reduce viral load to undetectable levels. What this means is that the amount of virus in the person's blood is so low that it cannot be detected by currently available blood tests, which in turn means that the person can stay strong and healthy much longer. It does **not** mean that this person can no longer transmit the virus or that the person no longer has the virus. As you'll see on the next slide, some virus remains even though it cannot be detected by a blood test.

#### **Medication-resistant HIV**

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

#### Visual



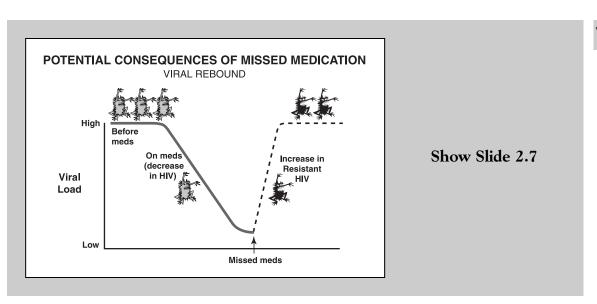
Remember that HIV multiplies by making copies of itself, and that some of these copies may be mutations, which means that it has changed slightly. Some of these mutations may not respond well to medication. When medication is taken as prescribed, the amount of HIV in the body is reduced, and the chance of producing medication resistant mutations is also reduced.

However, when a dose is missed or is not taken exactly as prescribed, HIV begins to multiply again, and there is now a window of opportunity for medication-resistant mutations to take hold and get stronger. Once this happens:

- The medications that the patient is currently taking will no longer be effective in reducing viral load.
- Alternative medications may also be ineffective against this form of the virus.

So, one of the serious consequences of not taking HIV medications as prescribed is that people infected with HIV may ruin their chances of being able to take a medication that could make it possible to live a longer and healthier life. So, if you are HIV-positive, you should never take a "drug holiday" (a break from medications) unless instructed to do so by your doctor. If you are HIV-negative, do not forget that this medication-resistant form of the virus can now be transmitted to you if you engage in high risk behavior with this person, and your treatment options will also be greatly reduced. Imagine finding out not only that are you infected with HIV, but also that you are infected with a strain of HIV that does not respond to some of the new highly active antiretroviral therapies. So don't be lulled into complacency by medical advances. If you are currently HIV-negative, you must continue to do everything in your power to prevent infection. If you are HIV-positive, there are additional reasons for taking your medications exactly as prescribed.

#### Viral Rebound



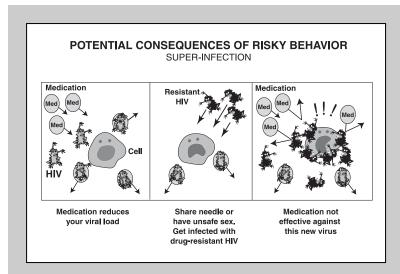
As shown in this slide, if you are HIV-positive, medication may reduce your viral load (the number of foreign invaders), but if you stop taking it against the advice of your doctor:

## Visual

- Your viral load may rebound; that is, increase to very high levels that won't respond to treatment. A high viral load makes you more infectious to others, so if you engage in high risk behavior you are even more likely to transmit the virus to your partner
- Your CD4 count may decrease leading to life-threatening opportunistic infections
- HIV may reseed in previously uninfected cells, making treatment more difficult

#### **Super-infection**

#### Visual



Show Slide 2.8

Imagine now that you are infected with HIV and have successfully reduced your viral load to almost undetectable levels by taking your medications exactly as prescribed. Sadly, though, you mistakenly believe that it is safe for you to share needles or have unprotected sex with someone else who is also HIV-positive. However, it turns out that your partner has been missing medication doses and has developed a strain of the virus that does not respond to the medication that you have been taking so diligently (or your partner could have developed this strain simply because the virus mutated). Because of your risky behavior with your partner, you become infected with this medication-resistant HIV, and now your own medications stop working for you. QUIZITEM Your viral load starts to increase, your CD4 count decreases, and your HIV progresses to AIDS. So you see how very important it is, whether you are HIV-positive or HIV-negative, to be well-informed, and to do everything in your power to prevent the transmission of this cunning and deadly virus.

