STEPS to Care Workbook

Partners In Health

STEPS TO CARE

This guide was adapted from material written by Heidi Behforouz, M.D. and staff of Boston's Prevention and Access to Care and Treatment (PACT) project, a project of Brigham and Women's Hospital and Partners in Health (PIH), a non- profit organization dedicated to providing a preferential option in health care for the poor. It is distributed by the New York City Department of Health and Mental Hygiene through their Care Coordination Program.

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Introduction

As a participant in the STEPS to Care Program, you are taking a step forward to improve your health. Together with your Patient Navigator, you will work through our educational and empowering curriculum to help you live a healthy life.

The goal of this workbook is to teach you more about HIV and your medications. We will also talk about personal things in your life, like relationships and certain risky behaviors. Together, we will think about the different challenges in your life and your support network.

The ultimate goal of the program is to help you become adherent to your medications, which means that you will learn to take your medications everyday as prescribed by your doctor. We understand that this is not always easy, and there are many things that can get in the way. We will help you identify barriers and support you as you work through them. You can live a healthy and fulfilling life with HIV.

What is HIV?

HIV is a **virus** that can make you sick.

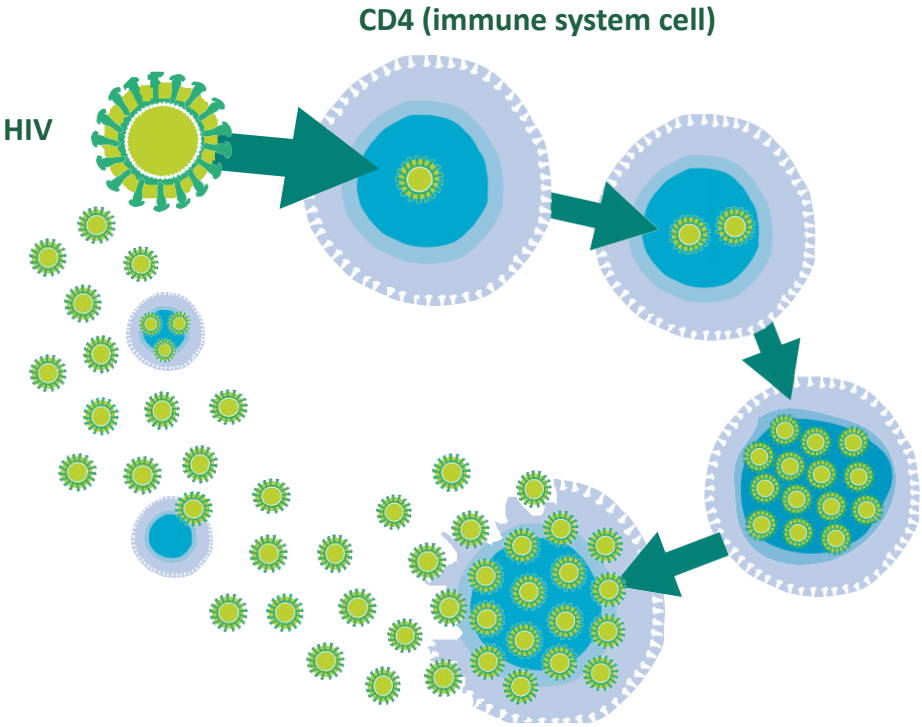
Viruses are small, infectious particles that can enter cells in your body. They can change the way cells function and even destroy them.

The flu, chicken pox and hepatitis are common viruses. Some can weaken your immune system. HIV is one of those viruses.

Your **immune system** protects your body by fighting off infections.

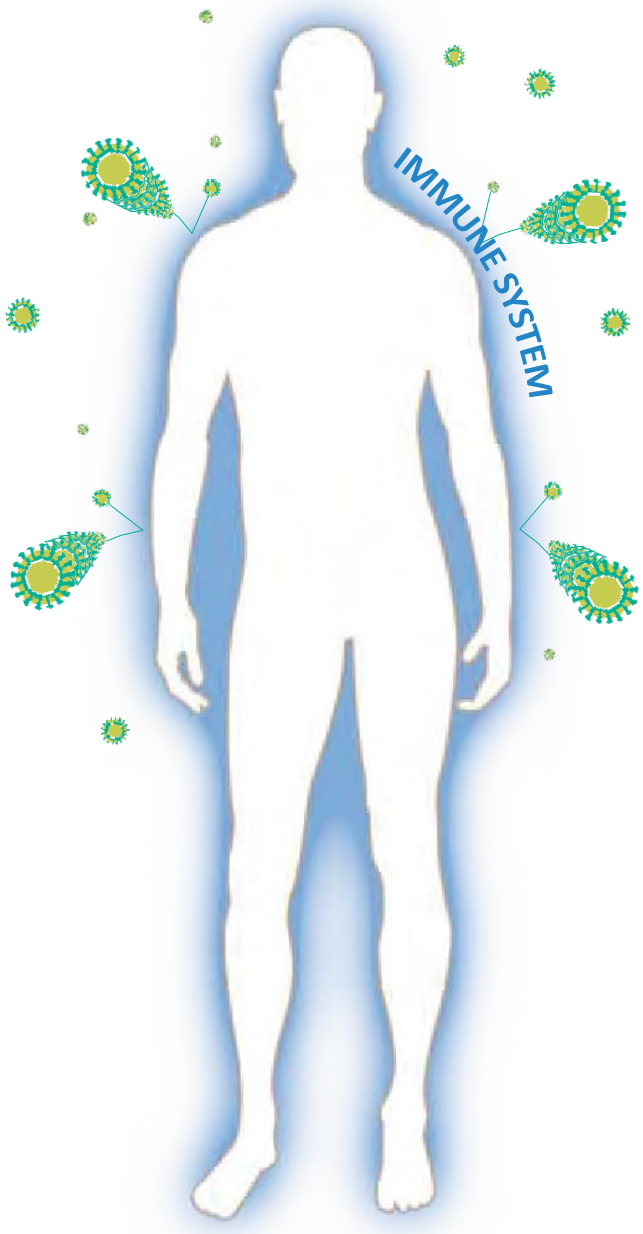
Your immune system is made up of many different cells that work together to protect your body against illness, including infections and certain cancers.

You can get more information here:
https://www.cdc.gov/hiv/basics/whatishiv.html.

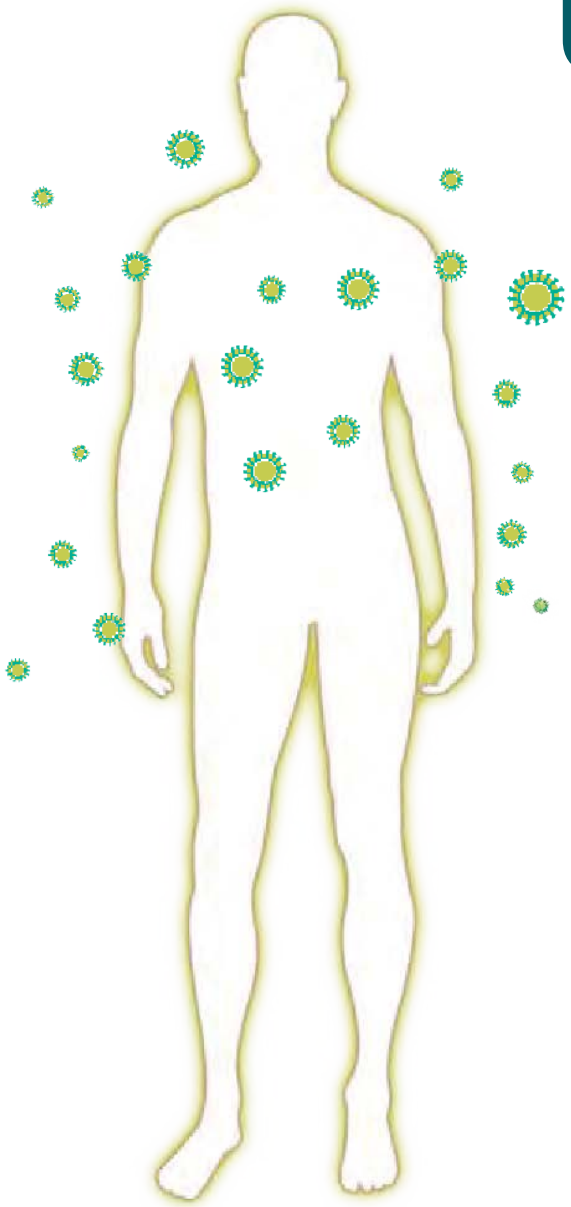


What is Your Immune System?

Your **immune system** protects your body by fighting off infections. It is made up of many different cells that work together to fight harmful organisms like bacteria, viruses, parasites and other things that can make you sick.



Strong Immune System
(fights off infections)



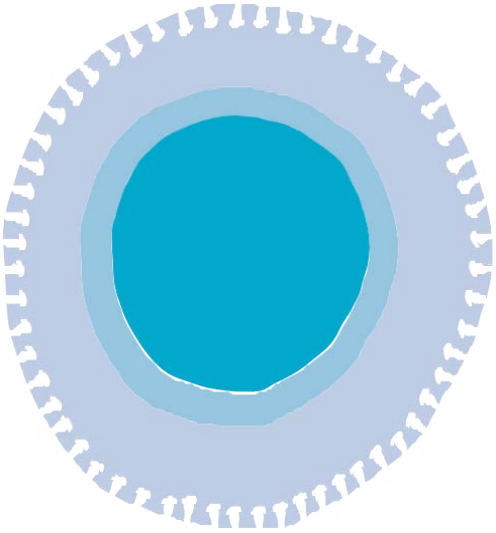
Weak Immune System
(can't fight off infections)

What are CD4 Cells?

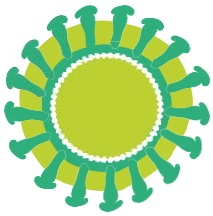
CD4 cells, also known as helper T cells or T cells, are an important part of your immune system. CD4 cells fight off infections and keep you from getting sick.

The more CD4 cells you have in your body, the healthier you'll be.

HIV attacks and destroys your CD4 cells. Taking your HIV medications helps keep HIV from destroying your CD4 cells.



