

HEALTH CARE PARTICIPATION

Skills to Be Learned

- 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

Being in recovery means being willing to make changes in your lifestyle. 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 chapter, 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 chapters, we cover specific strategies for reducing risk of infection so we will not do that here. What we will be doing in this chapter 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.

PATIENT

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

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

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 shown in the illustration, 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?

Do you know your Patient IQ?

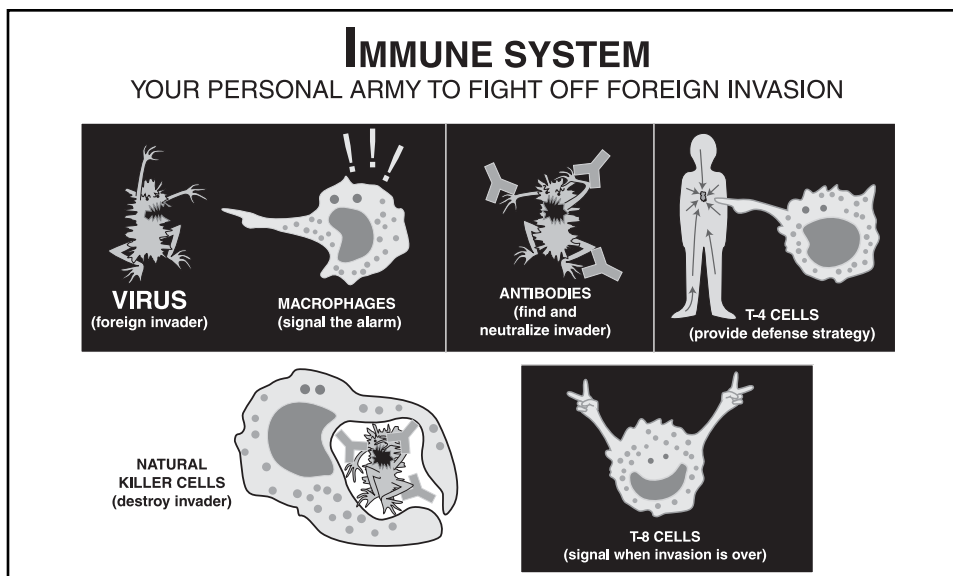
**Inform &
Question**

The first thing you need is a high Patient IQ. As shown in the illustration, 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.

Be informed about your immune system:

Your body's defense against infection is your immune system. The immune system is extremely complex. This illustration 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 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.

The names of some of the cells in the immune system are shown in the illustration and also described below:

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 about your immune system responds when it has been exposed to HIV.

Be informed about HIV

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

How HIV is transmitted

HIV stands for the human immunodeficiency virus (HIV). As its name implies, it weakens the immune system, your body's defense against infection. 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

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

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 vaginal, 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.

How to protect yourself from exposure to HIV:

- 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 just described 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

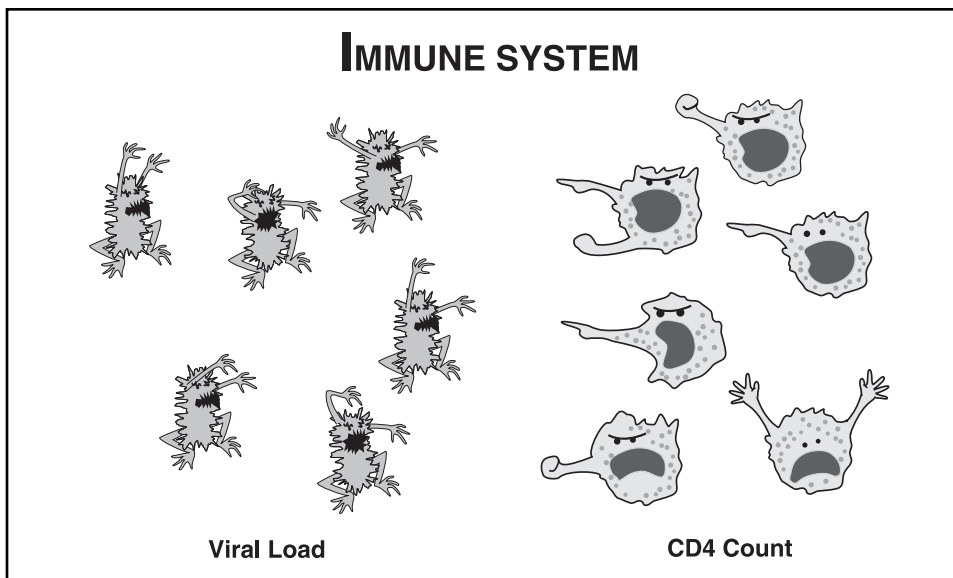
If you test negative:

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 detectable 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, otherwise they can unknowingly infect others.

