Chapter Six

HEALTH CARE PARTICIPATION

Skills to Be Learned

■ 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
Being told that you are infected with HIV is a life-altering event in many ways. 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 could affect both the length and quality of your life. Consider the word “patient.” 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.

In this chapter, 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 SUFERS

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

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**

**Answer:** As shown above, 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 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:**

The immune system is extremely complex. The illustration below 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 10 billion copies of itself; 1 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. The virus attacks the T-cells—those cells that would normally orchestrate the attack against viruses and infections. 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 one marker of the strength of your immune system. Your viral load is the amount of 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. The goal of HIV medications is to reduce your viral load to a level that it can no longer be detected in your blood so that your CD4 count (your T-cells) can increase and your immune system can get stronger and stronger. 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 (the virus). It is important, however, that you do not judge how well you are doing strictly by your CD4 count, as it can fluctuate. Some people 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 be able to "move in without a fight." When HIV 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 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 the progression of HIV.

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 test tubes, 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, including memory problems, problems with attention and concentration, and not being able to think clearly. You may think that your cognitive difficulties are due to HIV 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 and cause 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 you need all your strength to stay healthy.
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 causes impotence so that you cannot enjoy sexual feelings. You may then mistake sexual dysfunction as a medication side-effect, when the problem is actually due to cocaine use.
10. If you snort cocaine, you risk damage to nasal tissue and to the lungs; if you smoke cocaine, you also 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 use leads to depression and isolation, which leads to more drug use and this vicious cycle of self-medication 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 earlier, 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 drug use can kill you. Be smart. Show that you have a high patient IQ by informing yourself about the dangers of drug use. The good news is that if you stop using drugs, you may not only stop things from getting worse, you may also help things get better. For example, research has 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 it’s up to you. You alone can make the decision to 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.

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.

• 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.

To have a high Patient IQ, you should:

1. Ask about treatment options
2. Ask for information to be written. 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 accustomed 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 positive participant in your health care, 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 later in the chapter.
   • 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.

Patient Communication Skills

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. The illustration below depicts communication between patient and doctor.
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
   - 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
   - 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 (do you sit up straight, facing the doctor/nurse)
   - your facial expression (do you appear concerned, attentive)
   - eye contact (do you maintain good eye contact)
   - tone of voice (is your tone of voice one of concern, assertive but respectful)
Practice Exercise: Assessing Your Communication Skills

Instructions:

Following are two different scripts of a meeting between an HIV-positive patient and his/her doctor. Poor communication skills are demonstrated in the first script; good communication skills are demonstrated in the second. As you read each of the scripts, identify which of these communication approaches you use when visiting your own doctor. Then make a plan for how you will interact with your doctor at your next visit.

Script No. 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 antiretroviral 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 No. 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 pre-
scribe appetite stimulants, I’d like you to try a nutritional sup-
plement. 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 contain-
ers. 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?
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 medica-
tions, 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 med-
cations 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?

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.

Characteristics of Long-Term Survivors of HIV

At the end of this chapter you will find a list of characteristics of long-term survivors of HIV which was published in the Annals of the New York Academy of Sciences in 1987. 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!

Review

Let's review what we've covered so far. 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 chapter is all about. Now we are going to move on to discuss the importance of taking your medications exactly as prescribed.

**HIV Medications and Medication Adherence**

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.*

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.**

As shown in this illustration, one of the potential consequences of not taking your medication exactly as prescribed is development of medication resistant virus.
Earlier, we described 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 mutation 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.

**Viral Rebound.**

As shown in this illustration, 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.

As shown in this illustration, 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 an HIV mutation that does not respond to the medication you are currently taking you could potentially become reinfected with this medication resistant strain of the virus in addition to the virus you already have, and now your medication is no longer effective even though you have not missed a dose.

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. 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).

So, your behavior could have serious consequences both for yourself and for others. Remember, it's up to you. Your behavior is under your control. 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:

**Practice Exercise:**
**Developing Medication Adherence Skills**

At the end of this chapter you will find a Cost–Benefit Analysis Worksheet for Medication Adherence. A cost-benefit analysis for medication adherence is very personal; the perceived costs and benefits of taking medication are likely to differ for each individual. Begin this exercise by making a list of all the reasons why you do not want to take your medications. Write these in the column labeled “perceived costs.” Next to each of the “costs” that you list, rate the personal importance of this cost from 0–10 (not at all important–to the highest level of personal importance). Then in the next column, list the benefits that you perceive will occur from taking medication as prescribed. When you add up the costs and benefits, you can see if the benefits outweigh the costs. 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.