CD4 or T Cell



HIV

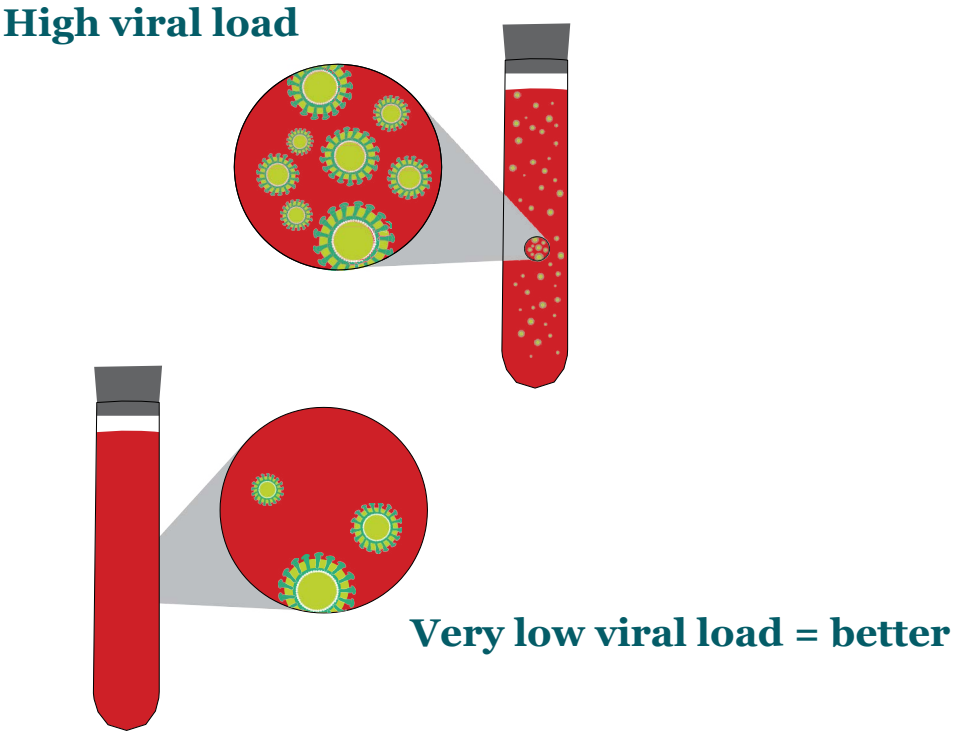
A healthy adult has between 500-1600 CD4 cells.
Your doctor tests your CD4 cell level to track how healthy you are and to see if your medications are working. Doctors now recommend starting ART right away, regardless of CD4 count. The goal is to protect enough CD4 cells so your immune system stays healthy.

What is a Viral Load?

The amount of **HIV** in your blood can be measured. This amount is called your **viral load**. Taking your medications every day, as prescribed, can get your viral load down to a very low or even undetectable level. An undetectable viral load, means the amount of virus in your blood is so low that it can't be detected. If your viral load is very low or undetectable, then the virus is under control to keep you healthy.

Q: Why is it important to have an undetectable viral load?

A: When your viral load is undetectable, you have the best chances of staying healthy. And if you take your HIV medication the right way every day and keep your viral load undetectable, then you have effectively no risk of transmitting HIV during sex.



What is AIDS?

ACQUIRED means you developed the disease and were not born with it.

IMMUNE means your immune system - your body's ability to protect you from diseases.

DEFICIENCY means a weakness in your body's system to fight disease.

SYNDROME is a group of health problems that make up a disease.

AIDS is the **most severe phase of HIV infection**. People with AIDS have such badly damaged immune systems that they get an increasing number of severe illnesses, called opportunistic illnesses.

Common symptoms of AIDS include chills, fever, sweats, swollen lymph glands, weakness, and weight loss. People are diagnosed with AIDS when their CD4 cell count drops below 200 cells/mm or if they develop certain opportunistic illnesses. People with AIDS can have a high viral load and be very infectious.

How Does HIV Become AIDS?

You don't actually "get" AIDS. Instead, a person with HIV may develop AIDS.

The word AIDS is used to describe when a person's CD4 cells are very low and his or her immune system can't protect the body from infections. You have AIDS if HIV destroys too many CD4 cells and your CD4 count drops below 200, or if you develop an opportunistic infection (an infection by something that normally does not cause disease unless the body's immune system is damaged and unable to fight off infection).

Taking your medication can prevent you from developing AIDS because it keeps your CD4 count up and your viral load down.

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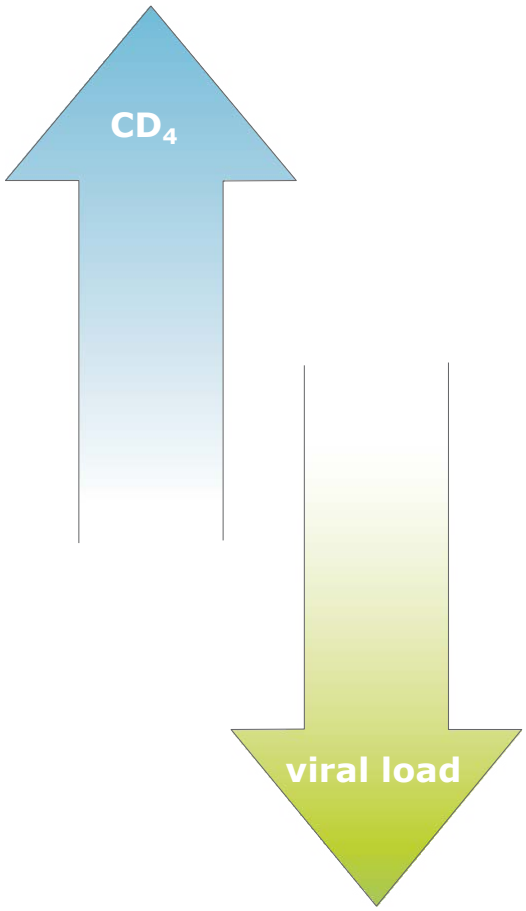
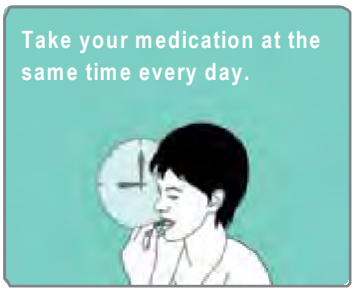
https://www.cdc.gov/hiv/basics/whatishiv.html.



What is Adherence?



The word adherence means to stick to or stay with something. Adherence is very important when taking your HIV medications. Taking them at the right time every day, as prescribed, is important to staying healthy.

ART: ART stands for anti-retroviral therapy, and means the same thing as HIV medications.

Taking your HIV medication on time and in the correct way will help you fight HIV. Your medication controls your viral load (which you want low) and your CD4 count (which you want high).

Adherence is

- Taking the right number of pills for the entire length of time necessary
- Taking medication at the same time every day
- Taking medication at the right number of hours apart
- Taking medication according to dietary instructions
- Following instructions about mixing your medication and other substances

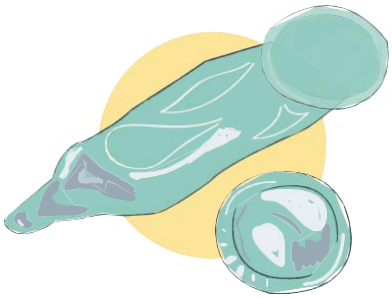
Why is adherence important?

- Taking your HIV medication the right way every day is the most important thing you can do to stay healthy. This keeps the virus under control so it doesn't replicate, or multiply in your body, and damage your CD4 cells. Not taking your medication regularly could make the virus resistant to the medication; this means the medication becomes less effective in fighting the HIV virus.

- If you are a pregnant woman, taking your HIV medication the right way every day protects your baby from HIV during pregnancy and delivery.
- If you take your HIV medication the right way every day and keep your viral load undetectable, then you have effectively no risk of transmitting HIV during sex.

What is Harm Reduction?

Practice safe sex

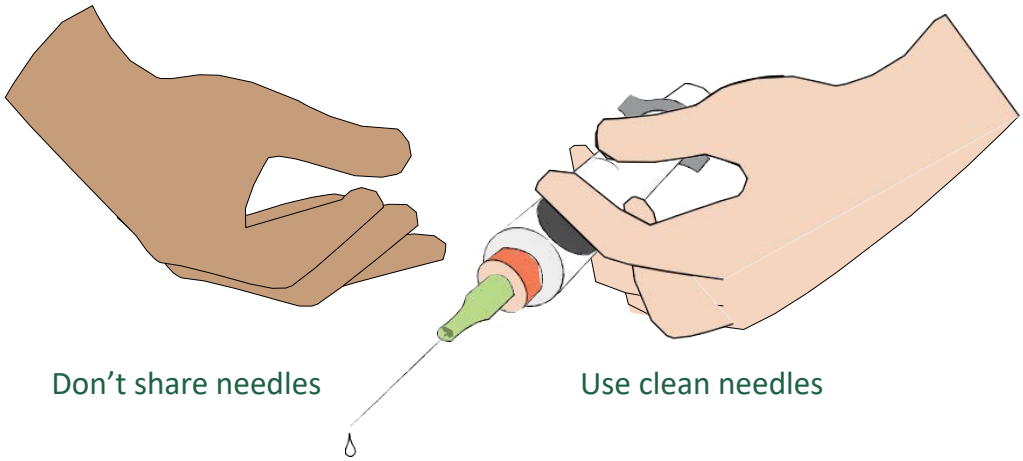


Harm reduction is any behavior or strategy that helps reduce risk or harm to yourself or others. For example, to reduce the risk of contracting or transmitting HIV, you can practice safer sex or safer drug use.

Another example of harm reduction for HIV is to decrease or stop drug using so it doesn't interfere with taking your medications.

One thing you can do to protect yourself is to learn how your behavior affects your adherence.

You can also protect others from HIV by practicing safer sex and safer drug use.



