



Facilitator's Guide for Health Promotion

Third Edition



CONTRIBUTORS

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. The New York City Department of Health and Mental Hygiene will distribute this Facilitator's Guide to facilitators working with patients enrolled in the Health Department's Care Coordination program.

Special thanks goes to the PACT project for sharing this information and allowing it to be reproduced with modifications.

Dr. Behforouz is the Executive Director of PACT, a community-based project in inner city Boston, whose mission is to improve health outcomes for underserved individuals with HIV/AIDS. PACT was a project of Brigham and Women's Hospital and Partners in Health, a non-profit health care organization dedicated to providing a preferential option for the poor.

The New York City Care Coordination program addresses HIV/AIDS through the integration of care navigation, social services and benefits coordination, health education and promotion, and treatment adherence.

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Overview

How should I use the Facilitator's Guide?

The **Facilitator's Guide** is a guide for the Patient Navigator (PN) to use during conversations with patients. Each Patient Navigator (PN) receives only one Facilitator's Guide that includes **core topics** to discuss with all patients.

Discretionary topics are suggested following an assessment by the Patient Navigator (PN) of the patient's needs and readiness.

What is the Care Coordination Workbook?

Each patient receives a **Care Coordination Workbook** full of information, tools and resources that correspond to the conversations in the Facilitator's Guide. The Patient Navigator (PN) works with the patient to study the tools in the Workbook during home visits. When the patient graduates from the Care Coordination Program, the patient keeps the completed Workbook as a resource.

How much time do I need to cover the Facilitator's Guide topics with my patient?

The Patient Navigator (PN) will discuss each topic in the Facilitator's Guide during the first 10 months of the patient's enrollment in the Care Coordination Program. Each topic is divided into conversations. Patient Navigators facilitate a series of conversations on one to two topics per month. Although you may not have time to complete an entire topic in one session, try to complete one or more conversations every time you meet. Typically, each Health Promotion session takes about 20-40 minutes.

How is the Facilitator's Guide organized?

Of the 16 topics in the Facilitator's Guide, only core topics (10) are recommended for all patients, while discretionary topics (06) require you to assess whether the topic is useful for the patient. You should also assess whether the patient is *ready* to discuss discretionary topics. Speak with your supervisor about which discretionary topics to discuss with each patient.

Each topic begins with its objectives, describes the necessary preparation for Patient Navigators, and includes conversations on that topic that coordinate with the Care Coordination Workbook. At the end of the topic, a prompt appears to remind the Patient Navigator to review the previous topic through a teach-back exercise.

Each topic consists of a series of conversation guides. The guides start with an objective to help the Patient Navigator understand how to focus while facilitating. Each conversation guide is structured somewhat differently. Most include a script that suggests what the Patient Navigator should say or explain and questions to ask the patient. These scripts are a guide. You do not need to follow them word for word, although you can if you so choose.

You will find the tools that accompany each conversation in the Facilitator's Guide alongside the conversation scripts and in the Workbook. The conversation guides include prompts, instructions and notes to the Patient Navigator on issues such as: how to assess whether a patient is ready to discuss something, how to complete a particular tool or exercise, issues to look out for or be sensitive to. The Patient Navigator is encouraged to elicit the patient's particular concerns and tailor the conversation specifically to that patient's needs.

Within core topics some conversations may be labeled discretionary, which requires you to assess whether the conversation is useful and appropriate for your patient. Sometimes a topic may be useful and appropriate for your patient, yet not all conversations about that topic will be. If you are unsure about whether to have a discretionary conversation with one of your patients, discuss with your supervisor.

Each topic concludes with a Wrap Up exercise to discuss what the patient learned and what questions remain. After every topic, administer a Topic Feedback Form to measure its effectiveness.

How should I schedule and structure sessions?

Since most topics involve private or potentially difficult topics, **we recommend finding a quiet and private place** and time in which to have these sessions. Structure each session for about 40 minutes, of which 15 minutes focus on the health promotion curriculum, with the remaining 25 minutes focused on building your relationship and connecting your patient to social and economic services. While some patients may need more time or less time to complete each session, as a general rule, the Patient Navigator should plan for 20-40 minutes per session.

It is important to stay on schedule as closely as possible to complete the topics prior to Graduation. This schedule allows us to give all patients the most consistent intervention. When a patient misses or cancels a session, the Patient Navigator should prioritize catching up with the missed topic to try to keep on track. If your patient misses sessions, talk to your supervisor about how best to catch up.

How do I document my sessions with patients?

Patient Navigators track conversation progress with each patient. At the end of each conversation, record the date of completion in a progress note in the patient database, print it out and put in the patient's chart. This tracking enables you to review which conversations were completed and when. It is important that you review which conversations have been completed with each patient during meetings with your supervisor. Your supervisor can help identify which conversations should be completed for a particular patient and when.

Topic 1: Introduction to the Health Promotion Curriculum

Learning objectives

After completing this topic, the patient will be able to:

- Anticipate the content of sessions with the PN.
- Understand the Care Coordination Program's goals.
- Identify patient's personal goals, and the barriers and facilitators of those goals.
- Complete or update the Comprehensive Care Plan.
- Identify a place to store the Care Coordination Workbook.

Preparation

- Label the Care Coordination Workbook.
- Bring the Care Coordination Workbook and the Comprehensive Care Plan.
- Review your patient's medication list, and know what each medication is for and when each should be taken.
- Ask the patient's provider if the medications on the list are active or if any have been discontinued.
- Review any special instructions for medications your patient is taking.
- Review conversations and PN instructions for this topic.

Topic overview

Conversation	Materials and Tools
A: Introduce PN Curriculum	Facilitator's Guide Table of Contents
B: Care Coordination Program's Goals	
C: Comprehensive Care Plan	CCP
D: Care Coordination Workbook storage	Care Coordination Workbook
Wrap Up	Comprehensive Care Plan

Conversation A: Initial Adherence Discussion

Objective: The objective of the Initial Adherence Conversation (next page) is to learn about your patient's adherence to HIV medications, prophylaxis medications, and other medications. The objective of this conversation is NOT to teach your patient about what is right or wrong. You just want to learn about how your patient takes their medications and get a measure of the patient's general understanding about them. After you complete the conversation, however, you can tell the patient if they are taking their medications correctly and explain any special instructions.

Before you start: Make sure you have reviewed what pills your patient is taking, know which ones are ART, which are prophylaxis, which treat opportunistic infections and which are non-HIV related. You should also know any special instructions regarding your patient's medications. Finally, you should have made a blank photocopy of the guided conversation to take with you to the health promotion session.

Note to PN: Frame this assessment as a way for you to learn about your patient. Be careful to avoid making it feel like a test. There are no right or wrong answers here.

Say: I'm going to ask you a series of questions so that I can learn more about you and get a sense of where you are with your adherence.

Say: I'm going to write down some of your answers so that you and I both have something to refer to later.

Ask: How do you feel about that?

Note to PN: If your patient does not want you to write down any answers, or if you notice that your patient is uncomfortable while you are writing, say: "It's okay, I don't have to write it down." If you don't write down your patient's answers, summarize them in your progress note so that you can refer back to them later.

Initial Adherence Assessment Form

Please complete this form for each patient, and place in the PN patient chart when completed. Ask the patient the following:

1. Can you tell me about your pills? Which ones do you take for your HIV? How do you take them? How many do you take and at what times?

2. Do you do anything special, like take them with food or on an empty stomach?

3. What are these other pills for? How do you take them?

4. I know it can be very hard to take pills every day... tell me, did you miss any of your HIV pills yesterday?

5. How about the day before?

6. And the day before that?

7. Did you miss any of your prophylaxis pills yesterday? (**Note to PN:** Make sure patient knows what you mean by prophylaxis pills — i.e., pills to prevent from getting sick/getting OIs)

8. How about the day before?

9. And the day before that?

10. Did you miss any of your other pills yesterday? (i.e., psychiatric pills, pills to control blood pressure, help with side effects, cure a particular illness, etc.).

11. How about the day before?

12. And the day before that?

13. In the past week, about how many times do you think you missed your HIV pills? Your prophylaxis pills? Your other pills?

14. How many times do you think you missed taking any pills in the past month?

15. **If the patient reports missed doses/pills, ask:** Can you tell me what made it hard to take them that day? **If the patient does not report missing any pills/doses, say:** How do you feel about that? Can you tell me what made it easier for you to take all of your doses?

16. In the past week or so, have you taken any medications later or earlier than you were supposed to? For example, did you ever forget your morning dose and take it when you remembered it in the afternoon?

17. **If yes, ask:** Which pills and how many times do you think that happened in the past week? How many times in the past month?

If your patient is on a BID regimen, ask:

18. In general, do you find you have a harder time with your morning pills or evening pills? Why do you think that is?

19. In general, do you have a harder time taking pills on weekends? If so, why?

20. Are there any times that you just won't take your pills? For instance, if you are going to go out and have a few drinks? Or if you are feeling low, or mad? Can you tell me about those times?

21. How often did that happen in the past week?

22. How many times did it happen in the past month?

23. Is there any one pill or pills that you have a harder time taking than the others? Can you tell me about that?

Conversation B: Introduce the Health Promotion Curriculum

Objective: The objective of this conversation is to discuss what the patient can anticipate during sessions with you over the next year.

Say: Let's talk about what you can anticipate during your sessions with me over the next year.

Turn to the Facilitator's Guide Table of Contents.

Say: These are 11 basic/16 expanded topics that we will discuss. **(Go over each topic listed in the Table of Contents.)**

Say: We can have a few different conversations about each of these topics.

Say: We will meet for **one session each week, month, or quarter** for as long as you need the Care Coordination Program. Each session will last 20 to 40 minutes.

Say: We will try to spend at least 20 minutes of each session discussing one of these topics listed in the Table of Contents.

Say: We can spend the rest of each session talking about other issues that are important to you.

Ask: How do you feel about all of that?

Ask: Which of these topics are the most relevant and interesting to you?

Conversation C: The Care Coordination Program's Health Education Goals

Objective: The objective of this conversation is for the patient to understand The Care Coordination Program's health education goals.

Say:

Let me tell you a little about the Care Coordination Program's health education goals. The goals are to:

- Strengthen your relationships with people who can support you.
- Help you feel comfortable talking to your medical and social service providers.
- Increase your ability to make appointments, arrange for transportation, and refill and adhere to medications.
- Enhance your positive sense of self and help you take control of your HIV disease.
- Improve your overall health and well-being.

Ask:

How do you feel about these goals?

Conversation D: Goal Setting

Objective: The objective of this conversation is to identify and discuss the patient's goals, the barriers making it difficult to achieve those goals, and the positive elements of the patient's life that will facilitate a good result.

Note to PN: The best goals are small, reachable steps that your patient has the ability to control. PNs are encouraged to make a photocopy of these adherence questions and to take notes on this conversation. Afterwards, the PN should use this information to update the Care Plan, which should be signed by the patient at the next home visit. Help your patient identify goals by asking open-ended questions and using motivational interviewing.

Ask: What are some of the things you would like to work on together?

If no response, ask: Today you opened the door for me and let me in. Can you tell me why you did that?

If no response, ask: Can you imagine your life without being hospitalized? Without feeling sick? What would that be like?

Repeat to check for understanding: So I hear you saying that your goals are [fill in what patient said].

Ask: What are the barriers that are preventing you from reaching these goals?

Ask: What makes it hard to take your medications?

Or, ask: What are some reasons why you might not attend your quarterly HIV visits?

If your patient has trouble identifying barriers, say: Different people have trouble reaching their goals for different reasons. Some people I know have told me that they have trouble reaching their goals because of:

Suggest specific examples from some of the following categories:

- A lack of knowledge
- A lack of resources
- A lack of confidence in adopting the new behavior
- A negative consequence when adopting a new behavior

Ask: Do any of these barriers sound familiar to you?

- What are the things that help you take your medications and look after your health?
- It seems to me that by accepting to be a part of the Care Coordination Program, you want to change things. Why now? Why do you have these goals now? What is different now? What is motivating you to do things differently?
- Were there times in your life that you were able to be adherent? What helped you be adherent during those times?
- Are there other things that motivate you? That can help you be successful?

If your patient has trouble identifying facilitators, suggest some of the following examples:

- A readiness or desire to change
- The information necessary to make the change
- The patient has a relative or friend for support while changing
- The access to the resources to make the change

**Summarize
what your
patient said:**

I hear you saying that there are several things in your life that will help you reach these goals. You have [fill in what patient said].

Say:

Based on this conversation, we will update your care plan to include the goals we talked about today. I will bring a copy of the care plan to our next home visit for you to sign.

Conversation E: Care Coordination Workbook Storage

Objective: The objective of this conversation is to identify a place to keep the Workbook. Ideally, the patient will keep the Workbook at home.

Present the patient with a copy of the Care Coordination Workbook.

Note to PN: Taking the Workbook home empowers the patient to integrate the tools completed during the PN sessions into everyday life. If the patient agrees to take the Workbook home, discuss ways to prevent it from getting lost. You may also want to discuss ways to help the patient keep the Workbook confidential, especially if disclosure is an issue.

Say: This Workbook is for you to keep. It is your own personal, private book. We're going to write and draw in it together during some of our conversations, and you can use it in your everyday life to look up useful information and to review the work that we do together. You can even decorate it if you like. Some patients paint their Workbooks or glue on photos or pictures from magazines to personalize it.

Ask: How do you feel about keeping this Workbook?

If patient refuses to keep the book, say: We like patients to keep the Workbook because there are resources and tools in it that can be helpful in your everyday life, even if I'm not here. For example [provide an example].

Say: Another reason we like patients to keep the Workbook is because it is your book and you own it; you are in control of it. For some people, keeping and using the Workbook is a symbol of taking control of their HIV disease.

Ask: How do you feel about that?

- What are the reasons why you might not want to keep the Workbook at home?
- The Workbook is unmarked on the outside so nobody can tell what it is for if they don't open it. Inside, however, there is personal information and information about HIV. Do you have any concerns about disclosure or people seeing the Workbook if it's in your home?
- Do you have any concerns about losing it or not being able to find it easily when I visit you?

Note to PN: If the patient has concerns about disclosure or misplacing the Workbook, or if the patient just does not want to keep it in the home, don't insist. You can keep the Workbook for the patient and bring it when you visit.

If the patient keeps the Workbook at home, try to identify a safe place to keep it.

Ask: Where would be a good place for you to keep the Workbook at your home?

Wrap Up

- Say:** We've talked about a lot today!
- Ask:** In your own words, what did you learn today?
- Ask:** What did you learn about setting goals?
- Ask:** What is one step you will take toward achieving these goals?
- Ask:** What questions came up for you that we can review for next time?
- Ask:** What's most important for me to know about you and what we talked about today?

Topic 2: Me and HIV

Learning objectives

After completing this topic, the patient will be able to:

- Identify the impact that HIV has on everyday life
- Share their perspective of HIV and treatment with the PN
- Share feelings about disclosure
- Share goals about health with the PN
- Begin to feel that a trusting relationship is being established with the PN

Preparation

- Bring the Care Coordination Workbook.
- Review your notes on this patient from the last topic you completed together, and identify areas that need review or reinforcement.
- Review conversations and instructions for this topic.