   
   **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

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

   As shown in the illustration, 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.

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.

4. 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.

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. At the end of this chapter you will find a Patient Information Sheet. Fill this sheet out with your health care provider. Keep it updated and readily available.

Practice Exercise: Medication Adherence

Instructions:

1. Turn to the Medication Adherence Worksheet at the end of the chapter.

2. On the worksheet is a hypothetical medication regimen for Patient Pat. 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.

3. 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 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.
Try to complete the practice exercise before reading the following examples.

**Examples of potential obstacles faced by Pat:**

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:**

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:

1. Use pill organizer and/or keep detailed daily planner.

2. As Medication D is taken upon arising and upon retiring, keep mediation 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 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 past 10 pm (alternatively, set an alarm; put “don't eat past 10” post-it note on refrigerator).
Example of a correctly completed Worksheet:

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

Quiz

1. Cocaine use may speed progression of HIV.
   a. True    b. False

2. Patient communication skills include:
   a. preparing a list of issues to discuss
   b. asking for information to be written down
   c. body language that shows you are an active partner in your health care
   d. all of the above
3. **What is the first thing you should do if you develop side effects when taking a medication?**

   a. take a “drug holiday”
   b. take less of the medication
   c. inform your health care provider
   d. take another drug to help you feel better

4. **Which of the following statements is true?**

   a. medication resistance can develop if you don’t take medication as prescribed
   b. if you are already HIV-positive, you cannot be reinfected
   c. if your viral load is reduced to undetectable level you can no longer infect anyone
   d. all of the above

5. **Which of the following is a memory aid that can help you adhere to your medication regimen?**

   a. using a pill organizer
   b. setting an alarm clock
   c. placing a “post-it” reminder note on the refrigerator
   d. all of the above

**Practice Exercise: Stress Management/Relaxation**

We recommend that you conclude each chapter by doing a ten-minute relaxation exercise. Use this time to practice meditation or deep breathing, or to play an audiotaped relaxation or visualization technique. Dim the lights, get comfortable in your chair, uncross your legs, and sit quietly with your eyes closed. 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. With practice, you can use meditation and relaxation in many areas of your life including helping you to cope better with HIV and to participate more fully in your health care. So use this time now to practice becoming centered, relaxed, and focused on adhering to medical recommendations.
Characteristics of Long-term Survivors of HIV

• A sense of personal responsibility for their health

• A sense that they can influence their own health outcome

• A commitment to life in terms of “unfinished business,” unmet goals, or as yet unfulfilled experiences and wishes

• A sense of meaningfulness and purpose in life

• Found new meaning in life as a result of the illness itself

• Engaged in physical fitness—exercise, dietary work

• Derived useful information from, and supportive contact with, a person with the same diagnosis shortly after the diagnosis

• Became altruistically involved with other affected persons

• Accepted the reality of the diagnosis in conjunction with a refusal to perceive the condition as a death sentence

• Developed a personalized means of active coping that they believe has beneficial health effects

• Assertive, able to say “no”

• The ability to withdraw from taxing involvements and to nurture themselves

• Sensitivity to other bodies, including psychological and physical needs

• Ability to communicate openly about their concerns

The Decisional Balance Sheet
(a cost–benefit analysis for following medical recommendations)

<table>
<thead>
<tr>
<th>Perceived Costs</th>
<th>Importance Rating (0–10)</th>
<th>Perceived Benefits</th>
<th>Importance Rating (0–10)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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<td></td>
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</tr>
<tr>
<td>TOTAL costs</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Cost:Benefit Ratio = ___
Medical Information Sheet  
(keep updated)

Patient Name ___________________________ Telephone No. _____________
Address __________________________________________________________

Primary Health Care Provider.
Name ___________________________ Telephone No. _____________
Address __________________________________________________________

“Medication Buddy”.
Name ___________________________ Telephone No. _____________
Address __________________________________________________________

Health Insurance Information.
ID No. ___________________________ Carrier __________________________
Allergies __________________________________________________________

Medications Prescribed.

<table>
<thead>
<tr>
<th>Medication Name</th>
<th>Dose</th>
<th>Special Instructions</th>
<th>Date Discontinued</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>
### Other Drugs Used.