#### **Health Care Participation**

Let's summarize what we've covered so far by giving you these take home messages:

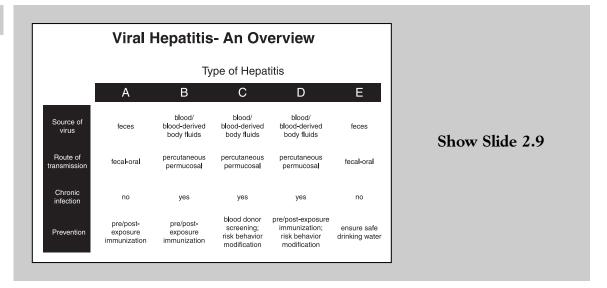
- 1. If you have engaged in any high risk behavior, get tested.
- **2.** If your test result is negative:
  - Don't forget the "window period" from infection to detectible antibodies can be up to 6 months.
  - Do not engage in any high risk behaviors, then get retested in 6 months.
  - Don't assume because you test negative, that this means that your partner is also HIV-negative
  - Don't become complacent. Think of this test result as a second chance.
     Do everything in your power to protect yourself and your loved ones from a potentially devastating illness.
- **3.** If your test result is HIV-positive:
  - Follow medical recommendations
  - Take medications exactly as prescribed
  - Engage in a healthy lifestyle
  - Do not engage in any high risk behavior, including drug use.
- 4. Being informed can save your life.

You will find all the information we cover today in your Client Workbook. There is a lot to understand and remember, so read it over often. Let's turn now to being well-informed about hepatitis:

#### Counselor provides information about hepatitis. (10 mins)

**Sources:** Centers for Disease Control and Prevention (CDC) and National Institute on Drug Abuse, NIH Publication Number 00-4812, Printed September 2000.

## Visual



As shown on this slide, there are five types of viral hepatitis. Hepatitis A, B, C, D, and E. Today, we will focus our discussion on hepatitis B and C because both occur at particularly high rates among drug users. Just like HIV, both of these types of hepatitis are transmitted through injection drug use and unsafe sexual practices. Between 1 million and 1.5 million Americans have active hepatitis B, and nearly 3 million Americans have active hepatitis C. In your client workbook you will find copies of brochures produced by the CDC that will give you information about hepatitis B and C. Let's go over the major points now.

Counselor refers group members to their client workbooks for HBV and HCV brochures

**QUESTION:** What is Hepatitis B?

#### Answer:

- Hepatitis B is a serious disease caused by a virus that attacks the liver. The virus, which is called hepatitis B virus (HBV), can cause lifelong infection, cirrhosis (scarring) of the liver, liver cancer, liver failure, and death.
- HBV can be prevented by vaccination **QUIZITEM** (but you must take all 3 shots).
- HBV is spread by contact with the blood or sexual fluids of an infected person.
- Clinical symptoms of hepatitis B may include fatigue and other flu-like symptoms, and jaundice (yellowing) of the skin and eyes.

**QUESTION:** What Is Hepatitis C?

#### **Answer:**

- Hepatitis C is a liver disease caused by the hepatitis C virus (HCV), which is found in the blood of persons who have this disease.
- There is **no vaccine** that protects you against hepatitis C, but some people can be treated.
- The infection is spread primarily through contact with the blood of an infected person, but may also be shed in genital secretions.
- HCV is serious for some persons, but not for others.
- Most people who get HCV carry the virus for the rest of their lives. Most
  of these persons have some liver damage but may not feel sick from the
  disease for many years.
- People with liver damage caused by HCV may develop cirrhosis (scarring) of the liver, liver cancer, or liver failure that may take many years to develop.
- Some clinical symptoms of HCV are jaundice, fatigue, abdominal pain, loss of appetite, nausea that comes and goes, and vomiting. However, not everyone who becomes infected gets the symptoms.