Topic overview

Conversation	Materials & tools
Review from last session	
A: Me and HIV	Talking to Others Discussion Guide (FG page 25)
B: My Life Goals	Scratch paper
C: Me, My HIV and Other People	Scratch paper
Wrap Up	Topic feedback form

Review

“Let’s go over what we talked about last time.” Review areas that were particularly challenging for your patient during your last session together.

Ask your patient to:

1. Demonstrate a skill that was learned from last session’s discussion;
2. Explain one of the key points from that session.

Conversation A: Me and HIV

Objective: The objective of this conversation is to learn about how your patient thinks and feels about HIV and HIV treatment, and how your patient is coping with their illness. This is an opportunity for you to listen deeply to your patient’s intellectual, social, emotional and spiritual thoughts and feelings about HIV and treatment. This conversation is designed to help you get to know your patient in a general way and to create a safe environment to discuss feelings and challenges faced by the patient. This is a **listening** rather than a **teaching** conversation. Try to avoid telling your patient that what they think or feel about HIV is wrong, even if you think it is. Instead, use this as an opportunity to learn as much as you can about your patient so that you understand what areas to work on and can meet your patient where they are at to help them overcome their adherence barriers.

Note to PN: Feel free to skip questions that do not seem relevant to your patient and to ask additional questions that do. After you cover the questions in the discussion guide, thank your patient for their openness and willingness to share. Mention the CCP and how some of these issues could be inserted into the CCP as goals.

A note on record-keeping: You do not need to write down your patient's answers during the conversation, but summarize them in your progress notes.

Say: Having HIV can be challenging to live with. Many people find it difficult to tell others, plan and set goals for themselves, or prioritize their health on a daily basis.

Ask: Would it be okay to discuss some of these topics about your illness with you?

If it is okay to discuss these topics, ask the questions in the following discussion guide. It is important to gauge your patient's readiness to talk. If you do proceed, it is important to offer the patient the option of choosing to not discuss a certain question.

Say: I want to know what you really think and feel about these questions. There are no wrong answers and I am not going to judge anything that you say.

If it is not okay with your patient to discuss these topics, or if you feel that your patient is not yet ready, skip this topic and return to it at a later date. Make a statement that gives you both the option of returning to the topic when the relationship is stronger or trust has been built. Example: "Okay, we can come back to this when you feel more comfortable."

Me and HIV Discussion Guide

Ask the following questions. You don't need to record answers; just listen.

1. How do you feel about having HIV?
2. Lots of people have different understandings and beliefs about HIV. I have worked with people who believe that they got HIV in complicated ways. What's the story behind your HIV?
3. What do your HIV pills mean to you? How do you feel about taking them?
4. What concerns you or scares you most about the illness?
5. Has having HIV changed your life? If so, how?
6. Tell me about what is important to you and what are some things that make it worth getting up every day. Are there things that you are not doing now that you'd like to do in the future?
7. Has having HIV changed your goals? If so, how?
8. What does being healthy mean to you?
9. What are your goals about your health?
10. Tell me about the people in your life... those who are closest to you upon whom you rely as well as those in your life who cause you stress or worry. What relationships are the most important to you?
11. Of these people, who knows about your HIV? Anyone else?
12. Is there anyone you would like to tell but just can't? Can you tell me about that? What are you worried would happen if you did? What good could come from letting that person know?

Conversation B: My Life Goals

Objective: The objective of this conversation is to repeat what the patient told you about their goals during the Me and HIV conversation to check for understanding.

Instructions for PN: Explain to the patient what you understand about their goals based on their responses to questions 6, 7, 8, and 9 of the Me and HIV Discussion Guide. Ask if you correctly understood what they said. Make any necessary changes to your understanding as together you write down answers to the following questions.

What were your goals before you knew you had HIV?

1. _____
2. _____
3. _____
4. _____
5. _____

What are your goals now that you have HIV?

1. _____
2. _____
3. _____
4. _____
5. _____

What can you do now to accomplish those goals?

1. _____
2. _____
3. _____
4. _____
5. _____

Conversation C: Me, My HIV, and Other People

Objective: The objective of this conversation is to repeat what the patient told you about disclosure during Conversation A: Me and HIV to check for understanding. It is also to record the patient's disclosure situation and disclosure goals so that you can both refer to it in future.

Instructions for PN: Explain to the patient what you understand about their disclosure situation and goals based on their responses to questions 10, 11, and 12 of the Me and HIV Discussion Guide. Ask if you correctly understood what was said. Make any necessary changes to your understanding as together you write down answers to the following questions.

Who knows

Who doesn't know

Who I'd like to tell

Wrap Up

- Say:** We've talked about a lot today!
- Ask:** In your own words, what did you learn today?
- Ask:** What did you learn about yourself?
- Ask:** What questions came up for you that we can review next time?
- Ask:** What's most important for me to know about you and what we talked about today?
- Say:** This is the beginning of many conversations that we will have together to try to help you understand and deal with your HIV. The types of questions we discussed today will slowly help us both feel comfortable and get to know each other.
- Say:** Thank you for your honesty and openness in today's discussion.

Topic 3: Using a Pillbox

Learning objectives

After completing this topic the patient will be able to:

- Tell the PN how to take each ART medication correctly.
- Organize all of their medications.
- Correctly use a pillbox.
- Read and understand a medication label.

Preparation

- Bring Care Coordination Workbook.
- Bring medication list filled out ahead of time to use as a check.
- Bring reference source to be able to recognize pills.
- Make sure the patient has medications at home to practice with (or bring medications with you).
- Have 2-4 empty pillboxes available.
- Review your notes on this patient from the last topic you completed together, and identify areas of confusion that need review.
- Review conversations and PN instructions for this topic.

Topic overview

Conversation	Materials & tools
Review from last session	
A: How to Read a Pill Bottle	Material: Patient's medication bottles Tool: How to Read a Pill Bottle (Wkbk. page 15)
B: Medication List	Tool: Medication List (Wkbk. page 14)
C: Benefits of Pillboxes	
D: Medication Organizing	
E: Filling a Pillbox	Tool: Filling a Pillbox (Wkbk. page 16) Tool: Medication List (Wkbk. page 14)
F: Correct use of Pillboxes	
Wrap Up	Topic Feedback Form

Review

“Let’s go over what we talked about last time.” Review any areas that were particularly challenging for your patient during your last session together. Ask your patient to:

- 1) Demonstrate a skill that was learned from last session’s discussion;
- 2) Explain to you one of the key points from that session.

Conversation A: How to Read a Pill Bottle

Objective: The objective of this conversation is to help your patient understand how to correctly read and follow the directions on medication labels.

Say: Medication labels have a lot of important information that you need to know.

Turn to Page 15 of the Care Coordination Workbook: How to Read a Pill Bottle.

Say: This image shows the different parts of a medication label.

Ask: Can you show me a pill bottle that has a medication label on it so that we can look at that too?

Instructions to PN: Go over each part of the label with your patient and answer any questions. If possible, go over the labels on your patient’s actual medication bottles in addition to the image in the Care Coordination Workbook. This exercise may help your patient to organize their medications and to fill out the Medication List tool with you in the next conversation.

The **instructions** on the medication label provide information about when and how often your patient needs to take the medication. Make sure that your patient understands the instructions for each medication and check to make sure the doctor’s instructions match what is on the label. Ask your patient

to explain the instructions for each medication to you to demonstrate their understanding. Encourage your patient to ask questions during medical visits to ensure they understand how to use their medications.

Be sure to go over the following points with your patient:

- The **expiration date** on each medication label, and why it is best to discard the medication past this date.
- The **pharmacy phone number and prescription number** on the medication label needed to order refills.
- Any **warning stickers** with information about safe storage, instructions for use, possible side effects, or other information. Be sure that your patient reads and understands these stickers on each of their medications and includes this information in the Medication List tool.
- If your patient does not feel comfortable reading English, ask the pharmacy if their medication labels can be printed in a language they are better able to read like **Spanish or French**.
- If your patient does not feel comfortable reading, mark the pill bottle in a way that allows the person to understand the same messaging **without using words**. For example, if medication should be taken three times a day, draw three lines on the bottle with a marker or draw a symbol of food if the medication should be taken with a meal. Some pharmacies have stickers with these kinds of symbols. To avoid confusion, **patients who have difficulty reading English should be using a pre-filled pillbox or blister pack if possible**. Stickers can also be placed in pillboxes if needed, like a sticker of a food item indicating that pills in a certain compartment of the pillbox go with food.

How to Read a Pill Bottle



Conversation B: Medication List

Objective: The objective of this conversation is to establish a medication list to use when discussing your patient's different medications. By the end of this conversation, the patient will know their list of medications, the names and appearances of each pill, what the pill does, and the correct way to take it (e.g., at 8 AM and 8 PM with a high fat snack).

Turn to Page 14 of the Care Coordination Workbook: Medication List.

Ask: Could you please show me all of your medications?

Ask: Can you pick one of these HIV medications to write into the table first?

Instructions to PN: Fill out each section of the Medication List together in the Care Coordination Workbook. Continue with each medication (both ARTs and other meds). Your patient can practice their new Medication Label reading skills if they are unsure about what to write in any of the columns.

- In the **Possible Side Effects** column, write down any side effects the patient experienced for each medication.
- In the **Things to Watch For** column, list any possible adverse effects that are associated with your patient's medications, and discuss what steps the patient should take if they were to notice any of these effects.
- Ask the patient what the provider suggested for side-effects management when they prescribed each regimen, and review together. Write it down in the **Other Instructions** column.
- Refer to the medication list that you filled out before the session if you are unsure of any of the information.

Instructions to PN: Your patient may have many different types of medications. Be sure that your patient understands what each medication is for. Explain the following types of medications to your patient, explaining which of their pills falls into each category:

What is ARV Therapy?

Antiretroviral drugs are referred to as **ARVs**. **ARV Therapy** is referred to as **ART**. The drugs do not kill the virus, but slow down the growth of the virus and HIV disease. Usually, the ART regimens include at least three different medications that fight the virus. This combination works to suppress the virus and decreases the chance of your virus developing resistance to ARTs. We will discuss this later.

What are prophylactic medications?

Prophylactic medications, also called **prophylaxis**, prevent the development of new infections, also called **Opportunistic Illnesses** (OIs). The best way to prevent OIs is to take ART as prescribed by your doctor since it helps keep your immune system strong and able to resist OIs. The addition of prophylaxis medications to ART makes it harder for infection to take hold of your body and cause you to become sick. Examples of prophylaxis medications are antibiotics or antifungals, which kill certain bacteria or fungi before they can develop into infections. Sometimes, despite taking ART and prophylaxis, people develop OIs. In this case doctors prescribe medications to treat these secondary infections, most often MAC or pneumonia or toxoplasmosis.

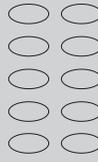
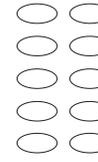
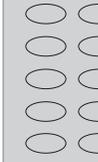
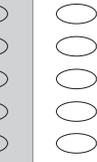
What about psychiatric medications?

Psychiatric medications do many different things. Often, they reduce symptoms of problems such as depression or anxiety. Some help regulate behaviors, alleviate psychotic symptoms (such as hearing voices) or help someone feel more like themselves. These medications are usually prescribed by a psychiatrist, a Primary Care Provider or HIV Specialist. Mental health medications can be just as important as medications for physical health.

Other Medications

Some people take other medications to control conditions like diabetes and high blood pressure, or to prevent heart attacks or keep kidneys healthy. These medications are very important and we will focus on your adherence to these medications as well. In addition, some medications control side effects. These might include medications that reduce nausea, diarrhea, or itchiness, such as Compazine, Imodium, or Benadryl.

Medication List

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

Conversation C: Benefits of Pillboxes (discretionary)

Objective: The objective of this conversation is to help your patient understand the benefits of using a pillbox.

Assessment: All Care Coordination patients should be using a pillbox. If your patient is already using a pillbox effectively, skip this section. If they are not yet using a pillbox, or not using a pillbox effectively, take the time for this conversation.

Instructions to PN: Explain to your patient what a pillbox is and show them an example of one.

Ask: Have you ever taken a pill out of the bottle and wondered 30 minutes later whether you took it or not?

Say: If you forget whether or not you took your pills yet, you just have to look at your pillbox to see if the pills are still in there. Pillboxes help to **ensure that you do not accidentally take too much medication**, which can happen easily if you forget you already took a dose and then take it again.

Say: Many different types of people find a pillbox helpful for a variety of reasons. Here are some reasons:

- Since some pills need to be taken daily, others two or three times per day and in some cases less often, using a pillbox can **eliminate confusion** about which pills to take when.
- A pillbox helps patients **organize** their medications.
- A pillbox gives people a **visual cue** when refills are needed.
- Using a pillbox can **eliminate unnecessary anxiety and frustration** because patients don't have to spend time searching for different medications, or thinking about which medications they should be taking at a given time; all they have to do is look in their pillbox.

Ask: What do you think about that?

Say: I think it would be helpful for you to use a pillbox because if missed medications are left in the pillbox then **I know when and what medications were missed**. This will allow us to look at your week-to-week adherence together and figure out how to help you become more adherent to your medications. I will never get mad or tell you that you **should** have taken your medications. Instead, we can look at the pillbox together and talk about what days and times were hard and why.

Say: Pillboxes also give us both something to reference in terms of your progress.

Say: I can bring you a **free** pillbox and support you to use it.

Ask: How do you feel about that?

Note to PN: Urge your patient to use a pillbox since, among other benefits, pillbox checks are the easiest and most reliable way for you to assess adherence.

If your patient chooses not to fill and manage their own pillbox, ask why not and see if you can come up with solutions to their concerns together.

If they still refuse, suggest alternatives. For example, your patient can use pre-filled pillboxes, blister packs, daily key chain pillboxes, beepers or pill counters. Work with your patient to find an option that works best for them. Ask your patient what support you can provide to help ensure the best option. If your patient is using a pre-filled pillbox or blister pack, you can still perform pillbox checks.

Otherwise, you may have to rely on their self-reported accounts of medication adherence, or do pill counts, or call your patient's pharmacy to get information regarding their refills.

If your patient still refuses to use a pillbox, make a statement that allows for discussion when the patient feels more ready. Example: "Okay, we can discuss using a pillbox later on when you are more interested in trying out that option."

Conversation D: Medication Organizing

Objective: The objective of this conversation is to set up a method of organizing the patient's medications.

Say: The **primary goal** of this topic is for you to recognize and understand the medications that you are supposed to be taking and to organize your pillbox.

Ask: Could you please show me all of your medications?

Instructions to PN: Go through each of your patient's medications, compare against the correct medication list, discard the expired pills and with the consent of the patient, organize the correct pills into a pillbox. Remember that the patient may have pills at home that are not on their medication list. If this is the case, it is best to contact the doctor (with the patient present) to determine if the patient is supposed to be on this medication or not. If so, the medication list should be corrected and the pill should be placed in the pillbox. If not, the medication should be donated. For pills that are unrecognizable to the patient and PN, attempt to identify them with the resource tool or call your Care Coordinator for help.

Conversation E: Filling a Pillbox (discretionary)

Objective: The objective of this conversation is to demonstrate how to properly fill a pillbox and to give your patient a chance to practice alone.

Turn to Page 16 of the Care Coordination Workbook: Filling a Pillbox.

Instructions to PN: Use the **Filling a Pillbox Checklist** as a guide to discuss the proper procedure. After you have filled the pillbox once, ask your patient to demonstrate how to fill it and **assist them as necessary until they feel comfortable filling it on their own.** Some patients may do it independently right away whereas others may need more support.