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.



This illustration 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.

As shown in the illustration, 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.

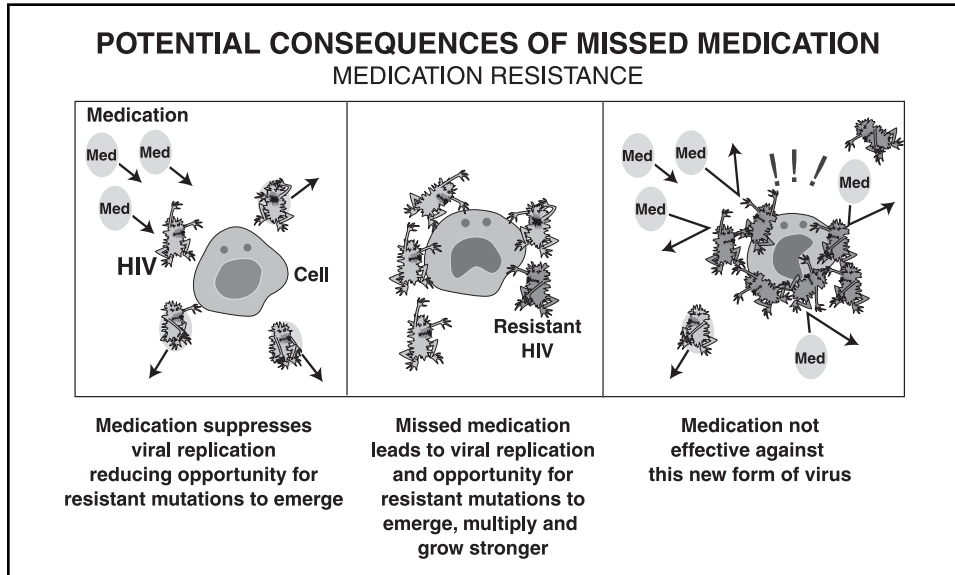
Treatment—HIV medications and importance of medication adherence:

Individuals who are infected with HIV may have to take a number of different medications, referred to as HAART—which stands for “highly active antiretroviral 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; some virus remains even though it cannot be detected by a blood test.**

Medication-resistant HIV

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



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:

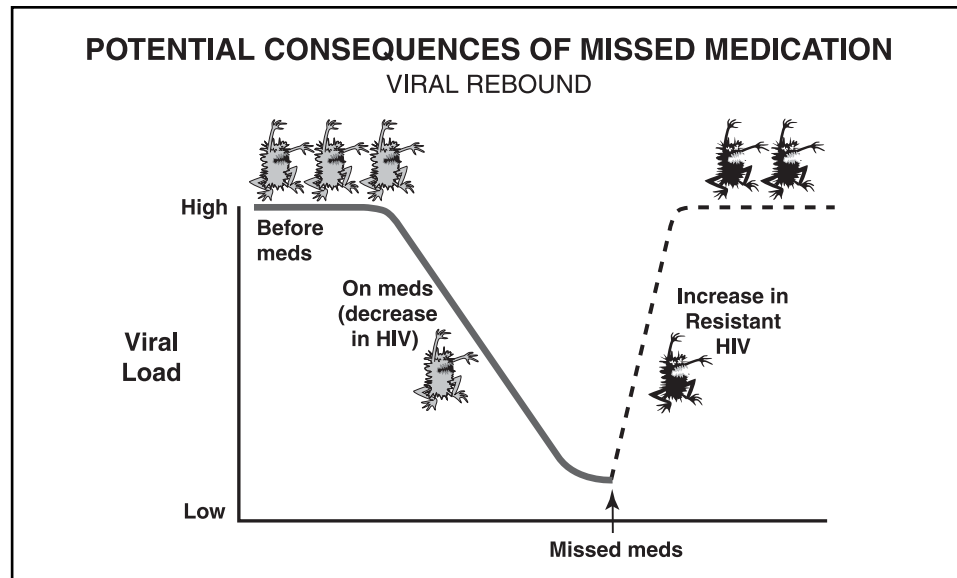
- The medications that the patient is currently taking will no longer be effective in reducing viral load.
- Alternative medications may also be ineffective against this form of the virus.