Don't share needles

Use clean needles

TOOLS

Medication List

Medication Name	What Does This Medication Treat?	How Many Times a Day?	How Many Pills Each Time?	With/Without Food? (circle)	Other Instructions	Possible Side-Effects	Things to Watch For
		____ x					
		____ x					
		____ x					
		____ x					
		____ x					
		____ x					
		____ x					

How to Read a Pill Bottle

Pharmacy Name and Pharmacy Address

Medication Name

Directions (How Much to Take)

Quantity and Refill Information

Pharmacy Number

Prescription Number

Doctor

Filling a Pillbox

- ☐ Keep all medications in one location.
- ☐ Look at your medication list to make sure you have all your medication.
- ☐ Start filling your pillbox with the first medication on your daily chart and continue in order.
- ☐ Pay attention to the color, size and shape of each pill.
- ☐ Check that all pills are placed correctly.
- ☐ Keep pillbox in an easy-to-find place.

Pharmacy Information

Pharmacy	
Pharmacy Name	Pharmacy Phone
Address	
Contact	
Doctor's Office (for refills)	
Allergies	
Notes	

Insurance	Insurance
Plan Name	Plan Name
Member/Group ID	Member/Group ID
Effective Date	Effective Date
Address	Address
Phone	Phone

Date

Refilling Medication

How do you receive your medication?		
☐ Medication Bottles	☐ Blister Packs	☐ Pre-filled Pillbox

How to Refill Your Medication
☐ Call for a refill. Be prepared to tell the pharmacy your name, date of birth and insurance information. Keep your pharmacy information tool handy.
☐ Arrange for medication delivery or transportation to the pharmacy.
☐ Pick up your medications. If you have questions ask the pharmacist.
☐ Check your medications. Do they look different than they normally look? If so, check with your pharmacy before taking it.
☐ Fill your pillbox.

Prescription Refills: Barriers and Solutions

Barriers	Solution
No refills left	• Call your doctor or clinic. Call or email your doctor or clinic, or request a renewal on your patient website/portal if available. • Ask if he/she can renew the prescription. • Try to call for a new prescription at least two weeks before it runs out.
Your insurance changed and no longer covers the medication	• Contact your doctor or clinic. • Ask him or her to submit a Prior Authorization form to the insurance company. • Once your medication is authorized order refills. • If it is refused by the insurance company, you may have to switch drugs. (Contact your doctor or clinic)
Your insurance plan expired	• To find out more about Medicaid and applying for Medicaid, go to Medicaid.gov to find contact information on Medicaid offices and services in your state. • Your patient navigator can help you find the resources you need and make an appointment with the right office. • If your medication will run out in less than a week, go to your hospital's benefits office or the hospital affiliated with your clinic to see if you can get a few days of medication for free. • If this doesn't work, call your doctor or clinic. He or she may be able to help get the medication.

Prescription Refills: Barriers and Solutions (cont.)

Barriers	Solution
The pharmacy is out of your medication.	• Ask your pharmacy to order it. Remember to get refills before you run out.
You can't pick up your refills.	• Contact the pharmacy and ask if they can deliver or mail the medication. • See if a friend or family member can pick it up before you run out.
You can't afford the co-pay.	• Contact your Patient Navigator
Your pharmacy gave you the wrong medication.	• Return it right away and talk to the pharmacist.
The person to whom you feel comfortable talking with at the pharmacy is out for the week.	• Contact your Patient Navigator

Daily Routine Chart

Questions To Ask

Sleeping

- What time do you usually wake up each day
- What time do you go to sleep?
- Do you ever eat close to bedtime
- Do you have a routine that you do when you wake up?
- Do you have a routine that you do before going to sleep?

Eating

- What time do you usually eat?
- Who do you eat with? Would you feel comfortable taking pills in front of them?
- Where do you eat? Could you bring your pills with you?
- How do you feel about meal times?
- Are there ways to take your pills on a full stomach without interfering with the social and other pleasures of eating?

Comings and Goings

- What times do you usually leave the house?
- What times do you usually come back home?
- What other things do you do at about the same time every day such as watching TV programs, the kids leaving for school, etc.)

Weekends

- Repeat the above questions for the weekend or other irregular days.

Things to make it work

- If you need a full stomach at a time other than a normal meal time, try a fatty snack like crackers with peanut butter.

Reminders

- What can you do to remind yourself when its time to take your pills?
- What changes your schedule?

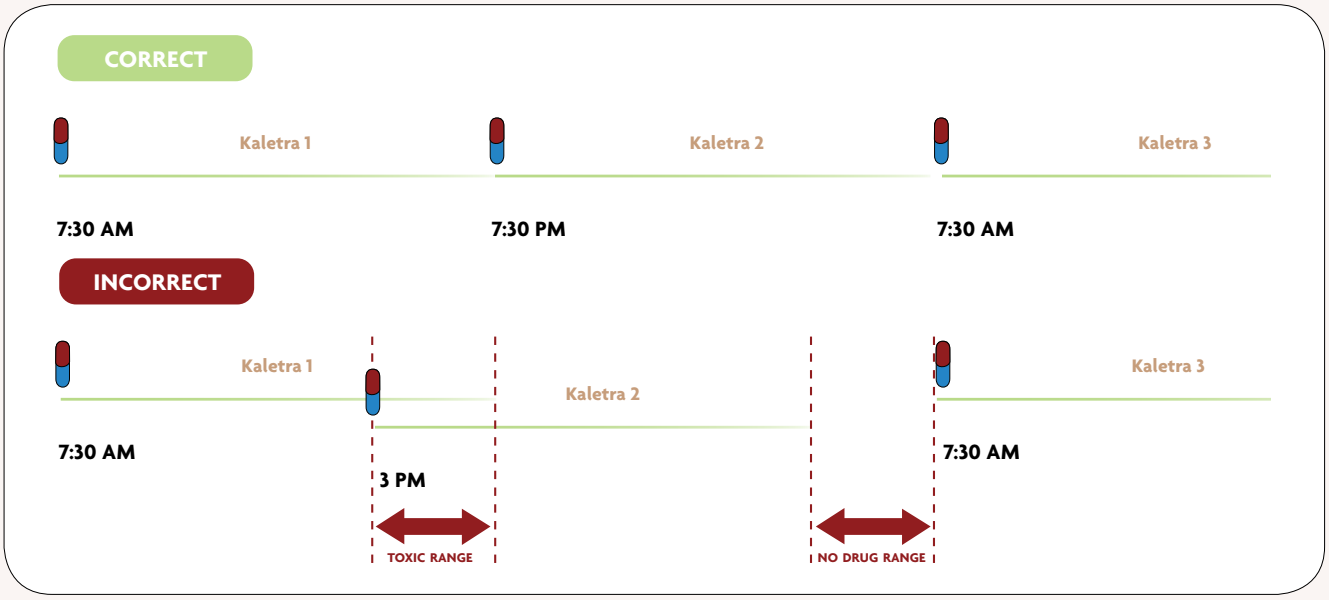
	Weekday	AM	Weekend
Medication name/ # of pills		6:00	
		7:00	
		8:00	
		9:00	
		10:00	
		11:00	

	Weekday	PM	Weekend
Medication name/ # of pills		12:00	
		1:00	
		2:00	
		3:00	
		4:00	
		5:00	
		6:00	
		7:00	
		8:00	
		9:00	
		10:00	
		11:00	

Pill Chart

Name of Medicine	Instructions	Time of Day Taken
		am pm
		am pm
		am pm
		am pm
		am pm

A Day in the Life of a Pill



Managing Side Effects

People with HIV can have many different symptoms and possible side effects of medication. It is important to discuss any symptoms with your doctor.

Call your doctor right away (or 911 if you can't reach your doctor) if you have:

- A rash or hives
- Rapid swelling, either in one area or over the entire body. Swelling is most serious when it involves the lips, tongue, mouth, or throat and interferes with breathing.
- Difficulty breathing or swallowing
- Low blood pressure, shock, and unconsciousness

Call your doctor within 24 hours if you have:

- Fever
- Confusion
- Abdominal pain
- Lightheadedness
- Severe weakness
- Severe headache
- Nausea or vomiting
- Jaundice (yellowing of the eyes and skin)
- Diarrhea including dark urine, lightheadedness, muscle cramps
- Blood in your stool

Talk to your doctor within a few days if you have:

- Muscle pain
- Mild weakness
- Mild headache
- Loss of appetite
- Changes in body fat
- Nerviousness or anxiety
- Burning or tingling in the feet
- Strange dreams or difficulty sleeping
- Any other symptoms that are troubling you

Symptoms Management Chart

Side Effect	Symptom Management	Important Notes
Diarrhea	• Try the BRAT diet (bananas, rice, applesauce, and toast). • Eat foods high in soluble fiber. This kind of fiber can slow the diarrhea by soaking up liquid. Soluble fiber is found in oatmeal, grits, and soft bread (but not in whole grain). • Try psyllium husk fiber bars (another source of soluble fiber). You can find these at health food stores and many groceries. Eating two of these bars and drinking a big glass of water before bedtime may help your diarrhea. • Your provider may recommend treatments such as calcium, loperamide (Imodium), methylcellulose (Citrucel), or psyllium (Metamucil). • Drink plenty of clear liquids. • Stay away from foods high in insoluble fiber, such as whole grains, brown rice, bran, or the skins of vegetables and fruits. These kinds of foods can make diarrhea worse. • Avoid milk products. • Don't eat too many greasy, high-fiber, or very sweet foods. • Don't take in too much caffeine. • Avoid raw or undercooked fish, chicken, and meat.	Contact your doctor if the diarrhea is bloody or continues for more than a day, if you have abdominal pain, or you start to become dehydrated.
Dry Mouth	• Rinse your mouth throughout the day with warm, salted water. • Carry sugarless candies, lozenges, or crushed ice with you to cool the mouth and give it moisture. • Try slippery elm or licorice tea (available in health food stores). They can moisten the mouth, and they taste great!	Ask your doctor about mouth rinse and other products to treat your dry mouth.
Fatigue	• Get plenty of rest. • Go to sleep and wake up at the same time every day. Changing your sleeping habits too much can actually make you feel tired. • Drink 8 to 12 glasses of water per day; if you want a caffeinated beverage, drink it in the morning. • Try to get some exercise every day. • Take a short nap during the day. • Decrease your work schedule if possible. • Keep prepackaged or easy-to-make food in the kitchen for times when you're too tired to cook. • Follow a healthy, balanced diet. Your VA health care provider may be able to help you create a meal plan.	Talk to your doctor about the possibility that you have anemia or other medical problems. Anemia means that you have a low red blood cell count, and it can make you feel tired.
Head-aches	For on-the-spot headache relief, try some of these suggestions: • Lie down and rest in a quiet, dark room. • Take a hot, relaxing bath. • Give yourself a "scalp massage"--massage the base of your skull with your thumbs and massage both temples gently. • Check with your doctor about taking an over-the-counter pain reliever, such as acetaminophen (Tylenol) or ibuprofen (Motrin, Advil). To prevent headaches from happening again, try the following: • Avoid things that can cause headaches, like chocolate, red wine, onions, hard cheese, and caffeine. • Reduce your stress level. • Drink 8 to 12 glasses of water per day.	Your doctor may be able to recommend some over-the-counter or prescription medications. If your pain is severe or lasts more than a day contact your doctor right away.
Nausea	• Eat smaller meals and snack more often. • The BRAT Diet (bananas, rice, applesauce, and toast) can help with nausea and diarrhea. • Keep dry crackers by your bed. Before getting out of bed in the morning, eat a few and stay in bed for a few minutes. This can help reduce nausea. • Try some herbal tea--such as peppermint or ginger tea. • Sip cold, carbonated drinks such as ginger ale.	Your doctor may be able to prescribe medications like Compazine.