Filling a Pillbox: Checklist

- Gather all medications in one location.

- Compare medications to medication list to make sure they are all on hand.

- Start filling pillbox with first medication listed on daily routine chart and fill in the correct sequence.

- Continue filling pillbox in order of daily routine.

- Pay attention to color, size, and shape of each pill as it is placed in pillbox.

- Place pillbox in proper location.

- Double check that all pills are placed correctly.

Conversation F: Correct Use of Pillboxes (discretionary)

Objective: The objective of this conversation is to help the patient understand how to use the pillbox, and how to avoid using it incorrectly.

Ask: Can you tell me about some incorrect ways to use a pillbox?

Fill in gaps in understanding: Some incorrect uses are:

- (1) Taking medications out of sequence from different pillboxes simultaneously;
- (2) Taking a double dose of medication;
- (3) Missing a dose of medication but taking the pills missed out of the pillbox;
- (4) Alternating between using a pillbox and taking the pills from a medication bottle.

Say: It is important to recognize the size, color and shape of pills and to double-check the box compartments during each dose to avoid errors.

Say: Many people find that using a pillbox is easier if they use one pillbox per week, change pillboxes on the same day of the week and leave a box with pills in it if they miss a dose. These strategies will also help us communicate honestly about adherence so that you can overcome barriers.

Say:

It is important to leave missed medication doses in the box so that you and I can know when and what you missed. That way we can work together to figure out what made it hard to take your medications those times. I won't judge you if you miss a dose. I'm not here to monitor you. I want you to develop skills to overcome barriers to adherence that will carry you into the future when I am no longer here.

Ask:

How do you feel about that?

Wrap Up

- Say:** We've talked about a lot today!
- Ask:** In your own words, what did you learn today?
- Ask:** What did you learn about the benefits of pillboxes?
- Ask:** What did you learn about how to read a medication label?
- Ask:** What questions came up for you that we can review for next time?
- Ask:** What's most important for me to know about you and what we talked about today?

Topic 4: Handling Your ART Medications

Learning objectives

After completing this topic the patient will be able to:

- Discuss and plan medication refills.
- Review the Pharmacy Plan with their PN.
- Practice filling and refilling their medications.

Preparation

- Bring Care Coordination Workbook.
- Fill out the information in the Pharmacy Information (Workbook, page 17) to use as a reference. Or, bring a copy of the most recently completed Pharmacy Information.
- Bring your patient's completed Medication List (Workbook, page 14) to use as a reference.
- Review your notes on this patient from the last topic you completed together, and identify areas that need review or reinforcement.
- Review the conversations and PN instructions on this topic.

Topic overview

Conversation	Materials & tools
Review from last session	
A: Pharmacy Information	Pharmacy Information checklist (Wkbk. page 17)
B: Refilling Medication	Refilling Medication checklist (Wkbk. page 18)
C: Barriers and Solutions	Barriers and Solutions table (Wkbk. page 19)
D: Practice calling the Pharmacy	Phone
E: When to call the Pharmacy	
F: Medication Logistics	
Wrap Up	

Review

“Let’s go over what we talked about last time.” Review any areas that were particularly challenging for your patient during your last session together. Ask your patient to:

- 1) Demonstrate a skill that was learned from last session’s discussion, and
- 2) Explain one of the key points from the last session.

Conversation A: Pharmacy Information

Objective: The objective of this conversation is to help your patient locate important information for filling and refilling prescriptions at a pharmacy.

Turn to Page 17 of the Care Coordination Workbook: Pharmacy Information.

Ask: Where do you normally keep your insurance card, pharmacy card, and social security cards?

Ask: Could you get them and show them to me?

Instructions to PN: Work with the patient to identify a reliable place to store these cards, if they don’t already have one. Write down the group number, plan number, member ID, social security number, and any other relevant numbers and include them in your progress report. Be sure they are listed on the Care Coordination Intake and Assessment when you get back to your agency.

Use the cards as needed while you fill out the full sheet- sized and wallet-sized Pharmacy tool with your patient. Encourage the patient to **put the completed wallet-sized Pharmacy Information in their wallet** and carry it wherever they go so that they can refill their medications anytime, anywhere. Ask the patient if they would be willing to **put up the full-size Pharmacy Information in the house, such as on the fridge**. If they accept, put it up together.

Pharmacy Information

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

Insurance
Plan Name
Effective Date
 Address
 Phone
Notes

Insurance
Type
Effective Date
 Address
 Phone
Notes

Date

Conversation B: Refilling Your Medication

Objective: The objective of this conversation is to give your patient the chance to practice filling and refilling medications. It is possible that your patient has not refilled their own medications, and will need extensive support building this skill.

Turn to Page 18 of the Care Coordination Workbook: Refilling Medication.

Instructions to PN:

- Walk through each step for refilling medications with your patient using this checklist.
- Some steps may not be relevant for all patients, in which case cross them out.
- To encourage better communication, it can be helpful to some patients if you **take them to the pharmacy and introduce your patient and yourself to the pharmacist and pharmacy staff**. If your patient does not have strong English skills, connect them with people at the pharmacy who speak the same language as them if possible, either in person or by phone.
- Highlight the importance of double-checking to make sure that you have the right medications and that the pharmacy did not make any mistakes.

Note to PN: Use this tool regularly as a framework for discussion; review it frequently with your patient to ensure they understand the different steps.

Refilling Medication

Refill type

- Medication Bottles
- Blister Packs
- Pre-filled Pillbox

Steps to refilling your medication

- Call for a refill. Be prepared to tell the pharmacy personal information such as your name, birth date and insurance information. Have the Pharmacy Information tool handy in case you need it.
- Prepare to get your medications. Arrange for delivery or transportation to the pharmacy. Imagine what your medications will look like when you get them.
- Get your medications. If you have questions about the medications, feel free to ask the pharmacist.
- Check your medications. Do your medications look different from usual? Double check to make sure you have the correct medications.
- Fill your pillbox.

Conversation C: Barriers and Solutions

Objective: The objective of this conversation is to help the patient feel more confident about filling and refilling their medication prescriptions, and more capable of troubleshooting problems. In this conversation, you will review possible barriers that a patient may face when trying to refill a prescription and discuss potential solutions for each barrier.

Instructions to PN: Read the following scenario to your patient, or paraphrase it in your own words. Feel free to create your own scenario if this one is not appropriate for your patient.

Scenario: *Maria takes several different daily medications, including ART. All of her medications are on the same refill schedule, and she calls the pharmacy to refill her prescriptions once a month. This month she called for her refill two days before she ran out of pills. The person who answered the phone told her that her ADAP (AIDS Drug Assistance Program) membership was expired and that she and her provider needed to fill out some forms to renew or she would have to pay a \$1 co-pay to the pharmacy for each medication before she could get them. Since she needed to pick up five medications, this came to \$5. Maria felt overwhelmed about filling out this paperwork. She also knew she would have trouble coming up with \$5 right away. So, discouraged, she hung up the phone without requesting her refill.*

Ask: What were the different barriers that prevented Maria from refilling her medications?

Say: Let's figure out solutions for Maria so that if something like this ever happens to you, you can handle it — you'll be in control.

Ask: How do you feel about that?

Turn to Page 19 of the Care Coordination Workbook: Barriers and Solutions.

Ask: What came up that prevented Maria from getting her meds?

Instructions to PN: Go over the different barriers that prevented Maria from getting her medications. Emphasize the barriers that are relevant or could become relevant to your patient and discuss how to address each one. Use the barriers and solutions table below for help.

Barriers and Solutions Table

What could a patient do if they call for a refill and...	The patient could:
No refills are left on their medication prescription	<ul style="list-style-type: none">• Call prescribing provider or clinic, explain the situation.• Ask if the provider can renew prescription.• Ideally, calling for a new prescription should take place when patient has at least two weeks of medications left.
Learns that their insurance policy has changed and no longer covers that medication	<ul style="list-style-type: none">• Contact provider, explain the situation.• Ask provider to submit a Prior Authorization form to the insurance company.• Check back with provider in 7-10 days to see if the provider has given patient's new authorization number to the pharmacy.• Once the insurance company sends authorization, order refills.• Sometimes Prior Authorization is refused by the insurance company and the patient has to be switched to another drug.

<p>Learns that their insurance plan or ADAP (AIDS Drug Assistance Program) membership has expired</p>	<ul style="list-style-type: none"> • If AIDS Drug Assistance Program (ADAP) eligible, fill out the renewal form and submit it to ADAP immediately via fax. • Call ADAP (1-800-228-2714) to let them know the form is on its way. ADAP may be able to approve 10-30 days of medications until paperwork is processed. • In the future, renewal forms can be sent to you at your agency if the patient needs your help remembering to renew every 6 months. • If patient has less than a week before medications run out, work with your Care Coordinator (and other clinic staff members) to see if she can get a few days worth of medications for free. • If this doesn't work, call the prescribing provider who can sometimes help to get the medications (for example through a relationship with the pharmacist or medication samples).
<p>The pharmacy is out of the medication</p>	<ul style="list-style-type: none"> • Ask if the pharmacy can order the medication and get refills before they run out.
<p>Orders their refill, but then cannot go to pick it up</p>	<ul style="list-style-type: none"> • Contact pharmacy and ask if it can deliver or mail medication. • If possible, patient could identify family/friends who can pick up the medication before they run out. • PN and patient should check if patient's current pharmacy has delivery services.

<p>The patient cannot afford co-pay</p>	<ul style="list-style-type: none"> • Patients can apply to ADAP if they cannot afford co-pays. • If the patient has state insurance, it is illegal for the pharmacy to withhold HIV or any other medications because the patient can't handle the co-pay.
<p>The patient receives the wrong medication</p>	<ul style="list-style-type: none"> • Return the medication immediately and discuss with the pharmacist.
<p>The one person that the patient feels comfortable talking with at the pharmacy is out</p>	<ul style="list-style-type: none"> • Contact PN PN options: <ul style="list-style-type: none"> • Sit with the patient while they call in the prescription and speak with somebody else. • PN might be able to make the refill request for the patient.

Conversation D: Practice Calling the Pharmacy

Objective: The objective of this conversation is to give the patient an opportunity to practice calling the pharmacy to refill a prescription so that they feel confident doing it alone.

Ask: Let's say that you are running out of one of your medications and need more. Who do you call?
What do you do?

Role play: PN, pretend that you are the person who answers the phone at the pharmacy, and ask your patient to practice calling in to make a refill request. Then, switch roles. Once your patient is ready, ask them to try calling in a refill request to the pharmacy themselves. You can sit with them and provide help as necessary while they order the refill the first time, or even the first several times, until they feel comfortable doing it alone.

Note to PN: Include in planning how to call the pharmacy if patient's phone is not in service.

Conversation E: When to Call the Pharmacy

Objective: The objective of this conversation is for the patient to understand why it is important to call the pharmacy to request refills seven days before a medication runs out.

Ask: When you call the pharmacy to request a refill, how many days of medication do you usually have left?

Say: It is important to call for refills when you still have at least seven days left of the medication.

Ask: Why do you think it is important to call the pharmacy seven days before running out of pills?

Fill in gaps in understanding: There are many reasons why you should call a week early! Here are just a few:

- People never know when they will get sick, have a family emergency, or have other obligations that make it difficult for them to pick up their refills from the pharmacy. By calling the pharmacy seven days in advance, a patient is more likely to be able to find transportation and a convenient time to pick up the refill before running out of pills.
- If the pharmacy is out of the medication it can reorder and have it ready in time.
- If the patient doesn't have any more refills left on a prescription, they will have time to call their physician and get a new prescription if necessary.
- If, when calling for a refill, a patient finds out that their insurance has expired or no longer covers the medication, there is time to find a solution rather than skipping pills while waiting for the application to be approved.

Ask: So why not call earlier than seven days to request refills?

Explain: Because most insurance policies will only pay starting seven days before you run out of pills.

Say: It's easier to refill all medication at once, so it is a good idea to have all on the same refill schedule. Are your medications currently on the same refill schedule?

If they are not, say: Sometimes the pharmacy can help by dispensing a certain number of each pill until refill schedules are aligned.

Instructions to PN: If not aligned already and the patient agrees, call the pharmacy together to ask them to align refill schedules. If the pharmacy can't help, you may need to speak to all of the prescribing physicians.

Conversation F: Medication Logistics

Objective: The objective of this conversation is to help the patient figure out the logistics involved in getting medications from the pharmacy to their home.

Instructions to PN: Discuss the following questions with your patient, and figure out the best solutions and strategies to answer each question together.

If your patient will be receiving pre-filled pillboxes, ask:

- How will the patient call the pharmacy for a refill?
- How will the patient get the pillboxes from the pharmacy?
- How will the patient check the pillboxes to make sure that they are filled correctly?
- How will the patient correct any problems there might be with the pillboxes?
- If the patient receives multiple pillboxes at a time, how will they keep from getting confused? Suggest that they number the pillboxes by week (1, 2, 3, and 4), and only have one pillbox out and visible at a time. It is important that they don't switch between different pillboxes day to day because this makes it easy to get confused. It helps if the patient only has one pillbox per week and changes pillboxes on the same day each week.

If your patient will be filling their own pillbox, ask:

- How will the patient call the pharmacy to let them know they need a refill?
- How will the patient get the medication from the pharmacy?
- How will the patient check the bottles to make sure they are the correct medications?
- How will the patient correct any problems there might be with the medications?
- On what day of the week will the patient fill and change the pillbox? They should change it on the same day each week, and tell you what day this is.

- It is important that patients keep from switching between pillboxes and pill bottles, because switching makes it hard to remember if the pills were taken or not.

If your patient will be receiving blister packs, ask:

- How will the patient let the pharmacy know that they need a refill?
- How will the patient get the blister packs from the pharmacy?
- How will the patient check the blister packs to make sure they are the correct medications?
- How will the patient correct any problems there might be with the blister packs?

For all patients, ask about storing medications:

- Where does the patient keep medication?
- Why did the patient choose this location?
- Does any medication need special storage (i.e., refrigeration)?
- Does the patient have small children so medication should be kept out of reach?
- Are there disclosure concerns?
- Does the location of medications fit into your patient's daily routine?

Wrap Up

- Say:** We've talked about a lot today!
- Ask:** In your own words, what did you learn today?
- Ask:** What did you learn about the importance of calling the pharmacy seven days in advance of running out of pills?
- Ask:** What is one barrier you learned how to overcome today when it comes to refilling medications?
- Ask:** What questions came up for you that we can review for next time?
- Ask:** What's most important for me to know about you and what we talked about today?

Topic 5: What is Adherence?

Learning objectives

After completing this topic, the patient will be able to:

- Explain the importance of adherence
- Identify barriers to adherence in their life
- Establish a routine for taking ART that works with their schedule

Preparation

- Bring the Care Coordination Workbook.
- Review patient's chart for documented problems in adherence.
- Review your notes on this patient from the last topic you completed together, and identify areas that need review or reinforcement.
- Review your notes from the Me and HIV conversation in Topic 2.
- Review the conversations and PN instructions for this topic.