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 you are 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

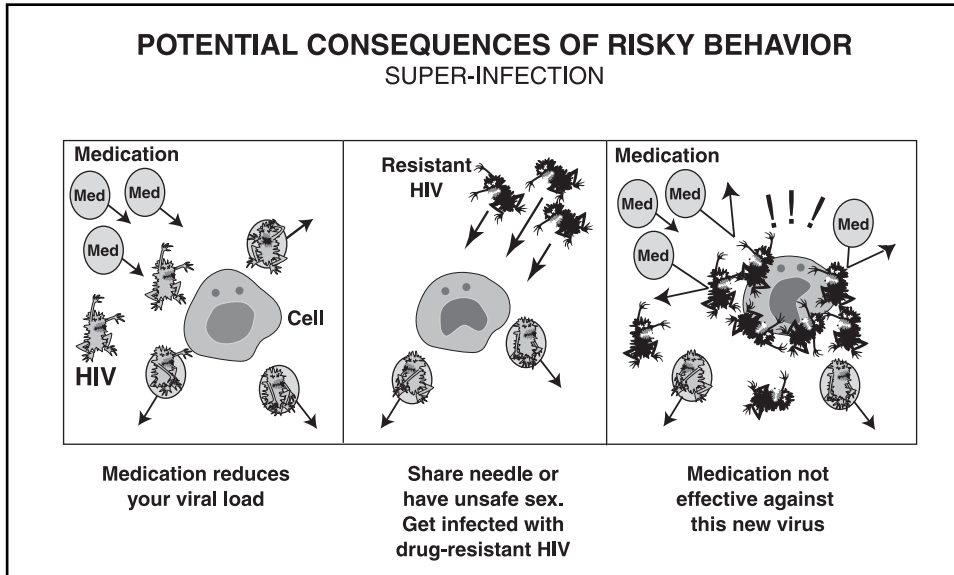
As shown in the illustration, if you are HIV-positive, medication may reduce your viral load (the number of foreign invaders), but if you stop taking it against the advice of your doctor:



- 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

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, as shown in the illustration, 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. 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.

Below is a summary of the important points to remember about HIV testing:

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.

Be Informed about Hepatitis:

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

Viral Hepatitis- An Overview					
Type of Hepatitis					
	A	B	C	D	E
Source of virus	feces	blood/ blood-derived body fluids	blood/ blood-derived body fluids	blood/ blood-derived body fluids	feces
Route of transmission	fecal-oral	percutaneous permucosal	percutaneous permucosal	percutaneous permucosal	fecal-oral
Chronic infection	no	yes	yes	yes	no
Prevention	pre/post- exposure immunization	pre/post- exposure immunization	blood donor screening; risk behavior modification	pre/post-exposure immunization; risk behavior modification	ensure safe drinking water

As shown in the illustration, there are five types of viral hepatitis. Hepatitis A, B, C, D, and E. In this chapter, we will focus 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. At the end of this chapter, you will find information about hepatitis B and C that is provided by the Centers for Disease Control and Prevention (CDC). The major points are also covered below:

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.

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

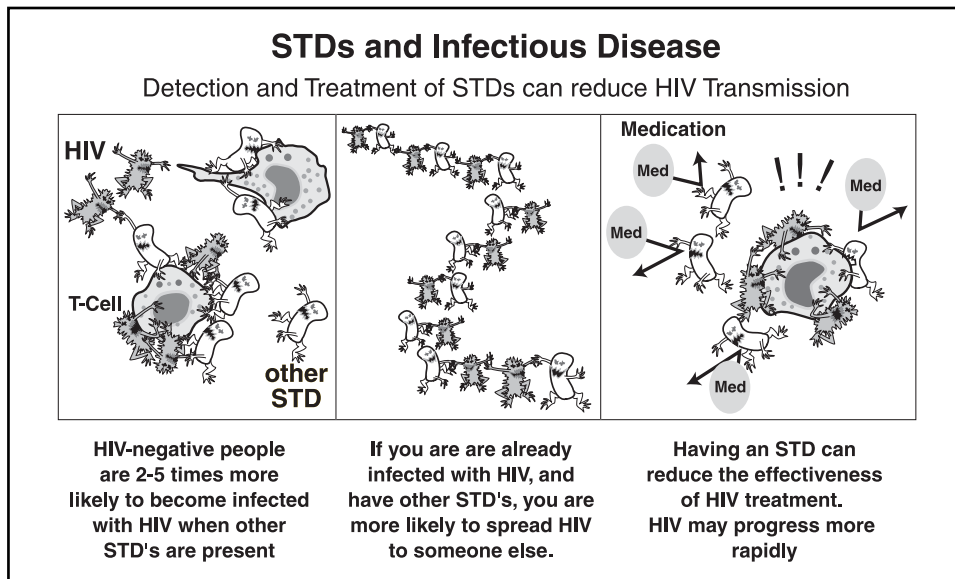
- See a doctor for additional tests to find out if you need treatment now.
- A doctor will take more blood from you and test it to see if HBV or HCV is damaging your liver.
- A doctor may also perform other tests to see how much damage has already been done to you.
- Do not drink alcohol; alcohol contributes 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.