<table>
<thead>
<tr>
<th>Drug name</th>
<th>Amount/Frequency</th>
<th>Date Discontinued</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alcohol</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nicotine</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Opiates</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cocaine</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Benzodiazepines</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Marijuana</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other:</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### “Alternative” or “Complementary” Therapies Used.

<table>
<thead>
<tr>
<th>Drug name</th>
<th>Amount/Frequency</th>
<th>Date Discontinued</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acupuncture</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Herbal remedies</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nutritional supplements</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Potential Obstacles to Adherence.

1) 
2) 
3) 
4) 
5) 
6) 

### Possible Solutions.

1) 
2) 
3) 
4) 
5) 
6) 

### Memory Aids.

1) 
2) 
3) 
4) 
5) 
6)
Medication Adherence Game Worksheet

Instructions: Patient Pat has been prescribed the following medications.

<table>
<thead>
<tr>
<th>Medication</th>
<th>Instructions for Use</th>
<th>Special Instructions</th>
</tr>
</thead>
<tbody>
<tr>
<td>(A) DDI (Didanosine)</td>
<td>2 tablets twice a day</td>
<td>Take a half-hour before a full meal</td>
</tr>
<tr>
<td>(B) Viramune (Nvirampine)</td>
<td>1 tablet twice a day</td>
<td></td>
</tr>
<tr>
<td>(C) Viracept (Nelfinavir Mesylate)</td>
<td>3 tablets 3 times a day</td>
<td>Take with a meal</td>
</tr>
<tr>
<td>(D) Erythromycin</td>
<td>1 pill 4 times a day</td>
<td>Do not eat 2 hours before or 2 hours after taking</td>
</tr>
</tbody>
</table>

Facts to know about Patient Pat:
Pat usually gets up at around 6:00 in the morning and goes to the clinic for methadone at 6:30. Pat usually eats 2 meals a day—breakfast at around 7:30 am, after returning from the methadone clinic, and dinner at around 6:30 pm. Pat works as a retail clerk from 9:00 am to 5:00 pm, sometimes goes out in the evening with friends, and goes to bed at around midnight. Two nights a week Pat bowls on a bowling league from 8:00 pm to 10 pm.

Potential Obstacles to Adherence          Possible Solutions
1)                                      
2)                                      
3)                                      
4)                                      
5)                                      
6)                                      

Memory Aids to Recommend to Pat:
1)                                      
2)                                      
3)                                      
4)                                      
5)                                      
6)                                      
Using the letters A, B, C, D to represent the prescribed medications, create Pat's daily medication schedule below (No. = number of pills).

<table>
<thead>
<tr>
<th>Time</th>
<th>A, B, C, D</th>
<th>No.</th>
</tr>
</thead>
<tbody>
<tr>
<td>6:00 AM</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6:30</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7:00</td>
<td></td>
<td></td>
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<tr>
<td>7:30</td>
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<td>8:00</td>
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<td>8:30</td>
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<td>9:00</td>
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<td>9:30</td>
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<td>10:00</td>
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<td>10:30</td>
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<tr>
<td>11:00</td>
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<tr>
<td>11:30</td>
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<td></td>
</tr>
<tr>
<td>Noon</td>
<td></td>
<td></td>
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<tr>
<td>12:30 PM</td>
<td></td>
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<tr>
<td>1:00</td>
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<td>1:30</td>
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<tr>
<td>2:00</td>
<td></td>
<td></td>
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<tr>
<td>2:30</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Time</th>
<th>A, B, C, D</th>
<th>No.</th>
</tr>
</thead>
<tbody>
<tr>
<td>3:00 PM</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3:30</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4:00</td>
<td></td>
<td></td>
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<tr>
<td>4:30</td>
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<tr>
<td>5:00</td>
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<tr>
<td>5:30</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6:00</td>
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<tr>
<td>6:30</td>
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<tr>
<td>7:00</td>
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<td>7:30</td>
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<td>8:30</td>
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<td>9:00</td>
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<tr>
<td>9:30</td>
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<tr>
<td>10:00</td>
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<td>10:30</td>
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<tr>
<td>11:00</td>
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<tr>
<td>11:30</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Midnight</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Being a **positive participant** involves taking responsibility for your health. 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.

The materials in this section contain important information about HIV, Hepatitis B (HBV), and Hepatitis C (HCV), as well as other diseases that occur at high rates among drug users, their sex partners, and their children.