Symptoms Management Chart (cont.)

Side Effect	Symptom Management	Important Notes
Nausea (cont.)	• Try eating ginger, such as in ginger tea, ginger ale, or ginger snaps. • Talk with your VA health care provider about whether you should take medicine for your nausea. • If you do vomit, be sure to "refuel" your body with fluids such as broth, carbonated beverages, juice, or popsicles. • Avoid things that can upset the stomach, such as alcohol, aspirin, caffeine, and smoking. • Avoid foods or smells that trigger nausea. • Avoid hot or spicy foods. • Avoid greasy or fried foods. • Don't lie down immediately after eating.	Contact your doctor right away if you vomit right after taking your medications or if you vomit several times in 24 hours.
Pain and Nerve Problems	• Massage your feet. This can help make the pain go away for a while. • Soak your feet in ice water to help with the pain. • Wear loose-fitting shoes and slippers. • When you're in bed, don't cover your feet with blankets or sheets. The bedding can press down on your feet and toes and make the pain worse. • Ask your doctor about taking an over-the-counter pain reliever to reduce the pain and swelling.	
Dry Skin	• Drink 8 to 12 glasses of water per day. • Avoid long, hot showers or baths. • Avoid soaps and skin products that contain alcohols or harsh chemicals. • Use moisturizing lotion after showers (such as Aquaphor, Absorbase, or Lac-Hydrin). • Use mild, unscented laundry detergents and avoid fabric softeners. • Use petroleum jelly on dry, itchy areas; your provider may recommend other agents to help. • Use sunscreen.	
Rash	• Avoid very hot showers or baths. Water that is too hot can irritate the skin. • Avoid being in the sun. Sun exposure can make your rash worse. • Try using unscented, non-soapy cleansers for bathing or showering. • Try rubbing or pressing on the itchy areas rather than scratching. • A rash that blisters, or involves your mouth, the palms of your hands, or the soles of your feet, or one that is accompanied by shortness of breath, can be dangerous: contact your care provider right away, or go to an emergency room for evaluation.	You should call your doctor to help find out what is causing the rash; you may need to go into clinic, as it is often difficult to treat a rash over the phone.
Weight Loss	• Be sure to keep track of your weight, by weighing yourself on scales and writing down how much you weigh. Tell your doctor if there are any changes. • Create your own high-protein drink by blending together yogurt, fruit (for sweetness), and powdered milk, whey protein, or soy protein. • Add dried milk powder, whey protein, soy protein, or egg white powder to foods (for example, scrambled eggs, casseroles, and milkshakes). • Between meals, try store-bought nutritional beverages or bars (such as Carnation Instant Breakfast, Benefit, Ensure, Scandishake, Boost High Protein, NuBasics). Look for ones that are high in proteins, not sugars or fats. • Spread peanut butter on toast, crackers, fruit, or vegetables. • Add cottage cheese to fruit and tomatoes. • Add canned tuna to casseroles and salads. • Add shredded cheese to sauces, soups, omelets, baked potatoes, and steamed vegetables. • Eat yogurt on your cereal or fruit. • Eat hard-boiled (hard-cooked) eggs. Use them in egg-salad sandwiches or slice and dice them for tossed salads. • Add diced or chopped meats to soups, salads, and sauces.	Your doctor can help monitor your weight over time and suggest resources and a safe program for maintaining your weight.

Symptom Management Action Plan

Side Effect	Impact on Adherence	Steps you are currently taking	What you can try now*	When to tell your PN or physician

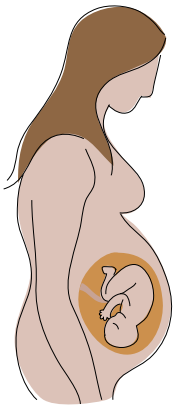
***See Symptoms Management Chart for Suggestions**

How is HIV Transmitted?

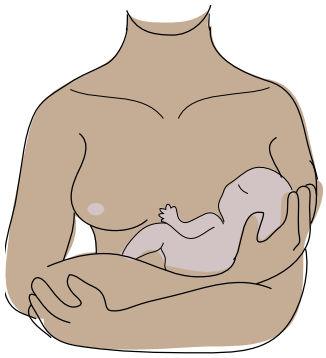
A person can get HIV from someone who is infected with the virus. Blood, breast milk, vaginal fluids, semen and pre-cum can carry HIV.

There is no way to tell if someone has the virus just by looking at them. The only way to know for sure whether you are infected is through a blood test.

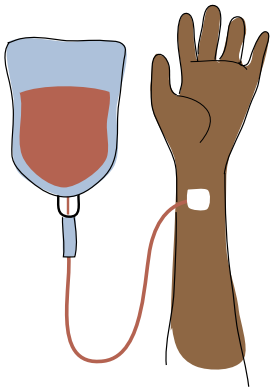
HIV can be transmitted by:



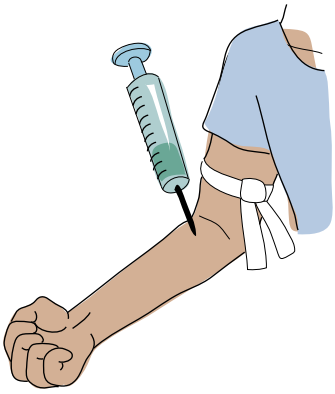
Someone who is HIV-positive and pregnant can pass the virus to their child



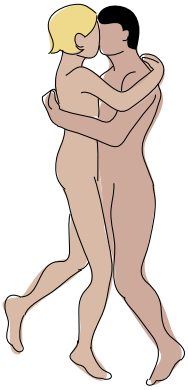
Someone who is HIV-positive and breastfeeding can pass the virus to their child



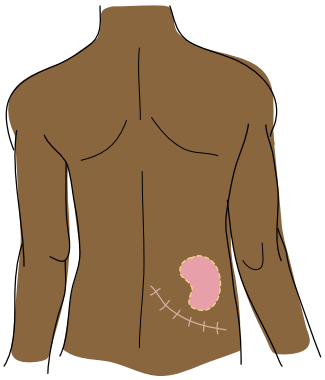
Blood transfusions



Sharing needles with someone who has HIV

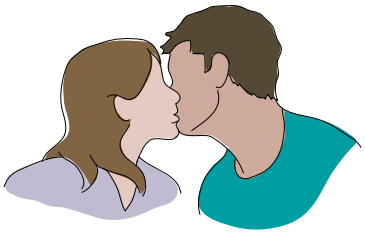


Unprotected anal, oral, or vaginal sex with a person infected with HIV

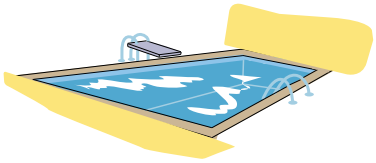


Transplanted organs from infected donors

You Can't Get HIV by:

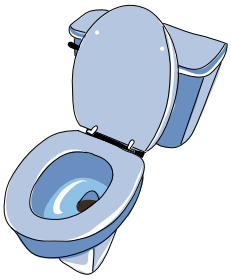


Kissing, touching or hugging



Going to a public bath or pool

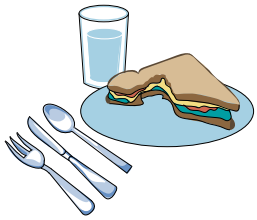
Sharing a telephone



Using a public or private bathroom

An insect bite

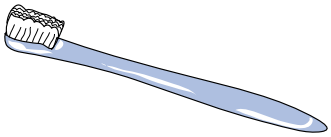
Coughing or sneezing



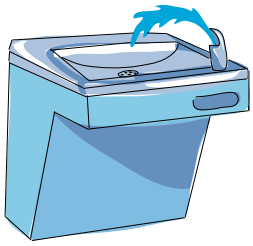
Eating foods prepared by someone who is infected with HIV

Shaking hands

Working or going to school with someone who is infected with HIV

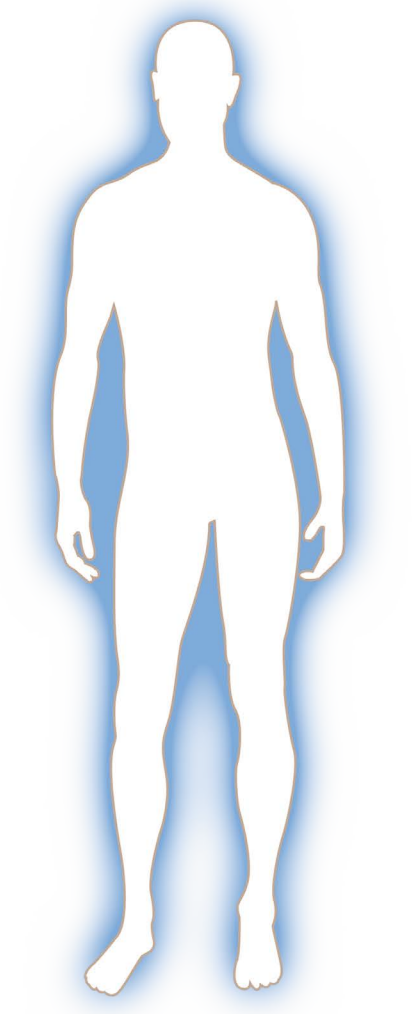


Sharing a toothbrush



Drinking from a public water fountain

Sites of Possible Infection



Notes:

Your CD4 Count and Viral Load

My CD4 count goal is:_____ My Viral Load goal is:_____

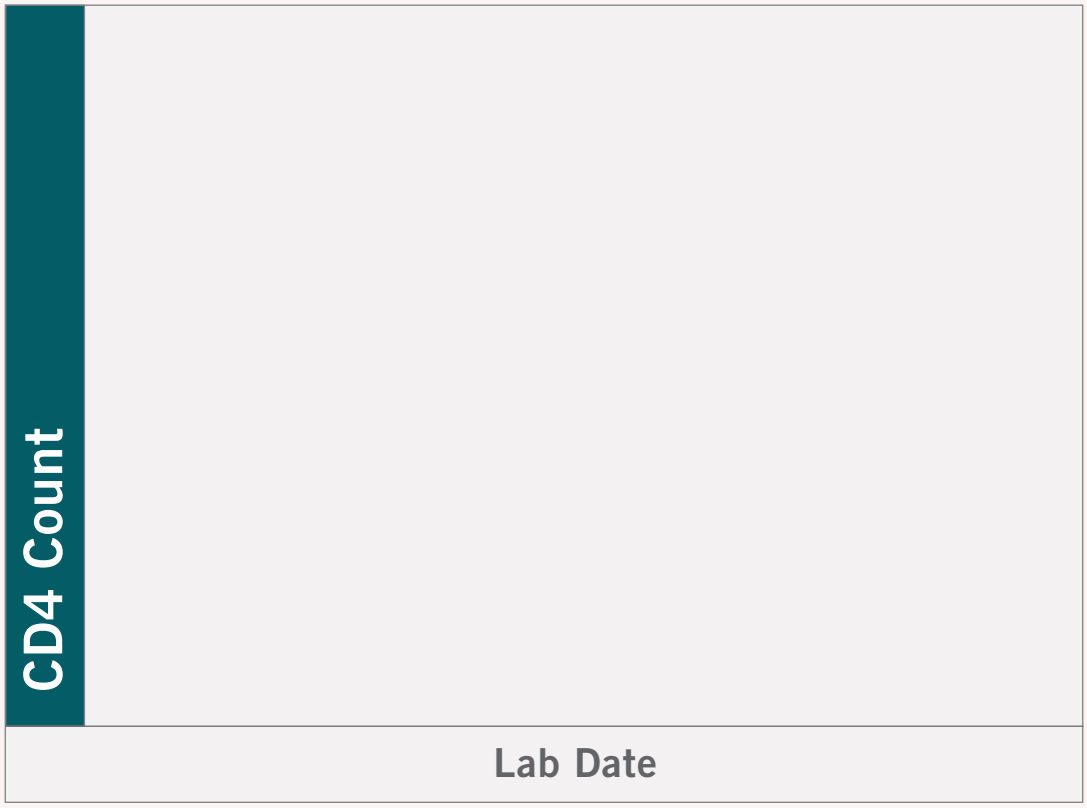
Lab Date	↑ CD4 Count	CD4 Trend	↓ Viral Load	Viral Load Trend

My CD4 and Viral Load Journal

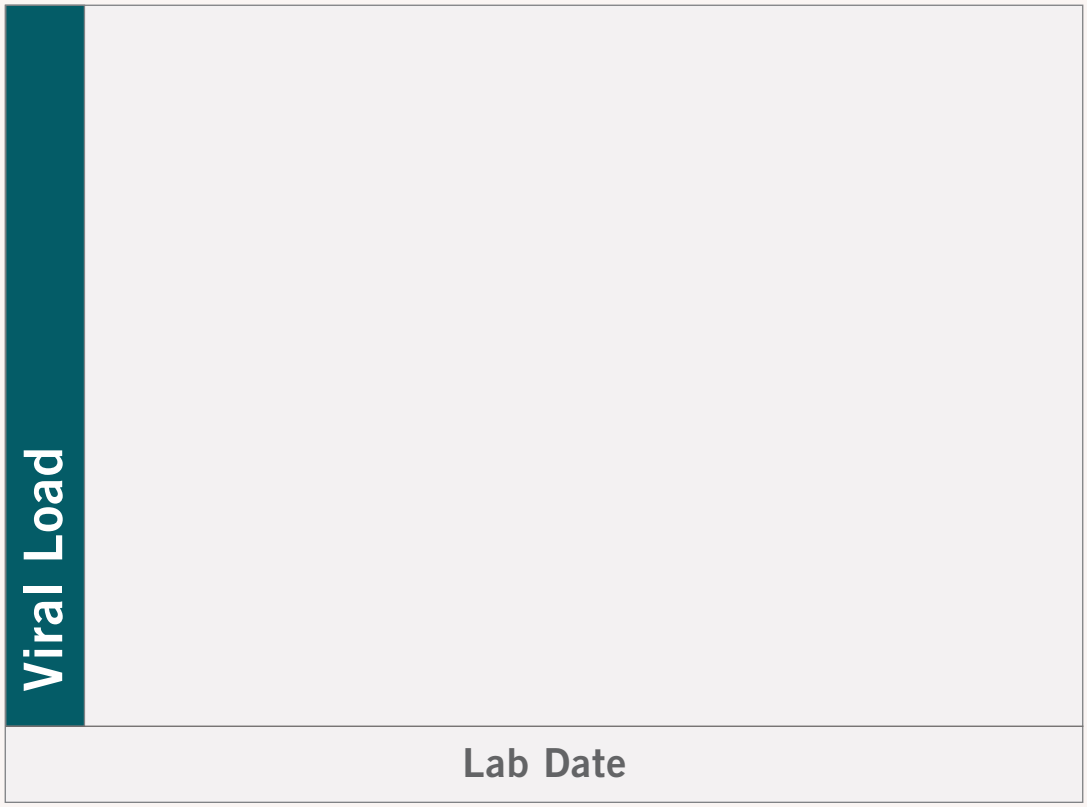
(See CD4 and Viral Load Graph on page 33)

	Notes related to my CD4 and viral load results
1	
2	
3	
4	
5	
6	
7	
8	
9	
10	
11	
12	
13	

CD4 Count Graph

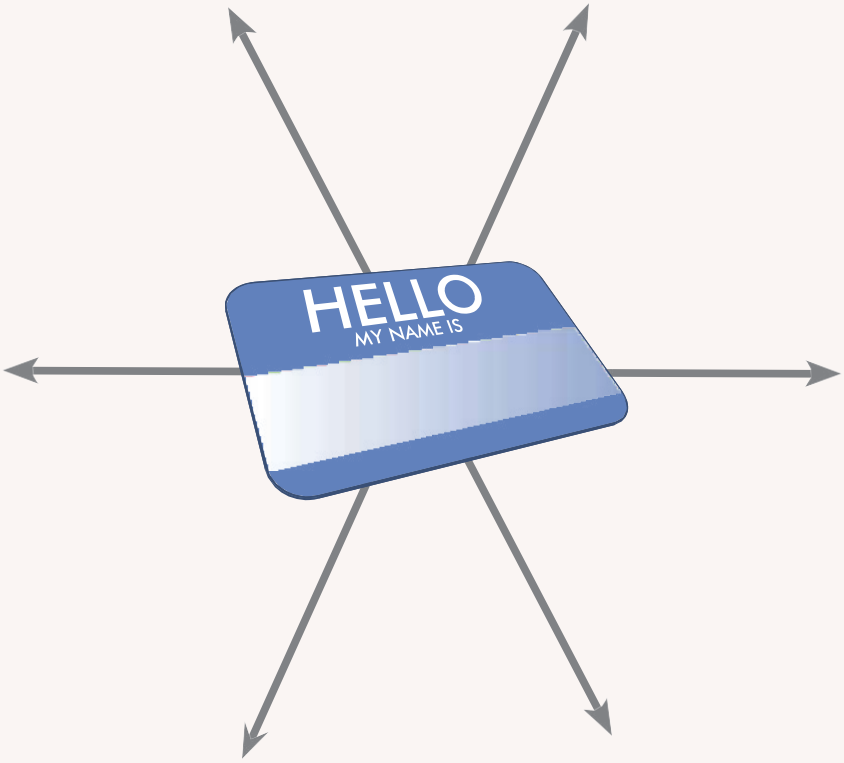


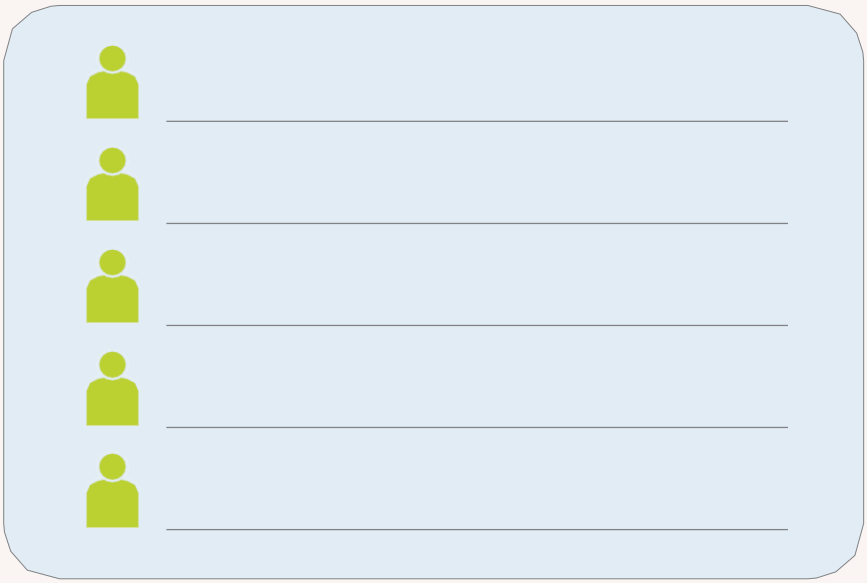
Viral Load Graph



My Support Network

Family Friends Medical Providers Social Services Community Services





My Support Network

People I've told about my HIV

Name	Reason for disclosure	Results

People I would like to tell about my HIV

	Pros	Cons

Talking to Others

CUT HERE

FOLD HERE

How do I talk about my illness?