There is now strong evidence that other STDs increase the risk of HIV transmission and, conversely, that STD treatment reduces the spread of HIV. As shown in the illustration, 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.

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"

As shown in the illustration, some of the reasons why people who use cocaine are at increased risk are:

- 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.

Getting Regular Medical Care

Developing a partnership with your health care providers

Getting regular medical care is important, 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.

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

As shown in the illustration, 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.

Health Care Participation

- 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.

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

The Q stands for QUESTION.

Question

THERE IS NO SUCH THING AS A STUPID QUESTION

- ask about treatment options
- ask for information to be written
- ask about medications
 - purpose
 - duration of treatment
 - expected time to desired outcome
 - possible side affects
 - consequences of missing or stopping medication
 - interaction with other drugs
- ask to be given a reminder before next appointment
- ask for an explanation if you do not understand

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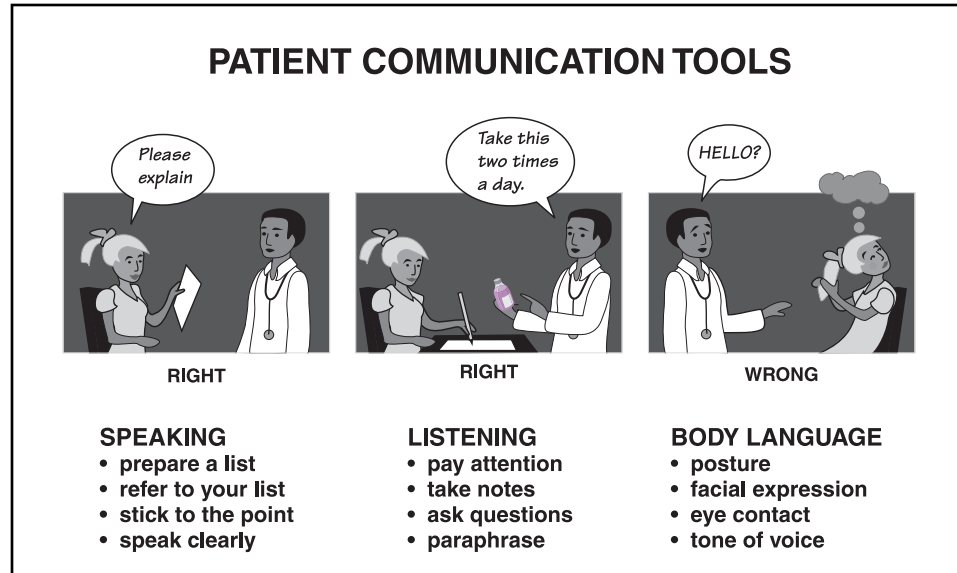
You should never be embarrassed to ask questions. Remember the only stupid question is the one that wasn't asked. You have a right to know what some one else is suggesting you do with your own body. So, as the illustration shows, if your health care provider informs you that you have a health problem, 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 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.

Communication skills needed for being a positive participant in your health care

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.



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

Medication adherence skills

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 earlier in this chapter, 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:

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. Examples of some of the costs and benefits of taking and not taking medications as prescribed for a hypothetical patient, we'll call Pat, are shown in the illustration.

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

Cost:Benefit Ratio = 1:2

For Patient Pat, the perceived costs of taking medication include concern about side-effects, inconvenience, concern about confidentiality, concern about interaction with cocaine, concern about what will happen if a dose is missed, financial concerns, diet restrictions, and difficulty swallowing pills. Next to each of these "costs" is a rating of personal importance from 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.