In order for this section to be as helpful as possible, it contains a number of medical terms that doctors and other health care professionals may use with their patients and when talking among themselves about these disorders. Some of these terms may be unfamiliar to you, and you may also find some difficult to read and pronounce. If this is the case, we encourage you to speak with your health care provider, counselor, or someone who is knowledgeable about the subject, and to become informed regarding the meaning and use of these terms. This could make your discussion with your health care providers much more productive and meaningful for you.

Remember that taking responsibility for your health means developing a high **Patient IQ.** “IQ” stands for Inform and Question: you need to **Inform** yourself about issues that trouble you; **Inform** your health care provider of your problems and concerns; and ask **Questions** of those who provide medical services to you.
The human immunodeficiency virus (HIV) is the virus that causes AIDS. 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.

More than one third of all AIDS cases reported in the United States are directly or indirectly associated with drug use.

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.

HIV is not spread by casual contact or insect bites. Only the following body fluids have been proven to spread HIV:

- Blood
- Semen
- Vaginal fluid
- Breast milk

Getting tested

The blood tests commonly used to detect HIV infection actually determine whether antibodies have been produced by your body to fight HIV. Antibodies are produced by your immune system in response to infection, so you would only have these particular HIV antibodies if in fact you had been infected.

The window period

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 vaginal, anal, or oral sex or sharing needles).
Health Care Participation

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.

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 must also be negative.** HIV is not necessarily transmitted every time there is exposure. So, for example, you could have had unprotected sex or shared drug paraphernalia with an HIV-positive partner without having become infected on that particular occasion. However, 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:*
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 or have become re-infected with a strain of the virus that does not respond well to medications. 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.

**Some people believe that they don’t have to worry about getting HIV any more because they think that it can be cured with medication. THIS IS NOT TRUE.** The truth is that despite medical advances, HIV remains a very serious disease that requires costly, and often complicated, treatment regimens that **may** slow the disease, but do not cure it.
## Viral Hepatitis—An Overview

<table>
<thead>
<tr>
<th>Type of Hepatitis</th>
<th>A</th>
<th>B</th>
<th>C</th>
<th>D</th>
<th>E</th>
</tr>
</thead>
<tbody>
<tr>
<td>Source of virus</td>
<td>feces</td>
<td>blood/ blood-derived body fluids</td>
<td>blood/ blood-derived body fluids</td>
<td>blood/ blood-derived body fluids</td>
<td>feces</td>
</tr>
<tr>
<td>Route of transmission</td>
<td>fecal-oral</td>
<td>percutaneous permucosal</td>
<td>percutaneous permucosal</td>
<td>percutaneous permucosal</td>
<td>fecal-oral</td>
</tr>
<tr>
<td>Chronic infection</td>
<td>no</td>
<td>yes</td>
<td>yes</td>
<td>yes</td>
<td>no</td>
</tr>
<tr>
<td>Prevention</td>
<td>pre/post-exposure immunization</td>
<td>pre/post-exposure immunization</td>
<td>blood donor screening; risk behavior modification</td>
<td>pre/post-exposure immunization; risk behavior modification</td>
<td>ensure safe drinking water</td>
</tr>
</tbody>
</table>

As shown in the above table, 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.

### What is Hepatitis B?

- 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** (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.
What Is Hepatitis C?

- 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. 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.

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.

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

Hepatitis B is a serious disease caused by the hepatitis B virus (HBV) that attacks the liver and can be spread to others.

Is hepatitis B a serious problem?

Yes. Each year, thousands of people of all ages get hepatitis B and about 5,000 die of chronic (life-long) liver problems caused by HBV infection. If you have had other types of hepatitis, such as hepatitis A or hepatitis C, you can still get hepatitis B.

How is hepatitis B spread?

- HBV is spread by contact with the blood of an infected person or by having sex with an infected person
- A woman who has hepatitis B can spread the virus to her baby during birth.
- HBV is spread by contact with the blood of an infected person or by having sex with an infected person

You cannot get HBV from:

- sneezing or coughing
- kissing or hugging
- sharing eating utensils of drinking glasses
- breast feeding
- food or water
- casual contact (such as an office setting)

How do you know if you have hepatitis B?

Only a blood test can tell for sure. See your doctor if you have symptoms of hepatitis (e.g., tiredness, stomach ache, joint pain, yellow skin or eyes), or if you think you have had direct contact with someone who has hepatitis B.

*It is very important that all pregnant women get a blood test for hepatitis B early in their pregnancy, since a woman who has hepatitis B can spread the virus to her baby during birth.*

How can you protect yourself from getting infected with HBV?