#### Meaning of Negative HBV or HCV Results

- Negative test results mean that antibodies to the hepatitis virus were not found in the blood. A negative test does not mean that a person is free of the virus. Since the test screens for virus levels that are present for a short period, a person can be infected and still test negative.
- If you have never been infected with HBV, you are eligible to receive HBV vaccinations. **QUIZ ITEM** However, for the vaccine to be effective you must receive a series of three shots. If you do not receive all 3 shots, you will not be successfully immunized against HBV.
- Anyone who continues to engage in risky behaviors should be retested in 6 months.

#### Meaning of Positive HBV or HCV Test Results

- A person who tests positive should get regular preventive medical care, including more testing and liver monitoring.
- Sexual partners, shooting buddies, and the children of those who test positive may be infected. They should be tested and become immunized against HBV if they are not infected. There is no immunization available for HCV.

- A person who tests positive may not have hepatitis symptoms such as jaundice (yellowing) of the skin and eyes, fatigue, and other flu-like symptoms.
- A person who tests positive should not donate or sell blood or donate an organ.
- A woman who tests positive risks passing the virus to her child if she is pregnant.

#### How To Slow or Prevent Onset of Serious Liver Disease

- See a doctor for additional tests to find out if you need treatment now.
- A doctor will take more blood from you and test it to see if HBV or HCV is damaging your liver.
- A doctor may also perform other tests to see how much damage has already been done to you.
- Do not drink alcohol; alcohol contributes to progression of liver disease.
- Almost 6 out of 10 heavy drinkers (58%) develop cirrhosis within 20 years of infection.
- A little more than 1 out of 10 people (12%) who **don't** drink will develop cirrhosis within 20 years of infection.

#### Facts About HIV/AIDS, HBV, and HCV that are often misunderstood

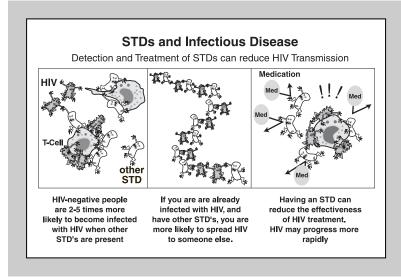
- You can't get HIV, HBV, or HCV from sneezing, hugging, or coughing, or from food or water; from sharing eating utensils or drinking glasses; or from casual contact. However, do not share toothbrushes, razors, or other personal care articles that might have blood on them.
- You can't get HIV, HBV, or HCV from a dry kiss.
- You can't get HIV, HBV, or HCV from clothes, a telephone, or a toilet seat.
- You can't get HIV, HBV, or HCV from a mosquito bite or other insect bites.

Counselor provides information about the role of other sexually-transmitted diseases (STDs) and the use of illicit drugs in susceptibility to acquiring and transmitting HIV, HBV, and HCV. (10 mins)

# Be informed about other blood-borne and sexually-transmitted diseases.

Other blood-borne and sexually-transmitted diseases, in addition to having negative consequences of their own, increase your risk for becoming infected with, and transmitting, HIV and hepatitis.