How do people in my community talk about this illness?

How to talk about my illness with someone I care about

Contact Information

Relationship	Name	Phone Number	Address
Primary Care Providers			
Other Care Providers			
Community Support Services			
Other Supporters			

Personal Contacts

Name	Relationship	Phone Number	Address

Emergency Contact

Name	Phone Number

Wallet Cards

Important Contact Information

Name: _____ Relationship: _____
Phone: _____
Address: _____

Name: _____ Relationship: _____
Phone: _____
Address: _____

Name: _____ Relationship: _____
Phone: _____
Address: _____

FOLD

EMERGENCY CONTACT
Name
Phone Number:

FOLD

Insurance Plan _____
Member ID/Group # _____
Address _____
Phone Number _____

Insurance Plan _____
Member ID/Group # _____
Address _____
Phone Number _____

Insurance Plan _____
Member ID/Group # _____
Address _____
Phone Number _____

PHARMACY PLAN

Pharmacy: _____ Pharmacy Phone: _____

Pharmacy Address: _____

Pharmacy Contact: _____

Doctor's Office (for refills): _____

Drug Allergies _____

Adherence Issues

Issue	Plan	Support types needed	Supporter names

Adherence Strengths and Difficulties

Adherence Strengths	Adherence Difficulties
1.	1.
2.	2.
3.	3.
4.	4.
5.	5.

Health Maintenance Appointment Tracker

Medical Appointments

Quarterly HIV Provider Visits	
Last Appt:	Next Appt:
Last Appt:	Next Appt:
Last Appt:	Next Appt:
Last Appt:	Next Appt:
Quarterly Blood Tests	
Last Appt:	Next Appt:
Last Appt:	Next Appt:
Last Appt:	Next Appt:
Last Appt:	Next Appt:
Annual Pap Smear	
Last Appt:	Next Appt:
Annual Test for TB	
Last Appt:	Next Appt:
Annual Hepatitis B Test	
Last Appt:	Next Appt:
OR Hepatitus B Vaccination	
First Shot:	
Second Shot:	
Third Shot:	
Annual Hepatitis C Test	
Last Appt:	Next Appt:
Annual Dentist Visit	
Last Appt:	Next Appt:
Annual Ophthalmologist (eye) Visit	
Last Appt:	Next Appt:

FOLD

FOLD

Preparing for Your Appointment

Before Your Visit

Patient ID:

Doctor/Provider:

Date:

Time:

Location:

How will I get there?

☐ Drive Myself ☐ Family/Friend ☐ Taxi/Car Service ☐ Other

Is the PN accompanying you? ☐ Yes ☐ No

Will you need an interpreter? ☐ Yes ☐ No

Questions and Answers

Q:	
A:	
Q:	
A:	
Q:	
A:	

After Your Visit

Before you leave your appointment

Do you need any medications refilled this month?

Your next appointment is with:

Date:

Time: ☐ AM ☐ PM

Location:

What did you talk about with your provider during this appointment?

Were any changes made to your medications? ☐ Yes ☐ No

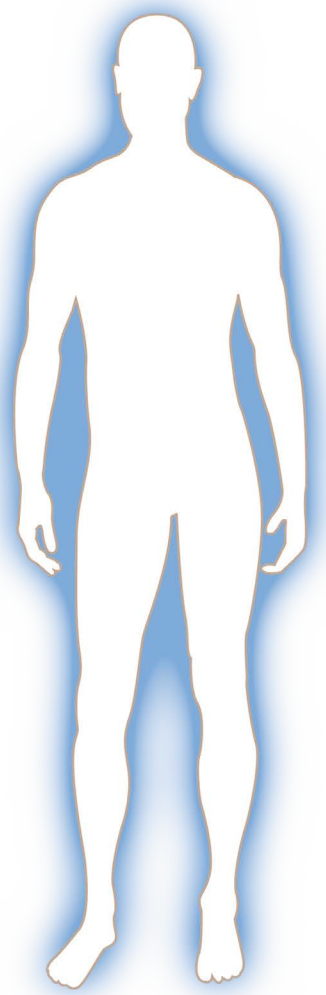
If yes, what were they?

Did I have any tests or were any ordered? ☐ Yes ☐ No

If yes, what were they?

Harm Reduction Body

This tool is designed to be used with your Patient Navigator. Before you meet with your Patient Navigator on this topic, you may consider listing types of sex you are familiar with or engage in, and how these behaviors may harm your body.



Notes:

But Why?