- Get vaccinated!
  - Hepatitis B vaccine is safe, effective, and your best protection.
Health Care Participation

• **Practice “safer” sex.**
  If you are having sex, but not with one steady partner, use latex condoms correctly every time you have sex and get vaccinated against hepatitis B. Men who have sex with men should be vaccinated against both hepatitis A and hepatitis B.

• **Don’t share anything that might have blood on it.**
  Never share anything that might have blood on it, such as a razor or toothbrush.
  If you shoot drugs, get help to stop or get into a treatment program. Don’t share needles, syringes, cookers, cottons, water, or rinse cups. Get vaccinated against hepatitis A and hepatitis B.

• **Think about the health risks if you are planning to get a tattoo or body piercing.**
  You can get infected if the artist or piercer doesn’t sterilize needles and equipment, use disposable gloves, and wash hands properly.

• **Follow standard precautions.**
  If you are a health-care worker, follow standard precautions and handle needles and sharps safely. Get vaccinated against hepatitis B.

Get hepatitis B vaccine if:

• your sex partner has hepatitis B
• you are a man who has sex with men
• you have had a sexually transmitted disease (e.g. gonorrhea, syphilis)
• you have sex with more than one partner
• you shoot drugs
• you live with someone who has life-long hepatitis B
• you have a job that exposes you to human blood
• you are a kidney dialysis patient
• you live or travel for more than six months in countries where hepatitis B is common

*Everyone under 19 years old should get vaccinated against hepatitis B!*

Is the vaccine safe?

Yes. Hepatitis B vaccine is safe and effective. Millions of people have received the vaccine worldwide since 1982. **You do not need booster shots** after you complete the three-shot vaccine series.

Should you get a blood test after the three shot vaccine series to be sure that you are protected?

Most people don’t need to get their blood tested after getting the vaccine.

You should get a blood test 1 to 2 months after you complete the series if:

• your sex partner has chronic hepatitis B
• your immune system is not working well (i.e., you are on dialysis or you have AIDS)
• you have a job that exposes you to human blood

*Babies born to infected mothers should get their blood tested at 9 to 15 months old to be sure that they are protected.*

*Source: Centers for Disease Control and Prevention (CDC) and National Institute on Drug Abuse (NIDA), NIH Publication Number 00-4812, printed September 2000.*
Almost 4 million Americans are infected with hepatitis C virus.

**What is hepatitis C?**

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. The infection is spread by contact with the blood of an infected person.

**How serious is hepatitis C?**

Hepatitis C is serious for some persons, but not for others. Most persons who get hepatitis C carry the virus for the rest of their lives. Most of these persons have some liver damage but many do not feel sick from the disease. Some persons with liver damage due to hepatitis C may develop cirrhosis (scarring) of the liver and liver failure which may take many years to develop.

**How can I protect myself from getting hepatitis C?**

HCV is spread primarily by exposure to human blood.

- Don’t ever shoot drugs! If you shoot drugs, stop and get into a treatment program. If you can’t stop, use a clean needle and works every time and don’t share them.
- Practice safer sex. If you have sex with multiple partners, lower your number of partners and always use barrier precautions, such as latex condoms.
- If you are a health care worker, always follow routine barrier precautions and safely handle needles and other sharps.
- Do not share toothbrushes, razors, or other personal care articles. They might have blood on them.

**Hepatitis C is not spread by:**

- sneezing
- hugging
- coughing
- sharing eating utensils or drinking glasses
- food or water
- casual contact
Could I already have hepatitis C?

Ask your doctor for a blood test for hepatitis C if:

• you received a blood transfusion or solid organ transplant (e.g., kidney, liver, heart) before 1992.
• you were treated with a blood product for clotting problems before 1987.
• you ever injected street drugs, even once.
• you were ever on long-term kidney dialysis.

Why should I be tested for hepatitis C?

Early diagnosis is important so you can be:

• counseled about how to prevent transmission of HCV to others.
• checked for liver disease and get treatment, if indicated.

Many people who are at risk for hepatitis C are at risk for hepatitis A and hepatitis B. Check with your doctor to see if you should get hepatitis A and hepatitis B vaccines.

There is no vaccine to prevent hepatitis C.