Conversation	Materials & tools
Review from last session	
A: Your patient's perceptions of treatment	
B: What is adherence?	Elements of Adherence Resource (FG page 1)
C: Why is adherence to ART important?	
D: Taking medications on time	Tool: Pill Chart (Wkbk. page 22) A Day in the Life of a Pill (Wkbk. page 23) Surrounding HIV (FG page 74)
E: Resistance	Conversation E1 guide (FG page 78) Conversation E2 guide (FG page 81) Conversation E3 guide (FG page 83) Conversation E4 guide (FG page 85) Conversation E5 guide (FG page 86)
F: Daily routine chart	Daily Routine Chart (Wkbk. page 21)
Wrap Up	

Review

“Let’s go over what we talked about last time.”

Review areas that were particularly challenging for your patient during your last session together. Ask your patient to:

- 1) Demonstrate a skill that was learned from last session’s discussion;
- 2) Explain one of the key points from that session.

Conversation A: Your Patient’s Perception of Treatment

Objective: The objective of this conversation is to deepen your understanding of your patient’s perspective of HIV treatment. This will help you to learn about the barriers to adherence in your patient’s life.

Preparation: Before beginning this conversation, review your notes from the Me and HIV conversation that you completed together in Topic 2.

Note to PN: Patients are non-adherent to their treatment for a variety of reasons and these reasons vary depending on the patient’s beliefs, mental health, socioeconomic situation, and many other factors. It is important not to assume that your patient has the same understanding of their treatment as you or their doctor. Show respect for your patient’s beliefs and create an open atmosphere so that they will trust that you are acting in their best interests. Do not try to correct them if you think what they believe is incorrect. Just listen.

- Ask:**
- What do you think is important to fight your HIV illness?

 - In your opinion, how can you become healthy?

 - What kind of treatment do you think you should receive?

- What are the most important results you hope to receive from this treatment?
- How do you understand the treatment that your provider has recommended to you?
- How do you think this treatment should be followed?
- What makes it difficult to follow your provider's recommendations?
- Is there anything that you think should be changed about your treatment?

Note to PN: Encourage your patient to tell you when they don't understand something about a provider's recommendations and when the treatment conflicts with their beliefs or lifestyle. Now that you know what your patient thinks about their treatment, you are better equipped to talk with them about adherence.

Conversation B: What is Adherence?

Objective: The objective of this conversation is to help your patient understand the details of what adherence is.

Ask: Have you heard the word *adherence*?

Ask: What do you think of when you hear the word *adherence*?

Fill in gaps in understanding:

Adherence is:

- Taking the **appropriate number** of pills the right number of times per day.
- Taking the pills at the **same time** every day.
- Taking the pills the right number of **hours apart**.
- Taking the pills according to **dietary instructions**.
- Following instructions in terms of **mixing pills and other substances**.

Note to PN: Consult the Elements of Adherence Resource on the next page for more information about adherence that may be useful to this conversation.

Elements of Adherence Resource

Adherence is:

- Taking the appropriate **number** of pills the right number of times per day. For example, for the medication Kaletra, patients usually take 3 capsules twice per day.
- Taking the pills at the **same time** every day. If you take the pills at a different time each day, there will be times when you have no medication in your body and other times when you have too much medication in your body.
- Taking the pills the right number of **hours apart**. It is not good to take pills too close together or too far apart.
 - Once a Day = 24 hours apart*
 - Twice a Day = 10-12 hours apart*
 - Three times a Day = 7-9 hours apart*

However, if you have an activity to do, it is better to take drugs two hours early or before going out rather than not taking the medications at all.

- Taking the pills according to **dietary instructions**. This may have to do with your body's ability to absorb the medication or with preventing side effects.
 - Empty Stomach = 2 hours before or after you've eaten anything*
 - With Food = generally with a meal containing some fat*
- Following instructions in terms of **mixing pills and other substances**. Ask your doctor which substances you should avoid with your particular regimen and make sure to let them know about any other medications, natural remedies or substances you are using. If you use **alcohol**, continue taking medications as prescribed even when planning to drink. A general guideline to consider if you choose to drink is to consume no more than two alcoholic beverages for a woman or three for a man. By following this guideline your liver does not have to decide between breaking down the pills or breaking down the alcohol.

Conversation C: Why is Adherence to ART Important?

Objective: The objective of this conversation is to help your patient understand the benefits of adherence. Some patients do not adhere to their ART regimen because they don't understand how adherence benefits them.

Instructions for PN: Ask your patient the following questions and answer your patient's questions to explain how resistance may counteract medication and how ART works to keep viral count low.

Ask: What is ART?

Say: ART is the medication that you take to suppress your HIV virus, which means preventing the virus from reproducing, or copying itself.

Ask: Why is adherence important?

Say: If a patient is almost completely adherent to their ART (misses only one or two out of 20 pills), the ART will:

- Reduce the number of copies of the HIV virus so that they can't attack and kill CD4 cells (important cells of the immune system that fight infections). This allows the immune system the time and space it needs to make new CD4 cells and rebuild itself. A strong immune system means fewer infections and makes it less likely to develop AIDS. After a few months of good adherence to ART, often the viral load drops so low that the copies of virus in the blood become undetectable. This doesn't mean that the virus is gone or that the person is cured, just that the levels are very low.
- Be effective. If a patient doesn't adhere well, they can develop resistance to their medications, which means that the medications may no longer work.

Ask: What is resistance?

Say: **Resistance** means the HIV virus has assumed a new form and that your medication can no longer keep the virus under control.

Ask: What happens if I miss a dose of medication?

Say: You risk losing control of the virus and giving it a chance to make new copies of itself. Sometimes the virus makes a bad copy (or mutant virus) that is not identical to the original (or wild type) virus. The medication will not be able to fight the mutant copy.

Ask: Why does the bad copy of the virus become the strong virus in the blood?

Say: Because medication controls the original, or wild type, virus it can't make copies. Since the medication doesn't work on the bad copies of the virus, many bad copies are made. Some people can have many different types of bad (mutant) viruses. As a result lots of different ART medications don't work and the amount of HIV in the blood rises sharply unless the doctor can find a combination of medications that can suppress the bad copies (mutants).

Ask: Why does adhering to ART help prevent resistance?

Say: When you take your medications every day at the right time, you reduce your virus level since your virus has no chance to copy itself. If the virus is not copying itself, it can't make non-identical copies, and resistance is less likely. The more doses you miss, the more chances you give the virus to make a non-identical copy.

Ask: Why is missing one out of five ART pills worse than missing three out of five ART pills?

Say: When both the original virus (wild type) and mutant (bad virus) are present in the blood stream, the original type dominates if you don't take medication. Missing many doses of ART strengthens the original virus. Once medication is introduced, the original virus becomes weak. When a person misses three out of five pills, there is replication but not enough medication around to select the bad (mutant) type of HIV. But when a person misses only one out of five ART pills, there is replication and enough medication to suppress the original (wild type) of the virus, leaving only bad copies. Because of this, **incremental improvements in adherence can actually be worse when it comes to resistance.** This is why we aim for patients to take at least 18-19 out of 20 pills at all times.

Conversation D: Taking Medications on Time

Objective: The objective of this conversation is to help your patient understand that it is important to take pills the recommended number of hours apart in order to maximize the drugs' efficacy and minimize the risk of drug resistance and toxicity (being poisonous).

Ask: Please select one medication that you are taking and tell me what times of day you take it.

Turn to Page 22 of the Care Coordination Workbook: Pill Chart.

Instructions to PN: List the patient's medications one by one on the Pill Chart along with the times of day taken.

Turn to Page 23 of the Care Coordination Workbook: A Day in the Life of a Pill.

Instructions to PN: Graph one of the HIV medications your patient listed on the Pill Chart to show the patient if he is taking this medication appropriately. Use the **Day in a Life of a Pill** diagram at the top as a model as you graph your patient's medication-taking practice.

Turn to the Surrounding HIV reference on page 74 of the Facilitator's Guide.

Instructions to PN Use the Surrounding HIV reference as a guide as you draw out the images in it for your patient on a piece of scratch paper. The goal is to give your patient a visual representation of the importance of taking medications on time.

Say: In order for HIV medications to work, it is important that you take them on time. It is okay if sometimes you take them an hour early or an hour late, but do everything you can to stay within one hour from your scheduled time.

Ask: Why is it important not to take medications early?

Fill in gaps in understanding: Taking medications too close together can lead to drug toxicity because you double the dose of drug in the bloodstream. Drugs become toxic (poisonous) when dosages are too high, too close together or inappropriately taken. Drug toxicity can cause side effects, organ damage and in extreme cases even death.

Ask: Why is it important not to take medications late?

Fill in gaps in Understanding: Taking medications too far apart allows the HIV virus to make more HIV viruses, which will make you feel worse. It also leads to resistance because there are not enough drugs in the bloodstream to keep fighting the virus.

Pill Chart

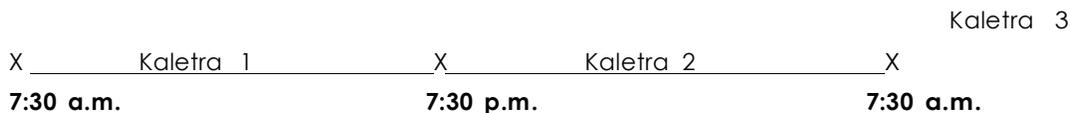
Name of Medication	Instructions	Time of Day Taken
		am pm

Conversation D Resource: A Day in the Life of a Pill

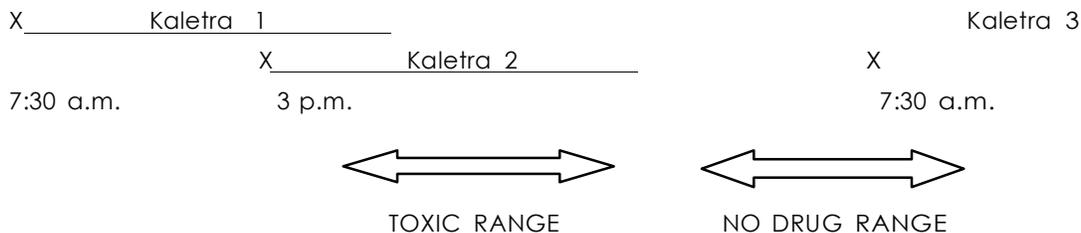
As an **example**, let's say you were taking Kaletra twice a day and took the second dose at 3 pm instead of 7:30 pm. That means between 3 pm and 7:30 pm, you would have a double dose of Kaletra in your body because the medications stay in your body for 12 hours. This situation can cause a problem because high levels of medications lead to worse side effects that can damage the body.

In addition, you would have no medications in your body between 3 am and 7:30 am because the 3 pm dose will have run its course by 3 am. This leaves five hours for the HIV virus to build up its numbers in the body and develop resistance to the Kaletra. This is best demonstrated in the following picture:

CORRECT ADMINISTRATION:



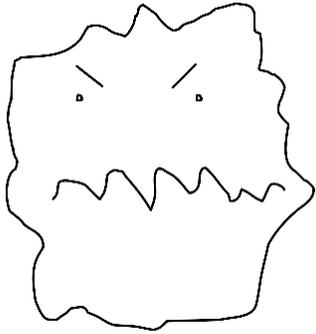
INCORRECT ADMINISTRATION:



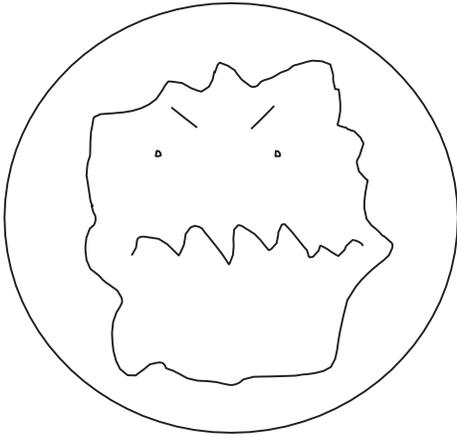
Teaching point: It is easier to draw this picture by hand for your patient than show them the diagram above. Pause and stop as you draw. Take your time with this section.

Conversation D Resource: Surrounding HIV

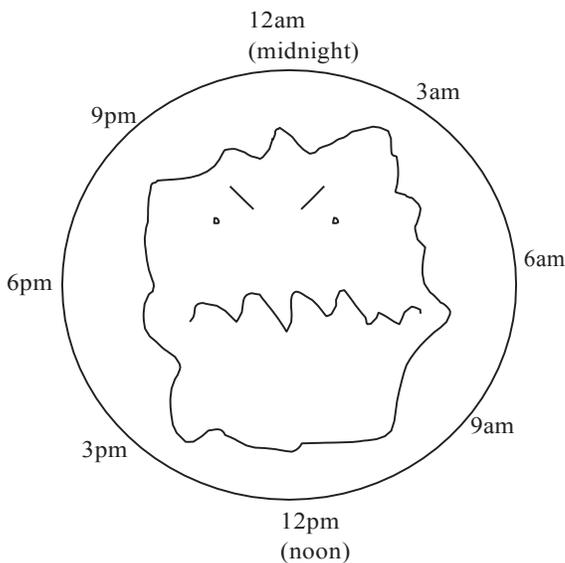
Instructions to PN: Talk about the following points with your patient. It is usually helpful to draw the pictures for your patient while you discuss.



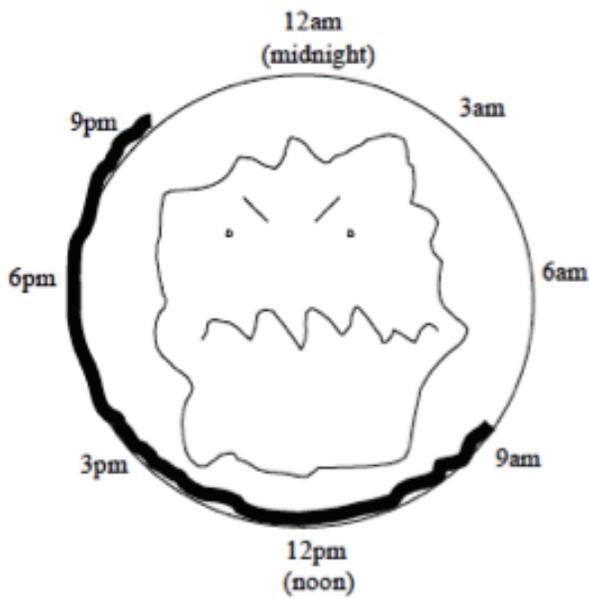
Here's HIV.



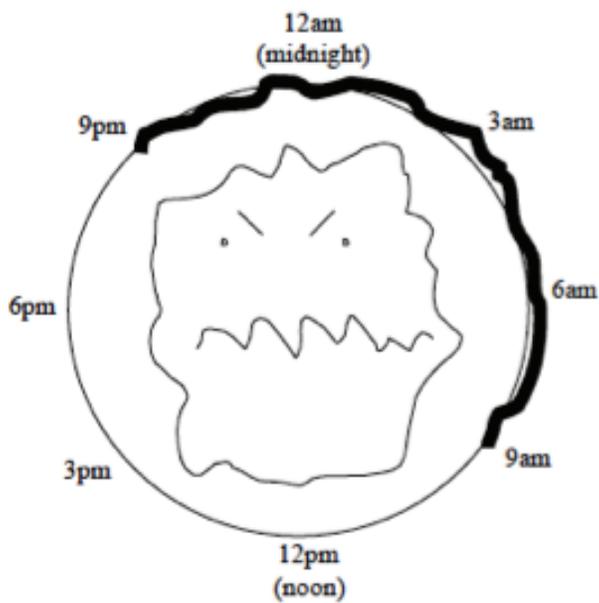
When you take HIV medications, they enclose the HIV like this and protect your body from being hurt by the HIV. The medications keep bad things out of your body.