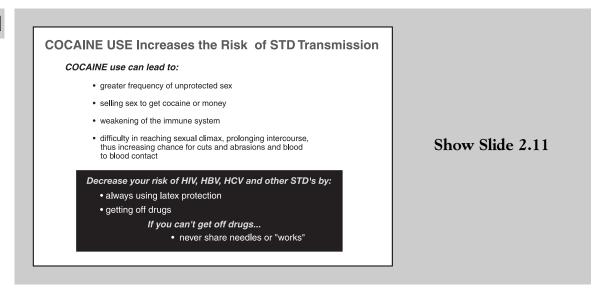
Show Slide 2.10

There is now strong evidence that other STDs increase the risk of HIV transmission and, conversely, that STD treatment reduces the spread of HIV. People are 2-5 times more likely to become infected with HIV when other STDs are present. Furthermore, people infected with HIV are more likely to infect their partners if either one of them also has an STD. This is because STDs that cause genital lesions make it easier for HIV to gain entry. Even if the STD does not cause lesions, they increase the number of HIV-target cells in genital secretions and therefore provide HIV with an easy target. If you are already infected with HIV, having another STD makes you even more infectious—you are more likely to spread HIV to someone else – and in addition, having an STD can reduce the effectiveness of HIV-treatment and contribute to HIV disease progression. So, there are very good reasons for everyone to be tested regularly for STDs. STDs can be prevented and treated. Detection and treatment of STDs can substantially reduce HIV transmission. So, be informed. Be a positive participant in your own health care.

# Be informed about the effect of continued drug use on your susceptibility to infection.

Use of illicit drugs also makes you more susceptible to infection and reduces the effectiveness of treatment. For example, sometimes people smoke crack or snort cocaine rather than inject it. But that doesn't mean they are safe. Even if they only smoke or snort, moderate and heavy cocaine users are still increasing their risk of contracting HIV, HBV, HCV, or other STDs. The slide shows some of the reasons why cocaine users increase their risk of infection:

#### Visual



- People often have more sex when they use cocaine, and they often forget to wear latex condoms or to ask their partner to wear a condom.
- Some people sell sex to get cocaine or to get money for cocaine. This may mean they have more sex or unprotected sex.
- Crack and cocaine may weaken the immune system, making it easier to get HIV, HBV, HCV, and other STDs.
- Crack and cocaine often make it difficult to reach sexual climax. This may lead to prolonged intercourse and increased chances for getting cuts and abrasions, which could result in blood-to-blood contact and the transmission of HIV, HBV, HCV, and other STDs.
- If you are a crack or cocaine user, you can decrease your chances of getting HIV, HBV, HCV, or other STDs by getting off drugs. If you can't get off drugs, don't share needles or "works." In addition, when having sex be sure to use latex condoms.

One last point before we take a break. People who inject drugs are at risk for other serious infections, besides HIV and hepatitis B and C. Use of alcohol swabs to clean the injection site prior to injection has been shown to reduce the occurrence of cellulitis, injection site abscesses, and, possibly, endocarditis among persons who inject drugs.

Counselor reminds group members to read the handouts in their Client Workbooks

I think you will find the printed material in your Client Workbook helpful for remembering what we have covered. Don't forget to read it over and

#### Health Care Participation

show it to your friends and partners. If your partners have been reluctant to use harm reduction strategies, this information may help convince them that being well-informed can save lives, including their own.

Let's take a break.

#### Break (10 mins)

**Break** 

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

**Review** 

Before the break we discussed the importance of being a positive participant in your health care. That means having a high Patient "IQ." People with a high Patient IQ keep themselves well-informed and ask relevant questions. Being well-informed includes having an understanding of how your body responds to infection, as well as how you can prevent infection. We learned that both HIV and hepatitis B and C can be transmitted by sharing needles and other works and by unsafe sex, and that STDs and cocaine use increase your risk of infection. If you are already infected with HIV or hepatitis, then having other STDs or using cocaine can interfere with treatment and can contribute to disease progression. If you have ever engaged in high risk behavior, such as sharing needles, sharing injection equipment, including cooker, cottons, and rinse water, or sharing drugs from the same syringe, or if you have had sex without using a condom, you should be be tested for HIV and hepatitis because early detection increases your chances for successful treatment and also reduces the spread of these infections to others. Remember, if you test negative, but have engaged in any high risk behavior in the past 6 months, you may actually have been infected, but the test cannot yet detect it, so you should be retested 6 months after your last risky behavior. If you test positive, you may be prescribed medications that may reduce your viral load so that it is undetectable. This does not mean that you are no longer infected, or that you cannot infect others. You will need to take these medications exactly as prescribed otherwise you risk multiplication of the virus and a poor response to treatment. If you are infected with hepatitis B or C you may be infected throughout your life and you have a greater chance of developing liver cancer or cirrhosis of the liver. There is no treatment for hepatitis viral infections. However, people who have not been infected with HBV can be immunized. Some things you can do to maintain your health and fight disease:

- Stop or at least reduce drug use
- Get tested and treated for STDs
- Get tested for HIV
- If you are HIV-positive, take all your medications exactly as prescribed
- Get tested for hepatitis B and C
- If you are HBV negative, get vaccinated
- If you are HBV or HCV positive, reduce or stop alcohol consumption
- Eat healthy foods
- Get proper rest
- Get proper exercise
- Think positively—consider joining a support group, and
- Get regular preventive medical care.

We will focus on this last point now—getting regular medical care.

#### Verbal

# Counselor provides instruction on developing a partnership with health care providers (5 mins)

Getting regular medical care is important for all of you, whether or not you are infected with HIV or hepatitis. Many people in addiction treatment have neglected their health over the years because getting and using drugs has been their Number One priority. Their primary relationship has been with their dealer. It is now time for your health to be Number One, and for you to develop a trusting relationship with your health care provider. In order to stay healthy you will need to form a partnership between you and your health care provider. The "I" in patient IQ stands for not only for being well-informed, but also for "informing" your health care provider of relevant information about you and your lifestyle. The "Q" stands for asking your health care provider relevant questions. Let's begin with how to inform your health care provider of relevant information.

Some people view doctors as authority figures and are reluctant to inform or question their doctors. However, individuals with a high Patient IQ do inform and question their doctors. They view doctors, nurses, and other health care workers as members of their health care team. Individuals with high Patient IQs know that they themselves are ultimately responsible for directing their team to manage their health, and they take an active role.

#### Visual

# Inform 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 2.12

As shown in this slide, if you are a positive participant in your health care, you will:

- 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. **QUIZITEM**
- 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.

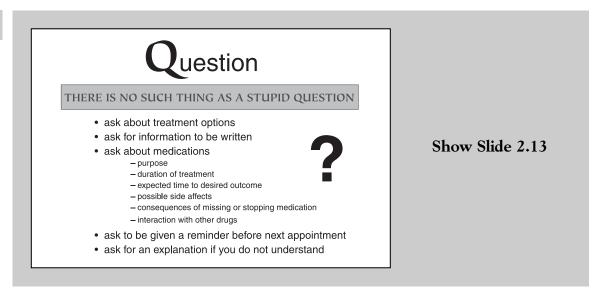
Always keep your medical information updated and readily available.

Let's turn now to the "Q" in Patient IQ.

#### The Q 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. So, as the slide shows, if your health care provider informs you that you have a health problem, you should:

#### Visual



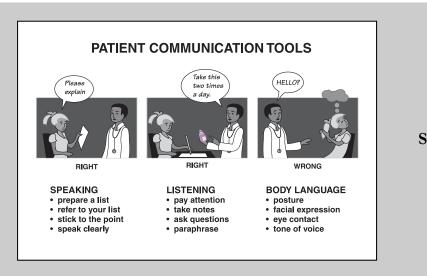
- **1.** Ask about treatment options
- **2.** Ask for information to be written. **QUIZITEM** It is easy to forget what you are told in a doctor's office. If you have it written down you will be able to read it over later.
- 3. If you are being prescribed medications, ask...
  - What is the specific 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.
  - 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.

Counselor provides instruction on patient communication skills. (5 mins)

**Verbal** 

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.