Source: Centers for Disease Control and Prevention (CDC) and National Institute on Drug Abuse (NIDA), NIH Publication Number 00-4812, printed September 2000.
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.
COCaine USE Increases the Risk of STD Transmission

**COCaine use can lead to:**

- greater frequency of unprotected sex
- selling sex to get cocaine or money
- weakening of the immune system
- difficulty in reaching sexual climax, prolonging intercourse, thus increasing chance for cuts and abrasions and blood to blood contact

**Decrease your risk of HIV, HBV, HCV and other STD's by:**

- always using latex protection
- getting off drugs

*If you can't get off drugs...*

- never share needles or "works"

- 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.

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.
Endocarditis
(Bacterial Endocarditis; Infective Endocarditis)

Basic information

Description
A noncontagious infection involving the heart muscle, heart valves, endocardium (lining of the heart chambers or valves).

Frequent signs and symptoms
Early symptoms:
• Fatigue and weakness.
• Intermittent fever, chills and excessive sweating, especially at night.
• Weight loss.
• Vague aches and pains.
• Heart murmur.

Late symptoms:
• Severe chills and high fever.
• Shortness of breath on exertion.
• Swelling of the feet, legs and abdomen.
• Rapid or irregular heartbeat.

Causes
Bacteria or fungi that enter the blood and infect the valves and heart lining of persons with damaged skin (See risks below). Bacteria or fungi further damage the heart valves, muscles and linings.

Risk increases with
Risk of heart-valve damage increases with:
• Rheumatic fever.
• Congenital heart disease.

Risk of endocarditis following heart valve damage increases with:
• Pregnancy.
• Injections of contaminated materials into the bloodstream, such as with self-administered intravenous drugs.
• Excess alcohol consumption.
• Use of Immunosuppressive drugs.
• Artificial heart valves.
Preventive measures
If you have heart-valve damage or a heart murmur
• Request antibiotics before medical procedures that may introduce bacteria into the blood. These include dental work, childbirth and surgery of the urinary or gastrointestinal tract.
• Don’t drink more than 1-2 if any alcoholic drinks in 1 day.
• Consult medical professional before becoming pregnant.
• Don’t use illicit drugs like heroin or cocaine.

Expected outcome
Usually curable with early diagnosis and treatment, but recovery may take weeks. If treatment is delayed, heart function deteriorates, resulting in congestive heart failure and death.

Possible complications
• Blood clots that may travel to the brain, kidneys or abdominal organs, causing infections, abscesses or stroke.
• Heart-rhythm disturbances (atrial fibrillation is most common).

Treatment
General measures
Diagnostic tests may include laboratory blood counts and blood cultures, electrocardiogram (method of diagnosing heart diseases by measuring electrical activity of the heart), X-rays of the heart and lungs, including echocardiogram (studying the heart by examining sound waves created by an instrument placed on the chest).
• The goal of treatment is to eradicate the infecting organism with medications, and supportive care for relieving symptoms.
• Hospital care during acute phase. Once stable, some patients can continue with treatment at home.
• Surgery to replace infected valve in some patients.
• If you have damaged heart valves, tell any doctor or dentist before any treatment or procedure. Preventive antibiotics will be needed in some situations.
• Ongoing dental hygiene is important to prevent infection.
• Once you have had endocarditis, stay under a doctor’s care to prevent a relapse.
• Wear a medical alert type bracelet or neck tag that indicates your medical problem. Carry a wallet card listing the antibiotic regimens needed for medical and dental procedure.

Medication
Antibiotics for many weeks to fight infection. Antibiotic treatment is often intravenous.
Health Care Participation

Activity
• Rest in bed until you are fully recovered. While in bed, flex your legs often to prevent clots from forming.
• Resume your normal activities, including sexual relations, when strength allows.

Diet
No special diet.

Notify our office if
You or a family member has symptoms of endocarditis.
The following occur during or after treatment:
• Weight gain without diet changes.
• Blood in the urine.
• Chest pain or shortness of breath.
• Sudden weakness or numbness in the muscles of the face, trunk, or limbs.

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Cirrhosis of the Liver

Basic information

Description
Chronic scarring of the liver, leading to loss of normal liver function. It is twice as common in men as in women. Congenital cirrhosis can affect infants or young children.

Frequent signs and symptoms
Early stages:
• Fatigue, weakness.
• Poor appetite: nausea; weight loss.
• Enlarged liver.
• Red palms.