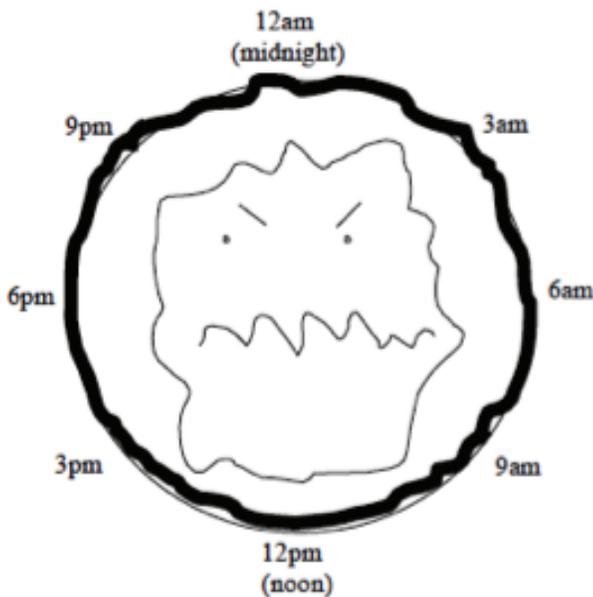
There's a **24-hour clock** on the HIV medications like this.



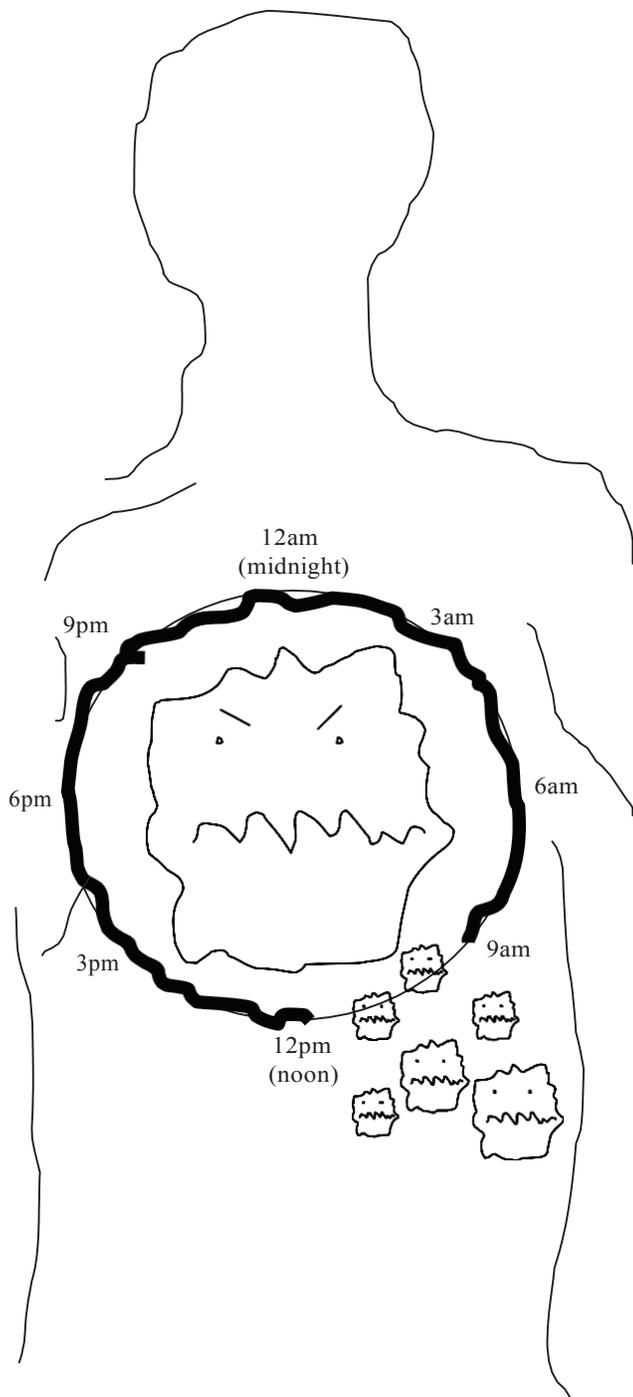
If you are supposed to take your pills at 9am and 9pm, then the morning pill keeps the HIV covered all day from 9am until 9pm.



If you take your evening pill at 9pm, then that keeps the HIV covered all night from 9pm until 9am.



If you take your morning pill and evening pill on time, then the pills keep the HIV covered all day and night, 24 hours a day. So your body is protected against HIV all the time!



BUT: if you forget to take your morning pill, and take it at noon instead of at 9am, then you are not protected against the HIV from 9am until noon. During this time, the HIV can make copies in your body.

The more HIV grows in your body, the more sick you will be. You can prevent HIV from making copies by taking your HIV pills every day at the right time.

Conversation E: Resistance

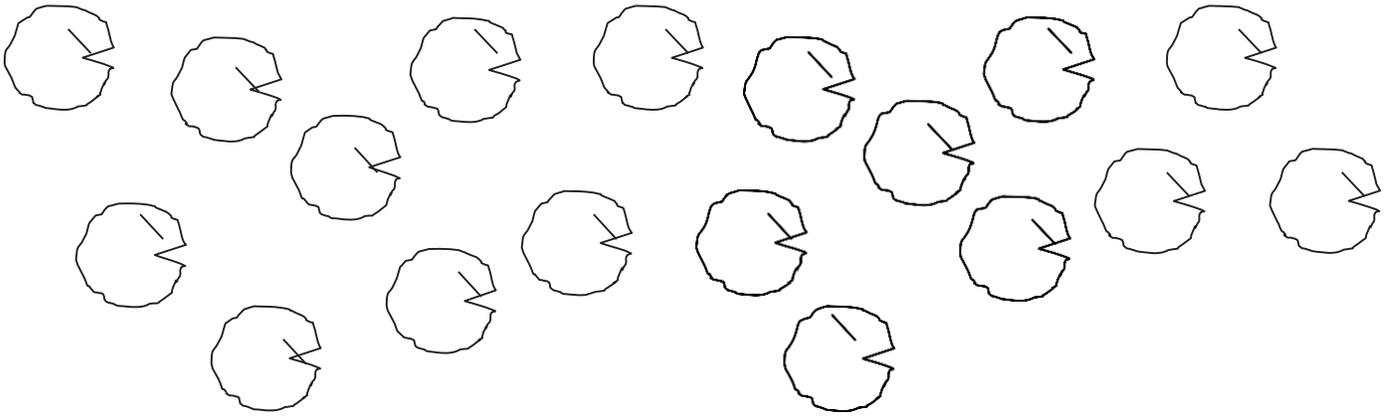
Objective: The objective of this conversation is to explain how resistance takes place in a way that your patient can understand and relate to. You want your patient to understand that taking 18 or 19 out of 20 pills is necessary to prevent resistance, and that taking around 15 out of 20 pills encourages resistance even more than taking 10 out of 20 pills does.

Instructions to PN: There are several different ways that you can go about discussing the idea of resistance with your patient. Based on your patient's interests and cognitive ability, **choose one or more of the five following conversations to use as a guide.**

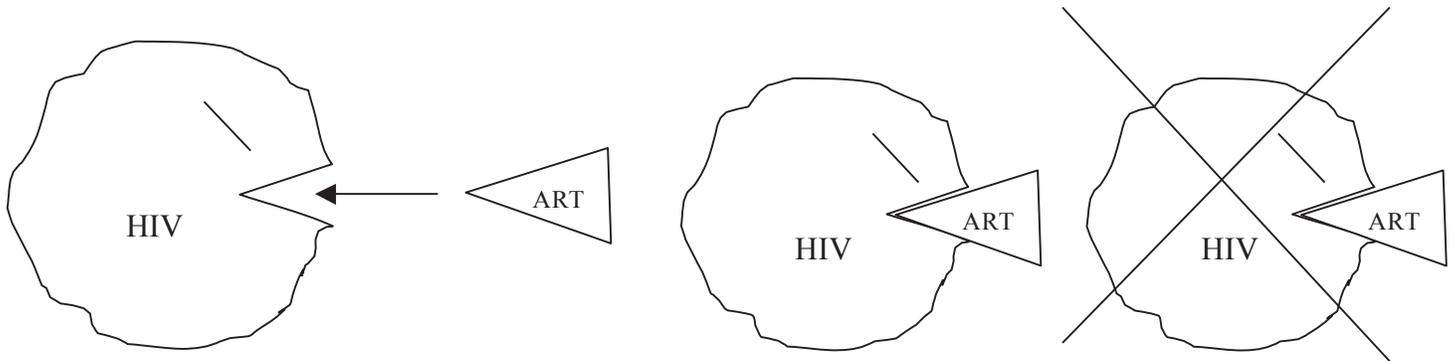
Conversation E1 Guide: Resistance

Instructions to PN: Talk about the following points with your patient. It is usually helpful to draw the pictures for your patient while you discuss.

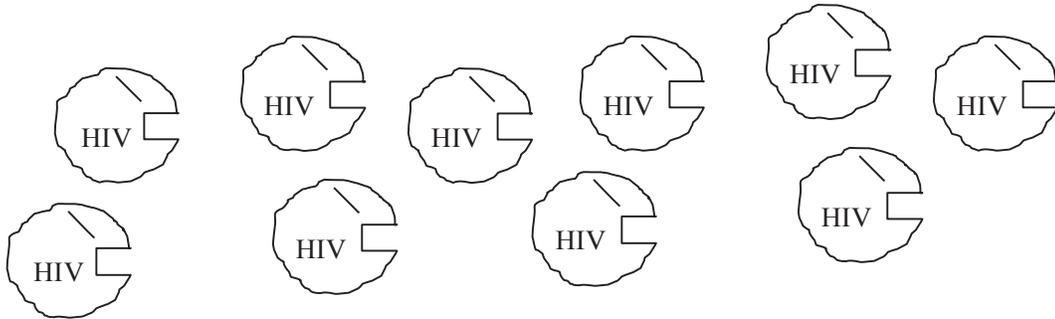
Say: When you have a lot of HIV in your blood, you are weak and sick.



Say: When you take your ART pills, they kill the HIV.



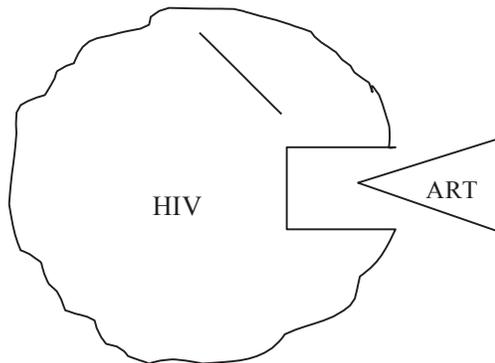
Say: If you miss more than 2 out of every 20 ART pills, the HIV can change shape. This new shape of HIV is called **resistant** because it **resists** the ART.
Sometimes it can also be called a **mutant** type of HIV.



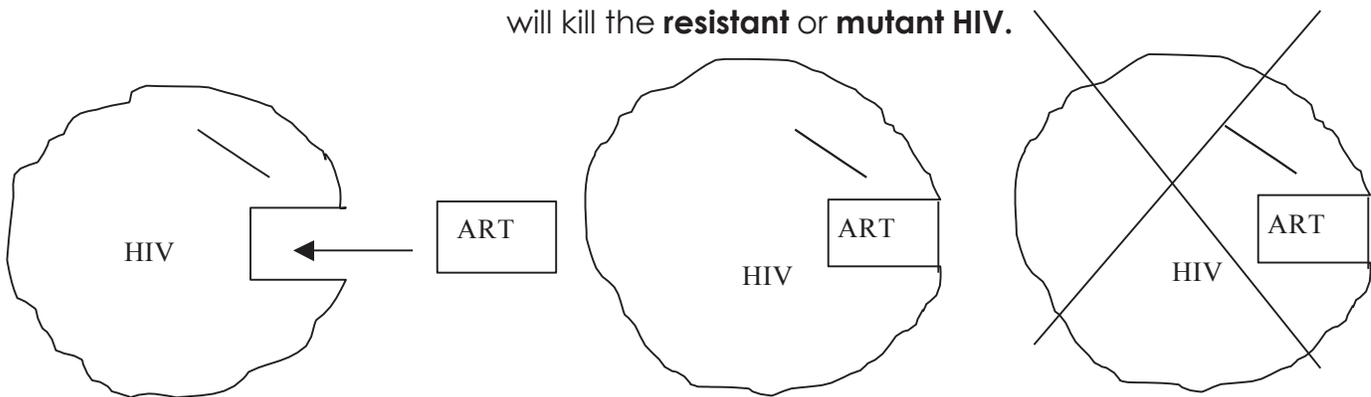
Say: The new shape of HIV doesn't fit into ART anymore.

Ask: Is there a problem with this?

Say: Yes! ART can't kill the HIV if it doesn't fit.



Say: You can switch medications, which means get a new type of ART pills that will kill the **resistant** or **mutant HIV**.

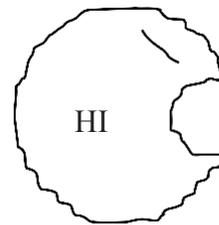


Ask: So if you can get a new type of ART that will still work, what's the problem?

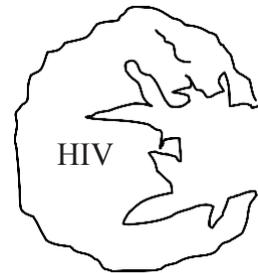
Fill in gaps in understanding: The new type of ART will probably have more side effects than the first type, so it might make you feel worse.

Say: The new type of ART might also be less convenient to take than the first type; for example, you might have to take it several times a day or inject it instead of just taking one or two pills a day.

Say: Also, if you keep missing more than two out of 20 pills, then the HIV can change shape again! Then you have to get another type of ART again which can be even harder to take or have more side effects.



Say: Sometimes the HIV changes to a shape that no ART will kill and so the HIV can take over your body and make you very sick.



Ask: So how do I prevent the HIV from changing shape?

Say: Take at least 18 or 19 out of every 20 ART pills on time to kill your HIV and prevent resistance!

Conversation E2 Guide: Resistance

Say: HIV reproduces quickly. Hundreds of HIV viruses replicate in your body all day long making hundreds of thousands of copies that make you weak and sick.

Say: Let's say that HIV is represented by the letter "A."

Instructions to PN: Draw something like the following for your patient.

AAAAAAAAAAAAAAAAAAAAAAAAA
AAAAAAAAAAAAAAAAAAAAAAAAA
AAAAAAAAAAAAAAAAAAAAAAAAA
AAAAAAAAAAAAAAAAAAAAAAAAA
AAAAAAAAAAAAAAAAAAAAAAAAA
AAAAAAAAAAAAAAAAAAAAAAAAA
AAAAAAAAAAAAAAAAAAAAAAAAA
AAAAAAAAA**b**AAAAAAAAAAAAA
AAAAAAAAAAAAAAAAAAAAAAAAA
AAAAAAAAAAAAAAAAAAAAAAAAA

Say: If you look closely, you will notice that in addition to many "A" HIV viruses one "b" HIV virus was made. The b virus is a mistake. When the HIV was making copies, it accidentally made the b virus instead of an A virus.