Safer Sex is Important
For People with HIV
AND Their Partners

Risk Continuum

Behavior and Risk Factor
Safer Behavior
Dangerous Behavior

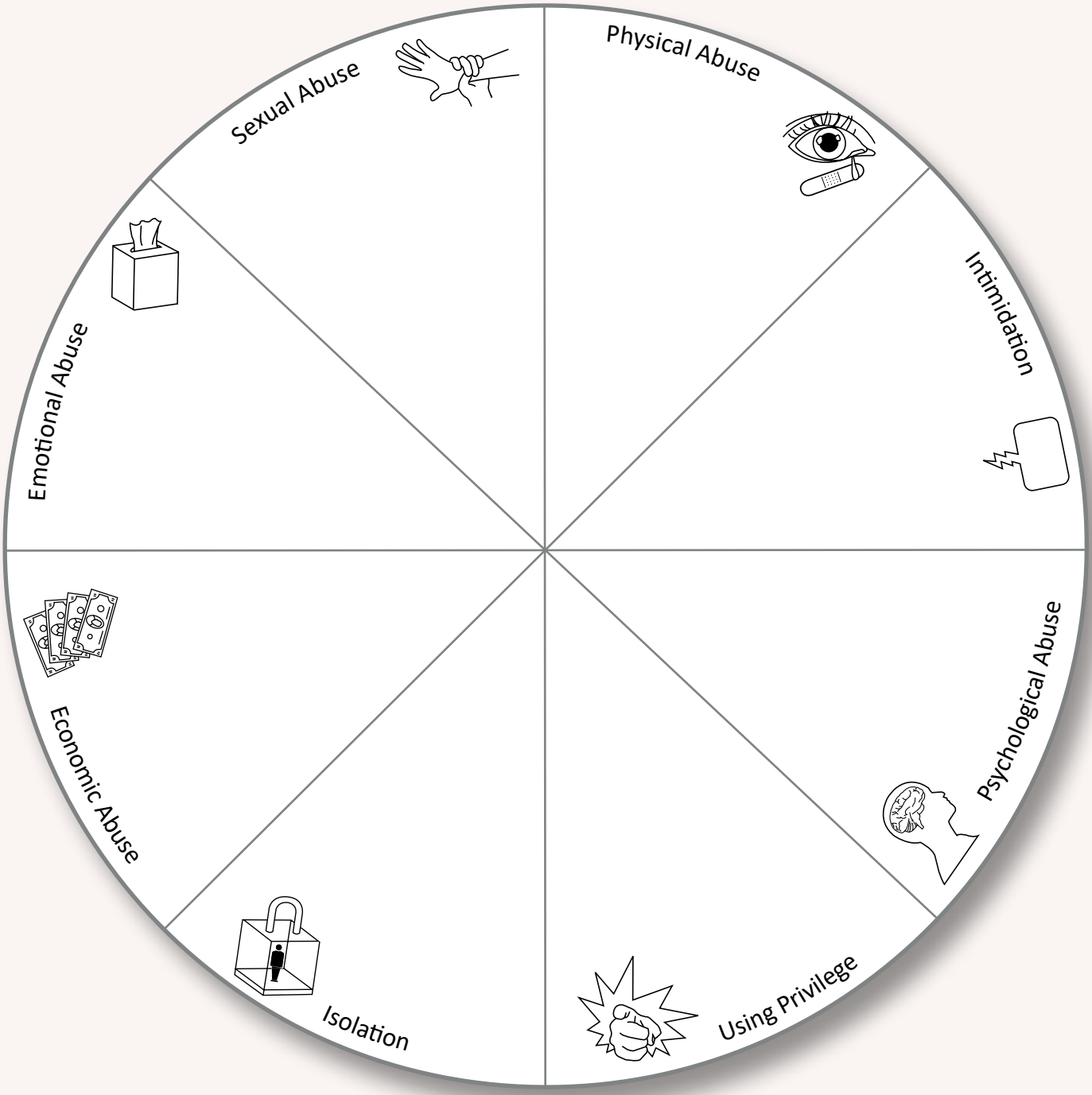
Substance Chart

Recreational Drug Name (and Street Names)	How it enters the body	Potential Health Consequenes	Interactions between Recreational Drugs and Antiretrovirals/ Other Prescription Drugs
Marijuana or THC (Blunt, dope, grass, herb, joint, pot, Mary Jane, skunk, weed, "tobaco," ganja, tree, T)	Swallowed, smoked, eaten	Eurphoria, slowed thinking and reaction time, hallucinations, delusions, paranoia, altered time sense, confusion, impaired balance and coordination, cough, impaired memory and learning, increased heart rate, anxiety, panic attacks, impotence, infertility Health benefits: increased appetite, reduced nausea and reduced pain	Interaction with: Protease Inhibitors (PIs), Sustiva (stocrin, efavirenz) and Atripla (efavirenz + tenofovir + emtricitabine)--no actual drug interactions, but may cause a false positive marijuana test Potential Results: PIs can increase marijuana levels, and smoked marijuana may lower PI levels. Lower levels of marijuana may be needed for medicinal purposes if PIs are being used.
Benzodiazepines (Ativan, Halcion, Librium, Valium, Xanax, candy, downers, sleeping pills, "pastillas," beans, the mix, klanopins called K, sanipex called zenys)	Swallowed, injected	Sedation, drowsiness, dizziness, decreased breathing, death	**Interaction with:** Kaletra (Aluvia, lopinavir/ritonavir), Norvir (ritonavir) and other Protease Inhibitors (PIs) various other antiretroviral therapy (ART) Alcohol and other sedatives **Potential Results:** Many PIs can increase the concentration of benzodiazepines in the body, making them more dangerous.
PCP and analogs (Phencyclidine, angel dust, dust, crank, pick-me-up, space, boat, hog, love boat, peace pill)	Swallowed, injected, smoked	Increased heart rate and blood pressure, impaired motor function, memory loss, numbness, nausea/ vomiting, panic, aggression, violence, loss of appetite, depression, seizures, chronic cognitive impairment	**Interaction with:** Protease Inhibitors (PIs) **Potential Results:** PIs block degradation of PCP, so PCP can be much more toxic if a patient is also taking PIs.
LSD (Acid, acido, blotter, boomers, cubes, microdot, yellow sunshine, purple haze, "Lucie-in-the-sky-with-diamonds," best trip, trippn)	Swallowed, absorbed through mouth or tissues	Altered states of perception and feeling, nausea, persistent perception disorder (flashbacks)	**Interaction with:** Protease inhibitors (PIs) and nonnucleoside reverse transcriptase inhibitor (NNRTIs) **Potential Results:** PIs and NNRTIs could potentially cause build up of LSD in the body, leading to increased toxic effects.
Ecstasy (E, Molly, happy, X)	Swallowed	Euphoria, confusion, sleep problems, anxiety, blurred vision, brain damage, depression, paranoia, nausea, chills, sweating, liver damage, seizures, kidney damage	**Interaction with:** Protease Inhibitors, especially Kaletra (Aluvia, lopinavir/ritonavir) and Norvir (ritonavir) Selective serotonin reuptake inhibitors SSRIs) **Potential Results:** Using certain ART medications with Ecstasy could result in life-threatening effects, such as heatstroke, dehydration and loss of consciousness.

Substance Chart (cont.)

Recreational Drug Name (and Street Names)	How it enters the body	Potential Health Consequenes	Interactions between Recreational Drugs and Antiretrovirals/ Other Prescription Drugs
Opiates **Heroin** (Brown sugar, dope, skunk, smack, junk, dogfood, manteca, manterian, estofa, tecata, chiva, caballo blanco) **Codeine** (Tylenol with Codeine; Captain Cody, Cody, packs, CD, the big bean) **Morphin** (pins and needles) **OxyContin** (oxies) **Vicodin** (V beans) **Percocet** (perks, pick me up) **Demerol** (DI) **Fentanyl**	Injected, smoked, snorted	Pain relief, euphoria, drowsiness, nausea, constipation, confusion, sedation, respiratory depression and arrest, and death.	**Interaction with:** Ritonavir Inhibitors **Potential Results:** Heroin can make an HIV+ person sicker. Ritonavir decreases the effectiveness of codeine.
Cocaine (Blow, bump, C, candy, Charlie, coke, crack, flake, rock, snow, toot, perico, basico, snow, fish scale, pasta, esqueleto)	Injected, smoked, snorted	Increased heart rate and blood pressure, increased mental alertness, rapid or irregular heart beat, reduced appetite, weight loss, heart failure, nervousness, insomnia **Also:** Long-term snorting can damage the nasal membrane. Smoking hot crack pipes can result in lip blisters/burns, which increase the risk of infections, especially during oral sex. If you use vinegar, lemon or other "organic" acid to make your crack injectable, you can get serious infections. Use ascorbic acid instead.	**Interaction with:** Protease inhibitors (PIs) Nonnucleoside reverse transcriptase inhibitors (NNRTIs) especially Viramune and Viramune XR (nevirapine), [Sustiva (stocrin, efavirenz), and Atripla (efavirenz + tenofovir + emtricitabine)] **Potential Results:** Cocaine is known to be toxic to the immune system and could reduce CD4 cells making someone living with HIV sicker. PIs and efavirenz can increase the effects of cocaine, so a given dose of cocaine is more toxic. Cocaine may increase the risk of liver toxicity with nevirapine use.
Methamphetamine (Crystal meth, crank, crystalspeed, Tina, tweak, ice, white snow, the diet, the thinning, the scar "Strawberry quick"=a mix of ecstacy, cocaine, and methamphetamine)	Swallowed, snorted, smoked, injected	Euphoria, increased energy and attentiveness, diarrhea, nausea, loss of appetite, insomnia, tremor, compulsive fascination with repetitive tasks, talkativeness, irritability, panic attacks, having very long sex sessions, sexual craving (in the long term, combined with male impotence resulting in preference for being the "bottom")	**Interaction with:** Kaletra (Aluvia, lopinavir/ritonavir) Norvir (ritonavir) Rescriptor delavirdine) Selective serotonin reuptake inhibitors SSRIs) **Potential Results:** Methamphetamines can increase levels of ritonavir in the body to more toxic levels.
Alcohol	Swallowed	Slurred speech, loss of inhibition, unsteady gait, hypothermia, impotence, memory loss, coma, and death. Chronic use can cause hepatitis, pancreatitis, liver failure, and chronic memory problems.	**Interaction with:** Agenerase (amprenavir) **Potential Results:** Alcohol use while taking ARVs could result in a decreased ability to maintain adherence. Chronic alcohol users are also at greater risk of infections; not taking your HIV meds can make this worse.
Tobacco/Cigarettes	Smoked, chewed	Weakened immune system, cancer (of lungs, mouth, throat, esophagus, and other), frequent colds, chronic bronchitis, emphysema, stroke, heart disease.	**Potential Results:** A harder time fighting off HIV-related infections, since tobacco weakens the immune system. Smoking increases the risk of lung infections like bacterial pneumonia and pneumocystis pneumonia (PCP). It increases the risk of thrush and whitish mouth sores, as well as mycobacterium avium complex (MAC). Smoking while taking some ARVs can worsen hepatitis. Those who smoke are more likely to experience side-effects of HIV medications, such as nausea and vomiting.

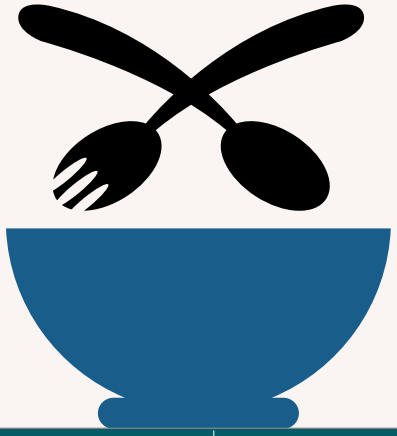
Power and Control Wheel



Safety Strategies Flow Chart (Optional)

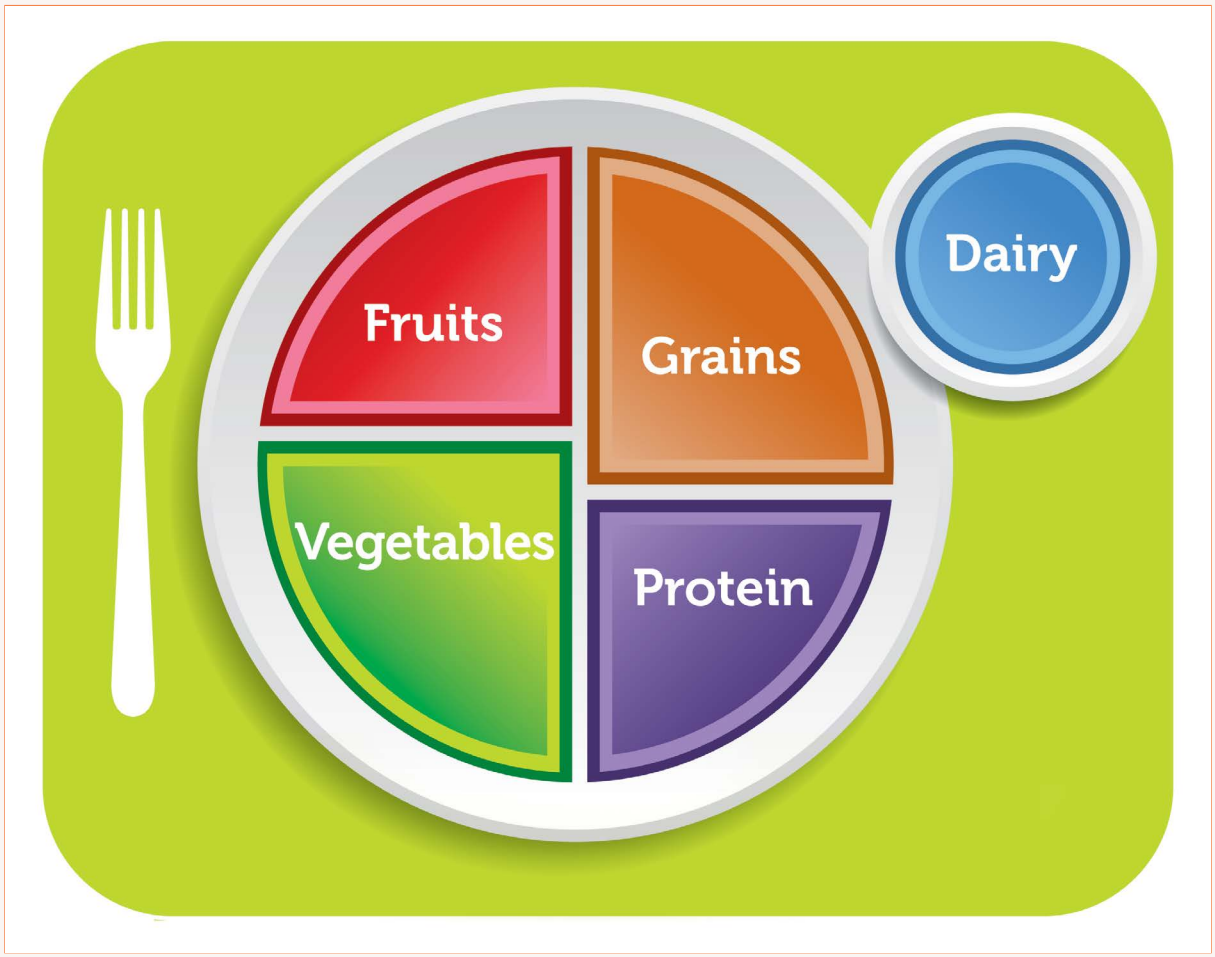
Unsafe Situations	Safety Strategies

Your Daily Diet



What time did you eat/drink?	How much did you eat/drink?	What did you eat/drink?
Breakfast		
Snack		
Lunch		
Snack		
Dinner		
Snack		

Food Plate



http://www.choosemyplate.gov/downloads/mini_poster_English_final.pdf

Partner Notification

Who is considered a partner?