Late stages:
• Jaundice (yellow skin and eyes).
• Dark yellow or brown urine.
• Spider blood vessels of the skin (fine vessels that spread out from a central point).
• Hair loss.
• Breast enlargement in men.
• Fluid accumulation in the abdomen and legs.
• Enlarged spleen.
• Diarrhea; stool may be black or bloody.
• Bleeding and bruising.
• Mental confusion, coma.

Causes
Inflammation of the liver, accompanied by destruction of liver cells, cell regeneration and scarring. These may be preceded by:
• Prolonged, excess alcohol consumption.
• Hepatitis.
• Exposure to toxic chemical.
• Inherited causes.
Risk increases with
• Poor nutrition.
• Hepatitis.
• Excess alcohol consumption. Individuals vary widely in the amount and duration of alcohol consumption necessary to cause cirrhosis.
• Occupational exposure to chemicals toxic to the liver.

Preventive measures
• Obtain treatment for alcoholism.
• Obtain prompt medical treatment for hepatitis.
• Survey your work environment for possible exposure to toxic chemicals.

Possible complications
• Cirrhosis can be arrested if the underlying cause can be removed. Liver damage is irreversible, but symptoms can be relieved or controlled. A near-normal life is possible if treated early and treatment succeeds.
• If the underlying cause is not removed, liver scarring will continue, resulting in death from liver failure.

General measures
• Life-threatening hemorrhage, especially from the esophagus and stomach.
• Liver cancer.
• Body poisoning and coma from a buildup of ammonia and other body waste.
• Sexual impotence.

Treatment

General measures
• Diagnostic tests may include laboratory studies, such as blood and urine tests of liver function, X-ray and/or biopsy of liver.
• Treatment methods may include drug treatment, dietary restrictions, rest and other supportive measures.
• If cirrhosis is caused by alcoholism, stop drinking. Ask for help from family, friends and community agencies. Contact an Alcoholics Anonymous group in your community.
• Additional Information available from the American Liver Foundation
  75 Maiden Lane
  Suite 603
  New York, NY 10038
  (800) GO-Liver (465-4837) toll-free
  (888) 4HEP-USA (443-7872) toll-free
  (212) 668-1000
  (212) 483-8179 fax
  info@liverfoundation.org
Medication
- Iron supplements for anemia resulting from or poor nutrition.
- Diuretics to reduce fluid retention.
- Antibiotics, such as neomycin, to reduce ammonia buildup.
- Stool softeners.

Activity
- Maintain as active a life as possible.
- Elevate swollen feet and legs when resting.

Diet
- In the early stages, eat a well-balanced diet that is high in carbohydrates, high in protein and low in salt.
- Late stages may require protein reduction.
- Vitamin and mineral supplements may be necessary.
- Don't drink alcohol.

Notify our office if
- You or a family member has symptoms of cirrhosis.
- The following occur during treatment:
  - Vomiting blood or passing black stool.
  - Mental confusion or coma.
  - Fever or other signs of infection (redness, swelling, tenderness or pain).

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Cellulitis

Basic information

Description
A noncontagious infection of connective tissue beneath the skin. It can affect skin anywhere on the body, but most likely on the face or lower legs. Erysipelas is the name of a severe cellulitis of the face.

Frequent signs and symptoms
• Sudden tenderness, swelling, and redness in an area of the skin. The area of cellulitis is initially 5cm to 20cm in diameter, and grows rapidly in the first 24 hours. A thin, red line often extends from the middle of the cellulitis toward the heart. Cellulitis does not develop into a boil.
• Fever, sometimes accompanied by chills and sweats.
• General ill feeling.
• Swollen lymph glands near the cellulitis (sometimes).

Causes
Infection from Staphylococcus or Streptococcus bacteria.

Risk increases with
• Use of immunosuppressive or cortisone drugs.
• Chronic illness, such as diabetes mellitus, or a recent infection that has lowered resistance.
• Any injury that breaks the skin, or underlying skin lesion.
• Intravenous drug use.
• Burns.
• Surgical wound.
• Diabetes mellitus.
• Immunosuppression due to illness or medications.

Preventive measures
• Avoid skin damage. Use protective clothing or gear if you participate in strenuous work or sports.
• Keep the skin clean.
• Avoid swimming if you have skin lesion.
Expected outcome
Usually curable in 7 to 10 days with treatment, unless the patient has a chronic disease or is receiving immunosuppressant treatment; in that case, cellulitis may lead to blood poisoning and become life threatening.