Say: The b virus is very weak and usually dies out quickly because all of the A viruses are stronger.

Say: Your HIV medications kill the A virus, and shut it down so that it can't make any more copies.

Say: If you take your HIV medications all the time and miss no more than one or two out of every 20 pills, when your doctor draws your blood they won't see any A viruses in it because the HIV medications will have killed them.

- If you take your HIV medications all the time and miss no more than one or two pills, there probably won't be any b viruses in your blood either since without sufficient A virus around making copies, the b virus is eliminated too.
- But, if you miss more than two HIV pills out of every 20, then the HIV medication won't be able to kill all of the viruses in your blood.
- This means that the A virus will be making enough copies to make mistakes and accidentally make b viruses. Since HIV medications kill the A viruses but not the b viruses, a lot of the A viruses will get killed, but the b viruses will survive.
- Once the b viruses don't have to compete with the A virus, which is getting killed by the HIV medications, they will get strong and start making copies; eventually they will go crazy and make lots of b virus copies!
- At this point, even if you take your HIV medications perfectly, you will still have a lot of HIV in your blood because the HIV medications don't kill the b virus.
- This situation is what we call "resistance": the HIV in your body at this point (which includes A and b viruses) is resistant to your medication. This means that the medication doesn't kill the HIV.
- In order to have resistance, two things must happen:
 1. The HIV virus in your blood needs to be making some copies.
 2. You need to have some HIV medications in your blood.

Conversation E3 Guide: Resistance

Instructions to PN: Explain the house metaphor about HIV and resistance to your patient, then do a teachback to identify areas of understanding and areas in need of clarification.

Say: Imagine that your body is a factory. One day . . .

. . . an intruder called HIV breaks in and tries to steal from your factory. Your HIV medication is your security system. Even with a perfect security system, it is possible that the intruder will still figure out how to break into your factory, but it will take them a long time and they might never figure it out. However, if you turn your security system off for a few hours or a day, the intruder can get in and start figuring out how your security system works. If you turn your security system off for a few hours a few times a week, the intruder will find out how your factory and security system work. This is what happens when you forget to take a couple of HIV pills. The HIV medication can't protect your body from HIV until you take your pills again, and so this allows the HIV the opportunity to get in and figure out how the HIV medication works—just like the intruder can get in and figure out the security system of a factory.

Even when you turn your security system back on after it has been off for a few hours, the intruder will be better able to break into the factory. For example, they might know when the guards go to sleep or what rooms have open windows. They might have figured out the secret code to the alarm system. Now the intruder is more likely to be able to steal from your factory even when the security system is on. This is how HIV works, because even if you take your HIV pills after forgetting a few doses, the HIV might have already figured out something about how the medications work. This makes the medication less effective at protecting the body against HIV. Once the HIV figures out how the HIV medications work, we say that the HIV is **resistant** to that medication.

What will you do? You will have to buy a new security system. Unfortunately, if you continue to leave the security system off for certain periods of time, the intruder will figure out the new security system as well and steal again. There are only a few security systems available so if you go through all of them there will be no other way to protect your factory.

Similarly, if HIV becomes resistant to your HIV medications, you can usually get a new HIV medication. However, if you continue to miss pills regularly, the HIV will figure out how to be resistant to those new pills. Eventually, you may go through all of the HIV medication options available and there will be no way to protect yourself against HIV. This is one important reason why adherence to HIV medications is important.

Ask: Tell me what this means to you.

Ask: Tell me what you understand now about HIV and resistance.

Instructions to PN: Fill in gaps in patient's understanding.



Conversation E4 Guide: Cocktails and Resistance

Instructions to PN: Explain the following baseball metaphor about HIV and the immune system to your patient. This metaphor is particularly helpful at explaining why an ART cocktail is important to prevent resistance.

Ask your patient to imagine that the immune system is a baseball pitcher, and that the HIV virus is the batter.

The pitcher, or immune system, can throw different balls—a curveball, a fastball, a sinkerball. These different balls are like the different HIV medications that the immune system uses to beat HIV.

If the pitcher only throws a fastball, the batter learns how to hit a fastball and score a home run every time. But if the pitcher can also throw a curveball and a sinkerball, the likelihood that the batter will hit a homerun decreases because the batter doesn't know what to expect.

The same is true for HIV. Imagine you have three different HIV medications that you are supposed to take every day, for example, Retrovir, Truvada and Kaletra. If you only take the Retrovir and leave the Truvada and Kaletra in your pillbox, your immune system can only throw the Retrovir at the HIV virus, just like the pitcher who only throws the fastball at the batter.

Like the batter who learns how to hit a homerun, the virus will figure out that you are only taking Retrovir. The virus will learn how to respond to Retrovir and become **resistant** to it, meaning that the Retrovir won't work. If you take the Retrovir, Truvada and Kaletra every day as your doctor recommends, it is like throwing a curveball, a fastball and a sinkerball at the HIV virus all at the same time. This makes it more difficult for the HIV to become resistant, so the medications will keep working.

Conversation E5 Guide: Cocktails and Resistance

Instructions to PN: This is an advanced conversation for a sophisticated patient who wants to understand the details of how HIV medications work in the body, and why adhering to a cocktail helps prevent resistance.

Say: There are several places where we can stop the HIV virus from making copies of itself.

- In order to make copies of itself, the virus first has to read its own genetic code. The code is a blueprint, or a set of instructions for building a new virus. In order to read its code, the virus has to use an enzyme called *reverse transcriptase*. It is possible to stop the virus here—by interrupting its ability to read its own code. The medications that do this, called *Reverse Transcriptase Inhibitors*, prevent the *reverse transcriptase* from working.
- After the virus makes a copy of its genetic code, it uses the enzyme *integrase* to insert a copy of its code into the nucleus of the infected cell. It is also possible to stop the virus here by taking a medication called an *Integrase Inhibitor*. Blocking *integrase* stops this step of viral reproduction and so an *integrase inhibitor* can arrest further spread of the virus.
- HIV also uses an enzyme called *protease*. After new viral proteins have been built, a new virus takes shape and pushes out of the infected cell. The insides of this new virus aren't fully formed yet and *protease* plays a key role like a pair of chemical scissors that cut long strands of protein to assemble the core of the virus. The *protease inhibitor* drugs block the enzyme by locking in between the two blades of the scissors so they can't cut anything.

Say: These are just a few examples of how different HIV medications work. It is important to take a cocktail of HIV medications in order to interrupt the HIV virus at several different points. If you don't take all of the medications your doctor prescribes, the virus is more likely to get away at certain points, which gives it the opportunity to grow stronger against other medications.¹

¹ Source: <http://www.thebody.com/content/art990.html>

Conversation F: Daily Routine Chart

Objective: The objective of this conversation is to help your patient figure out how to remember to take their ART. It will also help you assess your patient's situation. This conversation helps many patients to visualize adherence and how it fits into their day.

Note to PN: If it is not useful to your patient to fill in the tool, use this tool as your guide for a conversation about adherence planning. You don't have to fill out each hour, just use the tool to help structure events during the day.

Turn to Page 21 of the Care Coordination Workbook: Daily Routine Chart.

Instructions to PN: Ask your patient the questions in the column on the side of the tool as you fill in the calendar with his events and activities, including times to take their medications.

Things to consider:

- Schedules on Saturdays and Sundays often differ from weekdays, and should be considered carefully to find a plan that will allow adherence.
- Focus on what your patient does every day that could help them remember to take ART.
- Discuss your patient's lifestyle and reoccurring obstacles that should be factored into their routine. For example:
 - If visitors frequently stay at their house
 - If they are often away from home at dose time
 - Erratic schedule
 - Frequent oversleeping or sleeping through alarms
 - Using drugs or alcohol
 - Not having the right kind of food or beverage in the house with which to take the pills

Conversation F: Daily Routine Chart

	Weekday	Weekend	
6 am			<p><u>Sleeping</u></p> <ul style="list-style-type: none"> • 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? <p><u>Eating</u></p> <ul style="list-style-type: none"> • What times do you usually eat? • Who do you eat with? Would you feel comfortable taking pills in front of these people? • Where do you eat? Could you bring the pills with you? • How do you feel about mealtimes? Are there ways to take pills on a full stomach without interfering with the social and other pleasures of eating? <p><u>Comings and Goings</u></p> <ul style="list-style-type: none"> • What time do you usually leave the house? • What time do you usually come back home? • Are there other things you do at about the same time every day? (watch TV, send kids to school) <p><u>Weekends</u></p> <ul style="list-style-type: none"> • Repeat the above questions for weekend or nonworking days. <p><u>Things You Can Do to Make It Work</u></p> <p>If you need a full stomach at a time other than a mealtime try a snack with some fat like crackers with peanut butter.</p> <p><u>Reminders</u></p> <p>What can you do to remind yourself that it's time to take your pills? What makes your schedule change?</p>
7 am			
8 am			
9 am			
10 am			
11 am			
12 pm			
1 pm			
2 pm			
3 pm			
4 pm			
5 pm			
6 pm			
7 pm			
8 pm			
9 pm			
10 pm			
11 pm			
12 am			

Wrap Up

- Say:** We've talked about a lot today!
- Ask:** In your own words, what did you learn today?
- Ask:** What is your understanding of why it is important to be adherent to medications?
- Ask:** What did you learn about why resistance happens?
- Ask:** What did you learn about your daily routine?
- Ask:** What questions came up for you that we can review for next time?
- Ask:** What's most important for me to know about you and what we talked about today?

Topic 6: Side Effects

Learning Objectives

After completing this topic, the patient will be able to:

- Review their list of medications
- Identify side effects
- Plan how to manage symptoms and know when to contact their doctor

Preparation

- Bring Care Coordination Workbook.
- Review Medication List and bring it.
- Review patient's chart for concerns about side effects.
- Review your notes on this patient from the last topic you completed together, and identify any areas of confusion that need review.
- Review conversations and PN instructions for this topic.

Topic overview

Conversation	Materials and tools
Review from last session	
A: Understanding Side Effects	
B: Identifying Side Effects	Side Effects Chart (Wkbk. page 25) Medication List (Wkbk. page 14)
C: Severe Side Effects	
D: Managing Side Effects	Symptom Management Action Plan (Wkbk. page 27)
Wrap Up	

Review

“Let’s go over what we talked about last time.”

Review any areas that were particularly challenging for your patient during your last session together. **Ask your patient to:**

1. Demonstrate a skill that was learned from last session’s discussion;
2. Explain one of the key points from that session.

Assessment: This topic is for clients prescribed ART. Introduce this topic to all your patients and explain the benefits of discussing side effects. Some patients who have experienced serious side effects in the past may find this topic uncomfortable, while others who have not had serious side effects may find it more concerning than useful. In these cases, exercise discretion in determining whether or not to continue with the topic.

Note to PN: It is important to remember that **not all symptoms that your patient is experiencing are necessarily side effects**. Be careful not to label symptoms as side effects until you are sure they are not allergies or symptoms of other illness.

Background for PN: This topic reviews your patient’s medications, discusses the potential side effects of ART medications and introduces strategies for symptom management. Now that you have reviewed what each medication is for and the importance of adherence (Topic 5), discuss possible side effects and equip your patient with strategies for managing them so they can remain adherent to medications.

Conversation A: Understanding Side Effects

Objective: The objective of this conversation is to reinforce the idea that ARTs are good for your patient's health even if the short term effect is unpleasant, and that side effects are temporary and often treatable.

Say: Today we will talk about possible side effects that ART can cause.

Ask: Have you ever experienced side effects? If so, when?

Feedback: Respond to what your patient has just shared with you, validating their past experiences and acknowledging that side effects can be unpleasant and discouraging.

Say: As you might know, taking meds when you have side effects is definitely hard, and sometimes you end up feeling more sick than before you started your meds. But the good news is that there are many steps you and your doctor can take to reduce side effects. Even if you are not currently experiencing side effects, this is information for you to have in case you ever start a new medication or change your regimen.

Review of Essential Concepts

Say: The most common approach to treating HIV is through antiretroviral therapy, also referred to as HAART, ARVs, or ART. Health care providers will use the CD4 count and viral load as a measure of the success of these drugs.

Ask: Do you remember how ART can affect the CD4 and viral load of someone who is adherent?

Feedback: Congratulate your patient on any correct information they were able to provide. If needed, review the information below.

Say: Good adherence will cause your CD4 to increase and your immune system to get stronger. It will also reduce your viral load. But taking meds when experiencing side effects is hard. The purpose of this conversation is to discuss what is happening when you experience side effects and to offer you active steps to take to continue on your meds even when side effects occur.

Knowledge Assessment

Ask: Why do side effects occur in the first place?

Feedback: Medications often treat disease by killing or weakening the virus or bacteria causing the illness. Sometimes the meds may also disrupt some of your body's normal functions while your body gets used to the meds. In the meantime your body's reaction to the meds can cause uncomfortable side effects.

Emphasize: Even though side effects can be uncomfortable and unpleasant, they only last a short while. On the other hand, benefits of good adherence to ART are long term—they will help you live a healthier and longer life.

Analogy: Have you ever felt sore after exercising? We get sore after a workout because our muscles are working hard. But we know that if we keep exercising, the soreness eventually goes away and we're stronger and healthier. In the same way, people might feel sick when they first start their ART, but when they keep taking their meds the side effects go away and their immune systems get stronger.

Ask: Can you think of anything that someone could do to reduce side effects?

Say: Side effects can be reduced by changing **when and how** someone takes their medications, by making certain **lifestyle** changes, by taking additional medications to control side effects, or even by **changing medications** altogether. We will go over in more detail some of the ways you can reduce side effects a bit later in this topic.

Say: Remember:

- Side effects are usually **temporary** and often decrease or go away as the body adapts to the medication, usually within 4-6 weeks.
- Together we can work with your medical team to decide how to **reduce** any side effects you might be experiencing.

Conversation B: Identifying Side Effects

Turn to Page 25 of the Workbook: Side Effects Chart.

Objective: The objective of this conversation is to discuss any side effects your patient is experiencing, and to identify which of their medications might be the cause. Talk to your patient about some possible strategies for reducing his side effects.

If your patient is not experiencing any side effects, the objective is to help your patient understand that side effects can be minimized in the event that they occur. The point is not that your patient memorizes the strategies discussed, but that he knows that there are measures they and their providers can take if needed.

Turn to Page 14 of the Workbook: Medication List.

Note to PN: Refer to the medication list you filled out previously. It is important that this list is as accurate as possible, as it will be used during the discussion of side effects and symptom management.

Ask: What side effects are you experiencing?

If none, say: That's great that you aren't experiencing any side effects. Side effects can result from any medication, not just ART, and there are sometimes reasons to change one's ART regimen. Let's discuss some of the common side effects and ways in which they can be managed.

Turn back to Page 25 of the Workbook: Side Effects Chart.

For patients currently experiencing side effects, say:

Are you experiencing any of the following?

- Fatigue
- Rash
- Diarrhea
- Headache
- Anemia
- Nausea and vomiting
- Weight loss
- Depression

Ask: Are you experiencing any other symptoms?

Say: Let's talk about some ways that you can manage these symptoms.

Instructions to PN: For patients who are not currently experiencing side effects, skip to steps 4-5. For patients who are currently experiencing side effects, follow instructions 1-5.