Visual

Show Slide 2.14

#### **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)

#### **Verbal**

Counselor provides instruction on developing medication adherence skills. (5 mins)

**QUESTION:** How many people here are currently being prescribed at least one medication?

As we said earlier, when individuals enter drug treatment, they often find out that they have developed chronic medical conditions that need to be treated; not only the infectious diseases that we discussed already today, but also illnesses such as diabetes, high blood pressure, heart disease, depression, each of which may be managed with medication. Many people entering treatment are so used to medicating themselves that they have difficulty following treatment recommendations. So, 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 medication regimens that are sometimes quite complicated.

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

HHRP (a	cost-benefit a	nalysis for medication adherence) (example)	
Perceived Costs	Important Rating (0-1		mportance ating (0-10
Side-effects	8	Reduced Viral load	9
Inconvenience	4	Increased T-cell	9
Confidentiality	4	Longer Life	10
No cocaine us	e 6	See kids graduate	10
Worry about missing a dose	3	Less hopelessness	6
Financial	6	Less fear	6
Diet restriction	s 2	Quality of Life	10
Difficulty swallow	ring 2	Less sickness or pain	10
TOTAL costs	35	TOTAL benefits	70

Show Slide 2.15

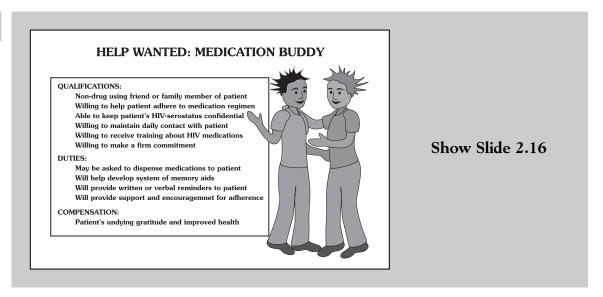
Counselor directs group members to their Client Workbooks for blank Decisional Balance Sheet

In your client workbook you will find a blank Decisional Balance Sheet, like the example shown in the slide, for you to complete a cost-benefit analysis of your own 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 sideeffects, 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 0-10, 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 2 to 1. 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. However, care needs to be taken in selecting this "medication buddy."

#### 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 medical problems.
- 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 2.17

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. QUIZ ITEM
- **d)** Placing post-it notes in conspicuous places (e.g., refrigerator, bathroom mirror). **QUIZ ITEM**
- **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.

#### **QUIZ ITEM**

**4.** Another important skill is to be able to problem solve with your health care providers. Use your patient IQ and inform your heath 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.

**5.** 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.

## Experiential/ Game

#### Medication Adherence Game. (20 mins)

#### 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 2 A tablets twice a day 30 minutes before a full meal; 1 B tablet twice a day; 3 C tablets 3 times a day with a meal; and 1 D tablet 4 times a day at least 2 hours before or 2 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 medication 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 10 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 and eats at 7:30, but has to take a pill 2 hours before a full meal.
- **2.** Pat eats only 2 meals a day, yet has to take one medication with meals 3 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 2 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 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 2 D tablets and 3 C tablets when making daily lunch; also leave a note inside the lunch box as reminder to take 3 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

#### **Health Care Participation**

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 of family member to remind Pat not to eat past 10 pm (alternatively, set an alarm; put "don't eat past 10" post-it note on refrigerator).

Example of a correctly completed Worksheet:

Time	Medication (A,B,C,D)	Quantity
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)	A=2; B=1
	then get ready for work (30mins earlier than usual)	
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 WITH IMMEDIATE FEEDBACK (5 mins)

As you know, we end each group with a quiz and a 10-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 HIV spread by casual contact and insect bites? The answer is **(b)** False. HIV is spread by blood, semen, vaginal secretions and breast milk.
- **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 you 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 infectious diseases listed currently has a vaccine that can prevent it? Answer: (**b**) There is no vaccine to prevent HIV or hepatitis C. There is a vaccine that can prevent hepatitis B. If you haven't already been immunized, talk to your health care provider about it.
- **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

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

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 10 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**