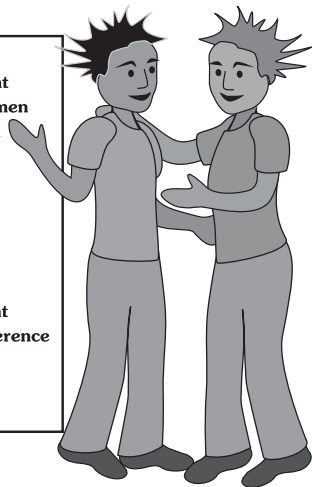
A “medication buddy” is someone who can help you adhere to your medication regimen. However, care needs to be taken in selecting this “medication buddy.”

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



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 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.



As shown in the illustration, these can include:

- a) Using a daily planner/appointment book and referring to it daily.
- b) Using computerized reminders that provide an alarm or signal when medication is due.
- c) Using alarm clocks, and beepers.
- d) Placing post-it notes in conspicuous places (e.g., refrigerator, bathroom mirror).
- e) Identifying cues in daily life that can serve as reminders (e.g., meal times, favorite TV shows).
- f) Location—medication placement (e.g., keeping medications next to something in your house that you know you will see at the time the medication is to be taken, such as next to the bed if medication to be taken upon awakening or retiring).

- g) Using pill organizers that contain all the pills that need to be taken at any given time. If you don't use a pill organizer, you should get into the habit of taking your medications in a specific order and setting the container aside, so that you know which ones you have already taken.
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. Write these on your Patient Information Sheet, located at the end of this chapter, and keep it updated.

Review

In this chapter we have emphasized 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 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 medica-

tions 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:

- Become informed and ask questions
- Stop or at least reduce drug use
- Get tested regularly for HIV, hepatitis B and C, and STDs
- If you are HIV-negative do not engage in high risk behavior
- If you are HIV-positive, take all your medications exactly as prescribed
- If you are HBV-negative, get vaccinated
- If you are HBV- or HCV-positive, reduce or stop alcohol consumption;
- Get regular preventive medical care
- Provide your health care provider with information, including any drug use or other high risk behaviors
- Develop good communication skills to help you become an active and positive participant in your health care
- Take all medications exactly as prescribed.

Read and review this chapter until you completely understand how it can affect your life and the lives of others. Share what you learn with 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.

Practice Exercise: Medication Adherence

Instructions

On the Medication Adherence Worksheet at the end of this chapter is a hypothetical medication regimen for Patient Pat whose cost-benefit analysis you saw earlier. Patient 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 is:

1. Propose a medication schedule that Pat can follow (a blank schedule is provided on Page 2 of the Worksheet).
2. 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).
3. Recommend memory aids that Pat can use on a daily basis.

Quiz

1. HIV is spread by casual contact and insect bites.
 - 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. For which of the following infectious diseases is there a vaccine that can prevent people from getting it?
 - a. HIV
 - b. hepatitis B
 - c. hepatitis C
 - 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 10-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 participate more fully in your health care. So use this time now to practice becoming centered, relaxed, and focused on your new healthy lifestyle.

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

HHRP

Perceived Costs	Importance Rating (0-10)	Perceived Benefits	Importance Rating (0-10)
TOTAL costs		TOTAL benefits	

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.

Medication Name	Dose	Special Instructions	Date Discontinued

Other Drugs Used.

Drug name	Amount/Frequency	Date Discontinued
Alcohol		
Nicotine		
Opiates		
Cocaine		
Benzodiazepines		
Marijuana		
Other:		

“Alternative” or “Complementary” Therapies Used.

Drug name	Amount/Frequency	Date Discontinued
Acupuncture		
Herbal remedies		
Nutritional supplements		
Other		

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.

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

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) _____

Health Care Participation

Using the letters A, B, C, D to represent the prescribed medications, create Pat's daily medication schedule below (No. = number of pills).

Time	A, B, C, D	No.
6:00 AM		
6:30		
7:00		
7:30		
8:00		
8:30		
9:00		
9:30		
10:00		
10:30		
11:00		
11:30		
Noon		
12:30 PM		
1:00		
1:30		
2:00		
2:30		

Time	A, B, C, D	No.
3:00 PM		
3:30		
4:00		
4:30		
5:00		
5:30		
6:00		
6:30		
7:00		
7:30		
8:00		
8:30		
9:00		
9:30		
10:00		
10:30		
11:00		
11:30		
Midnight		

Medical Language Statement

HHRP

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.

HIV / AIDS

HHRP

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).

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 detectable 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.

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 or 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.

- **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.

Hepatitis C Prevention

HHRP

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.

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.

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

HHRP

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.

Osteomyelitis

HHRP

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.

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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