1. Refer to the Side Effects chart and the list of side effects your patient identified.
2. Go through your patient's medication list and refer to the Side Effects Chart to try to determine which medications might be causing the symptoms identified.
3. Talk about the strategies your patient is currently using to manage these symptoms.
4. Go over other strategies in the chart that can minimize discomfort.
5. Also discuss when your patient should talk to their physician and what they should say.

Side Effects Chart

Side Effect	Medication	Symptom Management (see Resource Material: Symptom Management for more info)	Important Notes
Diarrhea	Often caused by Protease Inhibitors (PIs) Viracept (nelfinavir), Agenerase (amprenavir), Kaletra (Aluvia, lopinavir/ritonavir), Isentress (raltegravir), Aptivus (tipranavir), Prezista (darunavir) and, Norvir (ritonavir).	<ul style="list-style-type: none"> • Drink plenty of water and other clear liquids. • Try a diet of BRAT (Bananas, Rice, Apples and Toast). • Some foods that are good to eat are white bread, white rice, noodles, cottage cheese, yogurt, eggs, and potassium-rich foods like bananas, oranges, raisins, dried fruit and baked potatoes. 	Your doctor may prescribe something like Imodium to help reduce the diarrhea. Contact your doctor if the diarrhea is bloody <u>or</u> continues for more than a day, if you have abdominal pain, <u>or</u> you start to become dehydrated.
Nausea	Often caused by Norvir (ritonavir), Invirase (saquinavir), Agenerase (amprenavir), Kaletra (Aluvia, lopinavir/ritonavir), norvir, Isentress (raltegravir), Intelence (etravirine), Prezista (darunavir), combination drugs with the drug tenofovir in them (such as Atripla, Complera, Truvada, and Viread), and other Nucleoside/ Nucleotide Reverse Transcriptase Inhibitors (NRTIs).	<ul style="list-style-type: none"> • Eat something, even if it's just a little bit. • Don't eat large meals at night. • Don't lie down for at least 30 minutes after eating. • A small snack before bed or when you first wake up can help morning nausea. • Drink plenty of water. • Drink herbal teas like mint, peppermint, chamomile or ginger tea. • Go for a walk outside. 	Your doctor may be able to prescribe medications like Compazine. Contact your doctor right away if you vomit right after taking your medications or if you vomit several times in 24 hours.

Side Effect	Medication	Symptom Management (see Resource Material: Symptom Management for more info)	Important Notes
Rash	Often caused by Bactrim (sulfamethoxazole/ trimethoprim), Ziagen (abacavir) (sign of potentially fatal reaction), Sustiva, (Stocrin, efavirenz) Viramune and Viramune XR (nevirapine), Agenerase (amprenavir), Aptirus (tirpanavir), Selzentry (Celsentri, maraviroc), and other NRTI's (however, almost any drug can cause a rash)	<ul style="list-style-type: none"> • Take a cool bath. • Use a hypoallergenic moisturizer. • Avoid the sun, hot showers, scented lotions and perfumes. • Don't scratch the rash, it will make the itching worse and potentially cause damage to your skin. 	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.
Fatigue	Often caused by Sustiva (Stocrin, efavirenz), Eпивir and combination drugs with AZT in them (such as Combivir, Retrovir, and Trizivir	<ul style="list-style-type: none"> • Get plenty of rest. Relax or take an afternoon nap. • Eat a well balanced diet and take a daily multi-vitamin. • Get some exercise; it can boost your energy. 	
Headaches	Often caused by combination drugs with AZT in them (such as Combivir, Retrovir, and Trizivir), Zerit (stavudine, D4T), and Sustiva (Stocrin, efavirenz)	<ul style="list-style-type: none"> • Try yoga, meditation or acupuncture. • Take a break and give yourself some downtime. • Drink a lot of fluids; dehydration can cause headaches. • Try to avoid bright light, watching television and loud noise. 	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.

Side Effect	Medication	Symptom Management (see Resource Material: Symptom Management for more info)	Important Notes
Problems Sleeping	Often caused by Sustiva (Stocrin, efavirenz)	<ul style="list-style-type: none"> • Some people find that side-effects from Sustiva are easiest to cope with if you take it just before bed. • Eat at least 2 hours before going to bed. • Avoid large or high fat snacks around your Sustiva dose. 	Primary side effects of Sustiva are strange dreams, trouble sleeping and drowsiness.
Weight Loss	Could be caused by a variety of factors	<ul style="list-style-type: none"> • Include nutrition and exercise as part of a comprehensive treatment strategy for HIV. • Stay in touch with your doctor about your weight loss so you can diagnose and properly treat it. • When necessary, consider using supplements to replenish deficiencies. 	Your doctor can help monitor your weight over time and suggest resources and a safe program for maintaining your weight.
Depression	Could be caused by a variety of factors	<ul style="list-style-type: none"> • Identify resources and support systems. • Talk with your Patient Navigator. 	If you believe your depression is related to your medications, speak with your health care provider right away.

Conversation C: Severe Side Effects

Objective: The objective of this conversation is to acquaint your patient with some of the symptoms that may indicate a severe side effect caused by ART and to emphasize the importance of communicating symptoms to the doctor.

Note to PN: Though most side effects are common and usually go away after 4-6 weeks, some patients who experience more severe side effects or allergic reactions should **contact their doctor immediately**.

Ask: Are there any symptoms you are experiencing right now that you have not told your doctor about?

Feedback: If your patient has not talked to their doctor about their symptoms, ask if your patient wants to bring this up at the next appointment, or if you can call the doctor together, as is recommended with more severe side effects.

Say: It is important that you tell your doctor about any symptoms you experience. Today we will go over some simple strategies that can help reduce discomfort and side effects, but sometimes side effects can be severe and even dangerous. In these cases your doctor may want to change your medication or evaluate you further. Please keep your doctor informed of symptoms you experience. Some discomfort and side effects are normal, but if you experience symptoms that you think you may be severe, report them to your doctor immediately.

Turn to Page 24 of the Care Coordination Workbook: Managing Side Effects.

Say: This **Side Effects** chart lists possible symptoms caused by side effects in order of seriousness and is a guide to how quickly you should speak to your doctor after experiencing symptoms. If any of these symptoms makes you want to stop taking your medications, call your doctor immediately.

Instructions to PN: Review the Symptom Management Action Plan with your patient. If your patient is experiencing any side effects, make sure that the patient's doctor is aware of them. As you go over the chart together, identify any side effects that have not been discussed with your patient's provider, and make sure that the provider becomes informed.

Ask: What would you do if you experienced one of these side effects?

Instructions to PN: Make sure your patient has their doctor's beeper number and other necessary contact information.

Resource: Managing Symptoms

People with HIV can experience a range of symptoms, some of which are side effects of their medications. It is important to discuss any symptoms with your doctor. This is a general guide for how severe a side effect may become and when to contact a doctor. However, any time you are concerned about your health, call your doctor and PN as soon as possible.

Call your doctor immediately if you have the following. If you can't reach your doctor, call 911.

A rash or hives
Swollen eyes or a swollen tongue
Difficulty breathing or swallowing

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 leading to signs of dehydration (dark urine, lightheadedness, muscle cramps)
Bloody stool
Any other symptom that is especially disabling or distressing to you

Call your doctor within a few days or discuss with them at your next appointment if you experience:

Muscle pain
Mild weakness
Mild headaches
Loss of appetite
Changes in body fat
Nervousness or anxiety
Burning or tingling in the feet
Strange dreams or difficulty sleeping
Diarrhea without blood or dehydration

Very Severe Side Effects (discretionary)

Instructions to PN: If your patient is experiencing any of the following very severe side effects, acknowledge that it is hard and inform the provider. Share the following information if you think it would be useful to your patient. **Be careful not to scare your patient.** These are not common side effects, but in case they occur, it is important that your patient know what is happening.

Hypersensitivity Reaction or skin problems or rashes – an allergic reaction that may involve hives, swelling, itching, flushing, or rash.

Lactic Acidosis – deep and rapid breathing, vomiting and abdominal pain caused by buildup of lactic acid in the body.

Neuropathy or numbness in your legs – numbness, abnormal sensations, and steady burning and/or “pins and needles and/or electric shock” sensations.

Pancreatitis or stomach pain – severe upper abdominal pain that spreads to the back caused by inflammation of the pancreas.

Kidney Stones or kidney pain – acute and sudden pain, nausea and vomiting, restlessness, and possibly fever if an infection is present caused by the formation of solid stones inside the kidneys.

Lipodystrophy or wasting – a swollen belly along with loss of tissue from the face, arms and legs.

Bone Marrow Toxicity – a drop in numbers of important blood cells. A drop in the level of red blood cells can lead to a condition called *anemia*. Other blood cells that can be affected include bacteria-fighting white blood cells.

Liver Problems or pain in your liver – Those co-infected with Hepatitis C could have liver damage or advanced liver disease. Symptoms include abdominal pain (particularly upper right), jaundice, abdominal swelling, itchy skin, dark urine or pale stools, bloody or tar like stools, chronic fatigue, fever, nausea or loss of appetite.

Note to PN: Refer to Resource Material for more in-depth descriptions of each condition and the specific medications that could cause these side effects.

Some of these side effects can be dangerous or even fatal if not caught early and managed by a doctor. Others represent long-term complications that some people experience from HIV medications. In both cases, CALL YOUR PATIENT'S DOCTOR IMMEDIATELY. If your patient is experiencing any of these side effects, ask if you can call the doctor together.

Conversation D: Managing Side Effects

Objective: The objective of this conversation is to identify a few strategies that your patient is willing to adopt in managing their side effects.

Turn to Page 27 of Care Coordination Workbook: Symptom Management Action Plan.

Ask: Can you tell me about three of the side effects you most commonly experience?

If your patient is not currently experiencing side effects,

Ask: Choose a few common side effects.

Ask: How do these side effects impact your ability to take your medications?

Ask: What have you done about these side effects in the past, or what are you doing about them now?

Instructions to PN: On the **Symptom Management Action Plan**, write down how these side effects impact your patient's ability to be adherent, and what they have done about them in the past (or are doing now).

Note to PN: Refer to the **Symptom Management Resource** on page 109 of the Facilitator's Guide for suggestions.

Ask: Can you think of any strategies we talked about earlier that might help you deal with side effects in the future?

Instructions to PN: Have your patient fill out the Symptom Management Action Plan with the management strategies they would like to try. As part of this exercise, your patient should also identify when they should discuss side effects with their physician or PN.

Ask: When should you talk to your doctor about side effects?

Feedback: Always.

Ask: What will help you have this discussion with your doctor?

Instructions to PN: Brainstorm ideas such as bringing in this plan to show their doctor. Now that your patient knows possible causes and symptom management ideas, they can feel more comfortable discussing it with their doctor.

Symptom Management Action Plan

Side Effect	Impact on Adherence	What steps are you currently taking?	What might you try now?*	When should you tell your PN or physician about it?

*See the "Symptom Management Resource" on Page 109 for suggestions.

Wrap Up

Say: Today we talked a lot about symptoms that someone on ART can experience as well as ways that you can reduce the discomfort caused by these symptoms.

Ask: In your own words, what did you learn today?

Ask: Do you feel it is worth it for you to stick to your ART regimen even if your HIV meds make you feel bad or sick? Why or why not?

Ask: What's most important for me to know about you and what we talked about today?

Ask: What questions came up for you that we can review for next time?

Symptom Management Resource

Diarrhea

Often caused by Protease Inhibitors (PIs) Nelfinavir, Agenerase, Kaletra

- Diarrhea can dehydrate you so be sure to drink plenty of water and other clear liquids.
- Avoid caffeine, coffee, tea, cola and alcohol. These can make diarrhea worse.
- Eat smaller amounts of food. Eat more often.
- Avoid high fiber foods – whole grains, raw vegetables, beans, nuts, popcorn and fruit.
- A diet of BRAT (Bananas, Rice, Apples and Toast) is often recommended.
- Eat white bread, rice, noodles, bananas, cottage cheese, yogurt, eggs and baked potatoes.
- Avoid sweets and foods that are greasy or spicy.
- Unless told otherwise eat more potassium rich foods like bananas, oranges, potatoes.
- Your doctor may also be able to prescribe something like Imodium to reduce the diarrhea.
- Contact your doctor if the diarrhea is bloody or continues for more than a day or if you have abdominal pain or if you start to become dehydrated.

Nausea

Often Caused by Ritonavir, Saquinavir, Amprenavir, Kaletra, Tenofovir and other NRTI's

- Eat something, even if just a mouthful.
- Avoid fatty, greasy foods. Pasta, cereal, bananas and fresh fruit are good choices.
- If you eat a large meal try to eat it in the middle of the day rather than in the evening.
- Don't lie down for at least a half an hour after eating.
- A small snack before you go to bed can help morning nausea.
- Nibble on crackers when you first wake up in the morning.
- Some people find white rice with a little ginger and soy sauce very helpful and tasty.

Drink plenty of water.

- Drink herbal teas, such as mint, peppermint and chamomile. Ginger tea is especially good.
- Eat small pieces of ice, popsicles or ice cubes made from juice or tea.
- Keep hard candy on hand.
- Fresh air and gentle exercise like walking can help.
- Breathe deeply and slowly.
- Your doctor may be able to prescribe medications like Compazine.
- Contact your doctor right away if you vomit right after taking your medications or have repeated episodes of vomiting in 24 hours.

Rash

Often caused by Bactrim, Ziagen (sign of potentially fatal reaction), Sustiva, Amprenavir, and other NRTI's

- Cool baths can help.
- Hypoallergenic moisturizers can help.
- Avoid sun exposure, hot showers, scented lotions and perfumes.
- Don't scratch, or you will make the itching worse and potentially cause damage to your skin.
- Call your doctor to help assess what is causing the rash; you may need to go into a clinic, as it is often difficult to assess a rash over the phone.

Fatigue

Often Caused by Sustiva, Epivir, AZT, Combivir, Trizivir

- Get plenty of rest. Take an afternoon nap or just find some time to relax.
- Eat a well balanced diet. A daily multi-vitamin can help.
- Some gentle exercise can also boost your energy.

Headaches

Often Caused by AZT, D4T, Combivir, Trizivir, Sustiva

- Yoga, meditation and acupuncture have helped some people cope with headaches.
- Taking a break and giving your self some downtime can also help to reduce headaches.
- Dehydration can also cause headaches so drink a lot of fluids.

- Staying away from light, television and noise helps some people.
- Your doctor may be able to help you identify some over-the-counter or prescription medications.
- If pain is severe or lasts more than a day, contact your doctor to rule out any serious medical conditions.

Problems Sleeping

Often Caused by Sustiva

- Some of the primary side effects of Sustiva are strange dreams, trouble sleeping and drowsiness. Many people find that the side effects from Sustiva are easiest to cope with if you take it just before bed. However, eating before bed may aggravate nighttime side effects.
- Try to have your meal at least two hours before bedtime and take your Sustiva just before you go to sleep. You should also avoid large or high fat snacks around your Sustiva dose.