Possible complications
Blood poisoning, if bacteria enter the bloodstream.
Brain infection or meningitis, if cellulitis occurs on the central part of the face.

Treatment

General measures
• For diagnosis, laboratory studies or a skin biopsy may be recommended.
• The usual treatment is with an antibiotic.
• Use warm-water soaks to hasten healing and relieve pain and inflammation.
• If excess fluid is lost from the skin, hospitalization may be necessary to provide adequate hydration.
• Elevation and restricted movement of the affected area can help reduce swelling.

Medication
Antibiotics to fight infection. Finish the prescribed dose, even if symptoms disappear quickly.

Activity
Rest in bed until fever disappears and other symptoms improve. Resume your normal activities as soon as symptoms improve.

Diet
No special diet.

Notify our office if
You or a family member has symptoms of cellulitis, especially on the face. The following occur during treatment:
• Fever.
• Headache or vomiting.
• Drowsiness and lethargy.
• Blister over the area of cellulitis.
• Red streaks that continue to extend, despite treatment.
• New, unexplained symptoms develop. Drugs used in the treatment may produce side effects.

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Osteomyelitis

Basic information

Description
Infection of the bone and bone marrow. It can involve any bone in the body. In a child, the femur (upper-leg bone), tibia (lower-leg bone) or humerus or radius (bones in the arm) is usually affected. In an adult, the pelvis or spine is usually affected. It can affect both sexes and all ages, but is more common in rapidly growing children (5 to 14 years), especially males.

Frequent signs and symptoms
- Fever. Sometimes this is the only symptom.
- Pain, swelling, redness, warmth and tenderness in the area over the infected bone, especially when moving a near by joint. Nearby joints, especially the knee, may also be red, warm and swollen.
- If a child is too young to talk, signs of pain are reluctance to move an arm or leg or refusal to walk; limping; or screaming when the limb is touched or moved.
- Pus drainage through a skin abscess, without fever or severe pain (chronic osteomyelitis only).
- General ill feeling.

Causes
Usually staphylococcal infection, but many other bacteria may be responsible. The bacteria may spread to the bone through the bloodstream from the following sources.
- Compound fracture or other injury.
- Boil, carbuncle or any break in the skin.
- Middle-ear infection.
- Pneumonia.

Risk increases with
- Illness that has lowered resistance.
- Rapid growth during childhood.
- Diabetes mellitus.
- Implanted orthopedic device (artificial knee).
- Intravenous drug use.
Health Care Participation

**Preventive measures**
Obtain prompt medical treatment of any bacterial infection to prevent its spread to bone or other body parts.

**Expected outcome**
Usually curable with prompt and aggressive treatment.

**Possible complications**
- Abscess that breaks through the skin and won’t heal until the underlying bone heals.
- Permanent stiffness in a nearby joint (rare).
- Fracture.
- Loosening of implanted orthopedic device.
- May require amputation if circulation is blocked or severe gangrene infection occurs (rare).

**Treatment**

**General measures**
- Diagnostic tests may include laboratory blood studies and blood cultures to identify the bacteria, radionuclide bone scan, CT or MRI scans. X-rays often don’t show changes until 2 to 3 weeks after the infection begins.
- Treatment involves medications, rest and other supportive measures.
- Keep the involved limb level or slightly elevated and immobilized with pillows. Don’t let it dangle.
- Keep unaffected parts of the body as active as possible to prevent pressure sores during required, prolonged bed rest.
- Hospitalization may be necessary for surgery to remove pockets of infected bone, and/or to administer high doses of antibiotics sometimes intravenously.
- A previously implanted orthopedic device (artificial, knee) may need to be removed (sometimes a replacement can be implanted at the same time).

**Medication**
- Large doses of antibiotics. With powerful new antibiotics, intravenous administration, once a necessity, may no longer be needed. Antibiotics may be necessary, either orally or by injection for 8 to 10 weeks.
- Pain relievers.
- Laxatives, if constipation develops during prolonged bed rest.

**Activity**
Rest in bed until 2 to 3 weeks after symptoms disappear. Resume your normal activities gradually.
**Diet**
No special diet. Eat a nutritionally balanced diet. Take vitamin and mineral supplements if needed.

**Notify our office if**
You or your child has symptoms of osteomyelitis.
The following occur during treatment:
• An abscess forms over the infected bone, or drainage from an existing abscess increases.
• Fever.
• Pain becomes intolerable.
• New unexplained symptoms develop. Drugs used in treatment may produce side effects.

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