Parters are:

- **People you have sex with.** This includes vaginal, anal or oral sex.
- **People you have shared needles or works with** to inject drugs, hormones, steroids or even vitamins or medicine.

Your partners need to know that they **may have HIV** and that they should **get an HIV test**. Once you tell your partners they can get tested for HIV, they can also get medical care if they have HIV, and learn how to prevent giving HIV to others.

Should I tell others about my HIV?

It is a good idea to tell your health care providers so they can give you the proper medical care. If you like, you may want to tell family or friends. They can help support you as you get used to living with HIV.

Partner Notification

How can I prepare to tell my partner that he or she has been exposed to HIV?

Step 1: Weigh the pros and cons.	There are many reasons some people choose to tell their partners themselves. Telling your partner allows you to be open about your HIV infection and offer support as your partner gets the HIV test and learns the results. For some it may be better to have someone else tell your partner. You may want to consider having someone else tell your partner if you don't know how the person will react or think your partner may get angry and hurt you or someone else.
Step 2: Be ready to share facts about HIV.	Your partner will probably have questions after you tell them you have HIV. You should be prepared to share some basic information about how people get HIV, how and where to get tested for HIV, the difference between HIV and AIDS and how to prevent the spread of HIV.
Step 3: Decide if you want help.	Even if you want to tell your partner yourself, you do not have to do it alone. Sometimes it is helpful to have someone support you who can help answer any questions your partner may have about HIV, and help you in case your partner gets angry. If you want help, you should determine whose help you would like and ask if that person is willing. Some ideas can include your HIV case manager, doctor, counselor, or patient navigator.
Step 4: Find the right time and place.	When and where you talk to your partner can make a big difference. Think carefully about the right place and time to tell your partner. Try to find a place: • where you and your partner will feel comfortable • that offers some privacy • where you can feel safe and get help if necessary Talk to your partner at a time: • when you will be able to say all you want to say • when your partner can respond and ask questions • when your partner can schedule an HIV test
Step 5: Plan what you will say.	You may be nervous when the time comes to talk to your partner and you may have a hard time remembering what you want to say. Planning and practicing what you want to say can help you communicate clearly to your partner. However you choose to tell your partner, the most important thing to say is: I have HIV, you may also have HIV, and you should get tested. • There are lots of other things you may want to say. Think about, discuss and write down your ideas. • What was helpful to hear when you first tested positive? What are some sentences or phrases you want to say? How would you put them together? • Acting out the situation will help you when the time comes. If you have someone you trust, role play and practice what you want to say with that person.
Step 6: Prepare for a reaction.	It is difficult to know how your partner will react. Think about some possible reactions and then plan how you would handle each situation. Just remember that you are sharing this information because you want to protect your partner's health.
Step 7: Get support.	It is also difficult to know how you will feel after telling your partner. Identify someone whom you can talk to for support after you tell your partner. A counselor orHIV case manager can help you cope with your own feelings and reactions.

Definitions

Adherence	Adherence comes from the word "adhere." To adhere to something means to stick to or stay with something. Adherence is extremely important when taking your HIV medications.
AIDS	AIDS stands for Acquired Immune Deficiency Syndrome.
ART	Anti-retroviral therapy or ART are the medications that work to prevent HIV from copying itself in your body. ARVs or HAART are other names.
CD4	CD4 cells are immune cells that the HIV attacks. Sometimes they are also called T-cells or helper T-cells. The higher your CD4 count, the stronger your immune system is.
CD4 Count	This is a measure of CD4 cells in your body. Your CD4 count tells your doctor how strong your immune system is. A person with a CD4 count of less than 200 is said to have AIDS.
Cells	Cells are the building blocks of life. All living things consist of at least one cell. Cells contain genetic information and the machinery that carries out many of the processes of a living organism.
Hallucinogens	Hallucinogens, or psychedelics, are drugs that affect perception, sensation, thinking, self-awareness and emotions. LSD, acid, peyote and 'shrooms are hallucinogens.

Harm Reduction	Harm reduction is any behavior or strategy that helps to reduce risk or harm to yourself and others. For example, to reduce your risk of getting HIV, you can practice safer sex or safer drug use by using condoms or using clean needles.
HAART	HAART stands for highly active anti-retroviral therapy. Some people may refer to your ART regimen as HAART.
HIV	HIV stands for human immunodeficiency virus. HIV attacks CD4 cells and uses their machinery to make copies of itself. HIV is the virus that causes AIDS.
Immune System	The immune system is the body's infection fighter. It helps the body fight all kinds of illnesses including colds, flu, pneumonia and viruses such as HIV. The immune system is made up of many different types of cells that interact with each other and work together to serve as our defense against bacteria, viruses, fungi and parasites that cause infectious illnesses.
Opportunistic Infections	Opportunistic infections (OIs) are those infections that may harm the body when the immune system is weakened. When the immune system is strong and not weakened by HIV, it fights off OIs. Some examples of OIs include pneumocystitis pneumonia (PCP), thrush, mycobacterium avium complex (MAC), shingles and toxoplasmosis.
Sedatives	These are the drugs that slow down the brain and the central nervous system (CNS). They can cause calmness, relaxation, sleepiness, slowed breathing, slurred speech, staggering gait, poor judgment and slow, uncertain reflexes. Examples of sedatives are alcohol, Valium, pain killers (barbiturates) and heroin (opioids).

STDs	Sexually transmitted diseases (STDs) are also known as venereal diseases or sexually transmitted infections. STDs are diseases or infections that humans can transmit by means of sexual contact, such as vaginal intercourse, oral sex and anal sex. Practicing safe sex or harm reduction techniques can decrease your chances of getting STDs.
Side Effects	Side effects are the unwanted effects that your medications can cause. Common side effects of ART are nausea, vomiting and fatigue, among many others.
Stimulants	Stimulants are drugs that temporarily increase alertness and wakefulness. Examples of common stimulants are amphetamines such as crystal meth, cocaine and crack.
Viral Load	Viral load is a test to measure the amount of HIV in your blood. Your doctor often uses this test to see how well your anti-retroviral medications are working.
Undetectable Viral Load	An undetectable viral load is when there is so little virus in your blood that a test can't measure it. The virus is still present in the body, but in very small amounts.
Virus	A virus is a small infectious particle that needs the help of a host organism to reproduce or make copies of itself. A virus consists of genetic material (DNA or RNA) enclosed by a shell.

Resources

Health Care Provider		
Steps to Care Program		
Care Coordinator		
Patient Navigator		
311	Connects to many government services	3-1-1
911	Connects to ambulances, fire services and police	9-1-1
Addiction	SAMHSA's National Helpline/Treatment Referral Routing Service	800-662-4357
	National Council on Alcoholism and Drug Dependence	800-622-2255 https://www.ncadd.org/
AIDS	CDC-INFO / National AIDS Hotline	800-232-4636 https://www.cdc.gov/cdc-info
	AIDSinfo	800-448-0440 https://aidsinfo.nih.gov/
Crisis	The National Domestic Violence Hotline	800–799–7233 http://www.thehotline.org/
	National Sexual Assault Hotline	800-656-4673 https://www.rainn.org/about-national-sexual-assault-telephone-hotline
	Youthline	877-968-8491 Text **teen2teen** to 839863 http://oregonyouthline.org/
Housing	Office of Fair Housing and Equal Opportunity (FHEO)	800-669-9777 https://portal.hud.gov/hudportal/HUD?src=/topics/housing_discrimination
	Section 811 Supportive Housing for Persons with Disabilities Program	https://portal.hud.gov/hudportal/HUD?src=/program_offices/housing/mfh/grants/section811ptl

Jobs and Careers	Job Accommodation Network (JAN)	800-526-7234 http://askjan.org/
	DOL Office of Disability Employment Policy: Employment and Living with HIV/AIDS: A Resource Guide	https://www.dol.gov/odep/topics/hivaids/EmploymentLivingwithHIVAIDS.pdf
Mental Health	National Suicide Prevention Lifeline	800-273-TALK (8255) https://suicidepreventionlifeline.org/
	MentalHealth.gov	https://www.mentalhealth.gov/
	SAMHSA Treatment Referral Helpline	877-726-4727
Nutrition	Department of Veterans Affairs: Diet and Nutrition for People with HIV	https://www.hiv.va.gov/patient/daily/diet/index.asp
	Smart Nutrition 101	https://www.nutrition.gov/smart-nutrition-101
	USDA: HIV/AIDS: Diet and Disease	https://www.nal.usda.gov/fnic/aidshiv
STDs	CDC National STD Hotline	800-232-4636 https://www.cdc.gov/std/

Safety Plan

1 Develop an action plan for the 'worst case scenario" (e.g., make a code with neighbors to signal to call the police, program phone to dial 911 or a family member for help).

2 Identify "safe" people for support (e.g., family, friends, neighbors, health care providers, teachers, clergy, counselors, co-workers).

3 Find out about legal rights and options. Identify local resources.

4 Pack a bag with clothes, other essentials and copies of house and car keys in case they are needed quickly.

Safety Plan

5

Put important documents and other valuable items in a safe place, including:

- ☐ Identification
- ☐ Birth certificates
- ☐ Social security cards
- ☐ Passports, visa, work permits
- ☐ School and medical records
- ☐ Insurance cards and information
- ☐ Medication/ prescriptions
- ☐ Money, bankbooks, credit cards
- ☐ Keys to house, car and office
- ☐ Driver's license and car registration
- ☐ Welfare information
- ☐ Divorce papers
- ☐ Lease, rental agreement, house deed
- ☐ Address book
- ☐ Jewelry, sentimental items
- ☐ Children's favorite toys and blankets

6

Attend a support group for people in similar situations.

7

Gather as much information as possible and put together alternatives to your current situation.