Other potential side effects from medication:

Lipodystrophy or changes in fat distribution

Often caused by protease inhibitors and NRTI's

- Sunken cheeks in the face
- Prominent veins in the legs (not associated with heavy exercise or muscle building routines)
- Loss of fat in the legs, arms and shape in the buttocks
- Increase in fat around the gut (called *truncal* or *central obesity*). This is not the soft fat deposit under the skin that is associated with aging, but a rapid increase in girth caused by the accumulation of hard fat deposits behind the abdominal muscles
- Breast enlargement
- Fat pad on back of neck (sometimes called *buffalo hump*)
- Lipomas (fatty growths in different parts of the body)
- Also associated with problems with cholesterol, heart disease and diabetes

Some of the following side effects can be severe or even fatal if not caught early and managed by a doctor. Others represent the more serious long-term complications that some people experience from medications for their HIV.

In both cases CALL YOUR DOCTOR IMMEDIATELY.

Hypersensitivity Reaction

Often caused by Abacavir or Trizivir

- Skin rash AND two of the following – fever, nausea, vomiting, diarrhea, abdominal pain, tiredness, achiness, general ill feeling, sore throat, shortness of breath and cough
- If you've ever had a serious reaction to Abacavir never take it again, or you could experience life-threatening symptoms within hours.

Lactic Acidosis

Often caused by AZT, Epivir, D4T, DDI, Abacavir, Trizivir, Combivir

- Nausea
- Vomiting
- Severe fatigue
- Recent weight loss
- Rapid, deep breathing
- Cramps, muscle aches and numbness or tingling
- Muscle weakness that rapidly gets worse
- Since this condition can be fatal you must contact your doctor immediately if you have these symptoms. You will need a blood test to determine a diagnosis.

Neuropathy

Often caused by AZT, Epivir, D4T, DDI, Abacavir, Trizivir, Combivir

- Numbness, pain or tingling in the hands or feet and possible burning, throbbing or shooting pain
- Doctors can prescribe pain relievers
- Approaches like acupuncture can also help
- Replacing ill-fitting shoes, wearing comfortable shoes, keeping hands and feet cool and getting a massage can all help

Pancreatitis

Often caused by DDI and Kaletra

- Inflammation of the pancreas
- Upper abdominal pain and nausea, vomiting and fever

Kidney Stones

Often caused by Crixivan

- Sharp cramping pain in lower side, back and abdomen. Nausea and vomiting. Blood in the urine, need to urinate frequently and burning during urination. Fevers and chills may indicate an infection.
- Make sure to drink plenty of water when you are taking Crixivan.

Bone Marrow Toxicity

Often caused by AZT, Trizivir, Combivir

- Can cause low white and red blood cell counts resulting in anemia and an even further compromised immune system.

Liver Problems

Often Caused by Crixivan, Nelfinavir, Ritonavir, Saquinavir, Amprenavir, Kaletra

- High values on Liver Function Tests
- Abdominal pain (particularly upper right), jaundice, abdominal swelling, itchy skin, dark urine or pale stools, bloody or tar like stools, chronic fatigue, fever, nausea or loss of appetite.

Topic 7: What is HIV and How Does It Affect My Body?

Learning objectives

After completing this topic, the patient will be able to:

- Define HIV and discuss its effects on the immune system
- Define “opportunistic illness,” or OI, and identify ways to prevent OIs that commonly affect people with HIV and AIDS
- Tell the PN what a CD4 count is and what kind of trend is favorable (i.e., upward or downward?)
- Tell the PN what HIV Viral Load is and what kind of trend is favorable
- Discuss how medication fights HIV
- Identify ways in which HIV is transmitted and how to minimize risks of passing it to someone else

Preparation

- Bring Care Coordination Workbook.
- Bring patient’s CD4 and viral load count records; review before meeting.
- Review your notes on this patient from the last topic you completed together, and identify any areas that need review or reinforcement.
- Review the conversations and PN instructions contained in this topic.

Topic Overview

Conversation	Materials & tools
A: What is HIV and how does it affect my body?	
B: The Immune System	
C: What is HIV?	Scratch paper
D: What is AIDS?	
E: What is a viral load?	Knowing your CD4 and VL (Wkbk. page 32) My CD4 and Viral Load Journal (Wkbk. page 32)
F: What is an opportunistic infection?	Sites of Opportunistic Infection (Wkbk. page 30)
G: How is HIV transmitted?	How is HIV transmitted? (Wkbk. page 28)
Wrap Up	

Review

Let's go over what we talked about last time. Review any areas that were particularly challenging for your patient during your last session together.

Ask your patient to:

1. Demonstrate a skill that was learned from last session's discussion;
2. Explain to you one of the key points from last time.

Introduction to topic: This topic reviews information that will help your patient understand how HIV affects the body and how medications help fight HIV. You and your patient will discuss specifics about what HIV is, how it affects the immune system, how to prevent opportunistic illnesses, the significance of CD4 count and HIV viral load, how HIV is transmitted, how it is NOT transmitted and ways to minimize exposure and/or transmission. Patients have a wide range of knowledge and skills in these areas so it is important to use an exploratory model: work with information provided by the patient and go from there. **This topic contains a lot of information. Take time to make sure your patient understands each conversation before moving on.**

Note to PN: If your patient has a relatively strong understanding of these topics, it is a good idea to use an ask-tell-ask format when going through this topic.

Conversation A: What is HIV and How Does It Affect My Body?

Objective: The objective of this conversation is to gain an understanding of how your patient understands their HIV and how it has affected them.

Note to PN: Start the discussion by listening to how your patient describes HIV and its effect on their body. This will give you information about your patient's particular understanding.

Instructions for PN: Use information your patient has shared with you in the past to personalize some of the questions below:

- Have you ever gotten sick because of your HIV? (bring up specific instances you know of)
- How do you think HIV affects your body?
- What are some things you would like to know about HIV that you don't?

Now that you and your patient are in the same place in terms of their knowledge of HIV and the ways in which it affects their body, you can open the discussion to explaining some of these concepts.

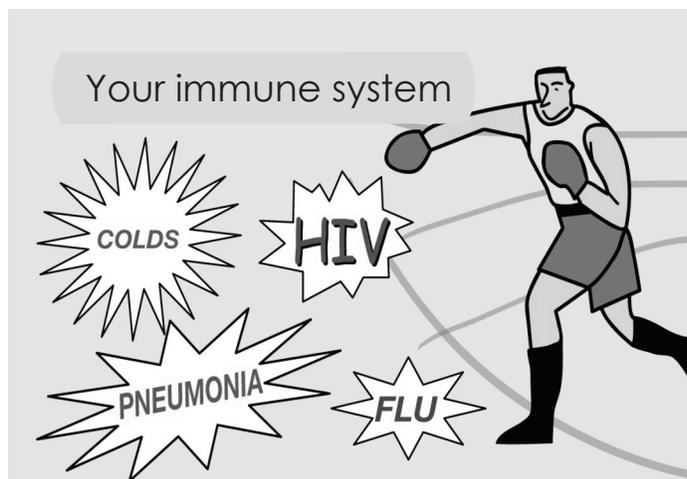
Conversation B: The Immune System

Objective: The objective of this conversation is to help your patient understand the important concepts of the immune system and CD4 cells so that they can better understand how ART works to keep them healthy.

Ask: How does your body try to keep you from getting sick from things like the common cold, bacteria in spoiled foods, or HIV?

Feedback: After discussing your patient's ideas, review the information below:

- Inside your body, including inside your blood, there is something called the **immune system**, the body's infection-fighter. It kills germs that you come in contact with every day and helps fight all kinds of illnesses including colds, infections and HIV.
- The immune system is made up of many different parts that interact with each other and serve as our defense against bacteria, viruses, fungi, and parasites that cause infectious illnesses.
- The immune system is also important for fighting off certain types of cancer, like lymphoma (a white blood cell cancer), cervical cancer and some types of skin cancers.
- The stronger your immune system, the more protection you have against things that can make you sick, such as HIV.



Graphic Source: Francois-Xavier Bagnoud Center at the University of Medicine and Dentistry of New Jersey (UMDNJ)

Say: One example of how the immune system works is fever. When you have a fever, your body temperature goes way up because the cells in your immune system are trying to fight off bacteria or viruses in your body that could make you sick. A fever will kill some bacteria and viruses because they can't survive at high temperatures.

Ask: What is a CD4 cell?

Feedback: Review the information below based on the patient's understanding:

- In the same way that a large house is built out of small bricks, your body is made up of small units called **cells**—hair cells, skin cells, liver cells, CD4 cells and other kinds of cells.
- A key part of the immune system is called a CD4 cell. The CD4 cell acts like the lieutenant of the immune system, telling the different parts of the immune system what to do when they come across an infection or a cancer cell. CD4 cells are also called T-helper cells or T4 cells.
- HIV specifically attacks and destroys CD4 cells. Once inside the CD4 cell HIV takes over. HIV uses the CD4 cell like a factory to produce more and more copies of itself (called **replication**). These new HIV copies are released into the body.
- As HIV spreads in your body, the number of CD4 cells drops. When this happens, your immune system becomes weak and you are at risk for many infections and cancers. You want to keep your CD4 cells as high as possible to protect yourself against getting sick.

- The more CD4 cells you have, the better job your body can do to kill germs and stay healthy.
- Antiretroviral therapy or ART (medications that fight HIV) prevent the HIV from infecting the CD4 cell or making copies of itself, and keep your CD4 cell count high.
- The good news is that even if your CD4 count is low, by taking ART you can stop HIV replication and your immune system can rebuild; your CD4 count can go up again!
- It is possible to find out how much HIV has damaged the immune system by measuring the number of CD4 cells in the blood. A healthy adult who doesn't have HIV usually has between 600-1600 CD4 cells. A person whose HIV disease is not well controlled and is at highest risk for getting sick will have CD4 counts below 200.

Conversation C: What Is HIV?

Note to PN: If you are continuing this topic from a previous session, start with a teachback exercise of what was previously covered.

Objective: The objective of this conversation is to help your patient understand what having HIV means with respect to what is going on in their body.

Ask: What is HIV?

Feedback: **HIV** is a **virus** (germ) that can make you sick. "HIV" stands for: **H**uman **I**mmunodeficiency **V**irus. Many people also refer to HIV as the "**AIDS virus.**"

Ask: What does Immunodeficiency mean?

Feedback: Immunodeficiency means that the immune system is deficient, or not as strong as it should be. HIV directly attacks the immune system and weakens it, so that a person may get sick more easily.

Ask: What is a Virus?

Fill in gaps in Understanding: A virus is a tiny particle too small to see that can't live on its own. It infects other living things (like human beings) in order to live and makes copies of itself. We call this process **replication**.

Say: A virus can only survive by living inside the cells of another living being, known as the "host." Once it finds a host, a virus makes copies of itself to grow stronger.

Say: Sometimes, a virus that infects human beings can make people sick. Viruses are “uninvited guests”—no one wants to get sick!

Ask: Can you name some viruses?

Feedback: Some examples include chicken pox, herpes, the flu, hepatitis A, B and C, influenza, and rabies.

Instructions to PN: Share the following analogy with your patient:

Analogy: *HIV is like a hijacker that breaks into the command center of your immune system (CD4 cells) and takes over. The command is now taken over by HIV and is being used to make more copies of HIV, instead of making CD4 cells. When your immune system is taken over by HIV, it can't take care of itself or protect you against HIV and other germs/cancers that it would normally defend you against. The good news is that we have medications, ART, that can fight HIV and free your immune system so that it can do its job to keep your body healthy.*

Instructions to PN: Take out a blank sheet of paper from the back of the Care Coordination Workbook.

Ask: Can you help me think of a visual way to show the relationship between HIV, CD4 and ART?

Instructions to PN: Help your patient draw out how good adherence to ART → less HIV → more CD4 → better health.

Suggestion: You could draw a seesaw with HIV on the lower end and CD4 on the end that is up. Draw ARTs hanging off the HIV end like weights.

Explanation: Taking ART holds down the level of HIV while your CD4 goes up and you start getting healthier.

Conversation D: What is Acquired Immune Deficiency Syndrome (AIDS)?

Note to PN: If you are continuing this topic from a previous session, start with a teachback exercise of what was previously covered.

Objective: The objective of this conversation is to help the patient understand the difference between HIV and AIDS.

Ask: What is AIDS?

Feedback: Review the concepts below as needed:

AIDS stands for:

Acquired
Immune
Deficiency
Syndrome

Acquired means you develop the problem as opposed to being born with it (congenital disease).

Immune Deficiency means a weakness in the body's immune system—your body's defense against infections and some cancers.

Syndrome means a group of health problems that make up a disease.

Say:

- Remember, you don't catch AIDS.
- If you are infected with HIV you could **develop** AIDS.
- When your CD4 cell count drops very low, the immune system becomes weak and your body becomes open to infections. If the virus destroys too many CD4 cells and your count drops *below 200, or* you develop a serious infection or cancer, your diagnosis changes to AIDS.

Note to PN: Because the technical definition of AIDS is a CD4 count below 200 or the development of an OI, we tell our patients that the AIDS diagnosis is technically reversible. However, you should discuss this together with your patient and their doctor so everyone is on the same page.

Say: If you take ART as prescribed, the HIV virus will stop replicating and your CD4 count can go up above 200. This means your immune system is getting stronger and you can get better from serious infections or even some types of cancer. When this happens, you still have HIV but you don't have AIDS anymore! However, it is good to be aware that some people view AIDS as being irreversible. This definition is mostly used for research purposes; it makes it easier to track the number of cases of AIDS (to see how many people have AIDS and how fast it is spreading).

Say: Everyone with AIDS has HIV but not everyone with HIV has AIDS. If you take care of yourself and take medications, the HIV infection can be controlled and you can avoid getting sick with AIDS. If you don't take your medications well, your body gets weak and you get sick. If you become really sick from HIV, you might develop AIDS.

Conversation E: What is a Viral Load?

Note to PN: If you are continuing this topic from a previous session, start with a teachback exercise of what was covered.

Objective: The objective of this conversation is to define the term *viral load* and to help your patient understand why having a low viral load should be the goal.

Ask: What is a viral load?

Feedback: Review the information below as needed:

- The amount of HIV in an infected person's blood can be measured. It is called the **HIV viral load**. To measure your viral load, a sample of blood is drawn from your arm. A machine then counts the number of viruses in every milliliter of blood. A milliliter is 1/5 of one teaspoon.
- The viral load can range from less than 50 copies/ml to 1,000,000 copies/ml. A high viral load of more than 100,000 copies/ml blood means there are many viruses in your blood that will damage your immune system more quickly. A low viral load below 1,000 copies/ml blood means with fewer viruses in your blood the immune system will weaken more slowly.
- The lower the viral load the better.

Ask: Why is a lower viral load better?

Fill in gaps in understanding: Because your immune system is not getting damaged as much and can stay strong enough to protect you from infections and cancers.

Explaining Viral Load

Instructions to PN: Help your patient understand the effects of high and low viral loads by using the following analogy of a physical load:

Analogy: *A high viral load is heavy, hard to carry and tires out your body after a while. On the other hand, a low viral load is light, easy to carry and does not do as much harm to your body as a heavy load. A lower viral load is a good goal to work towards.*

Ask: What does **undetectable viral load** mean?

Feedback:

- Undetectable viral load is when there is so little virus in your blood that the test can't find enough viruses to count. This is the best possible viral load result.
- Even though there are not enough viruses for the test to count, the virus still exists in your body; there are just fewer copies of it.
- You need to keep tracking your medications every day, on time, to keep your viral load.

Ask: What do you think could happen if you are able to take all your medications on time every day?

Fill in gaps in understanding:

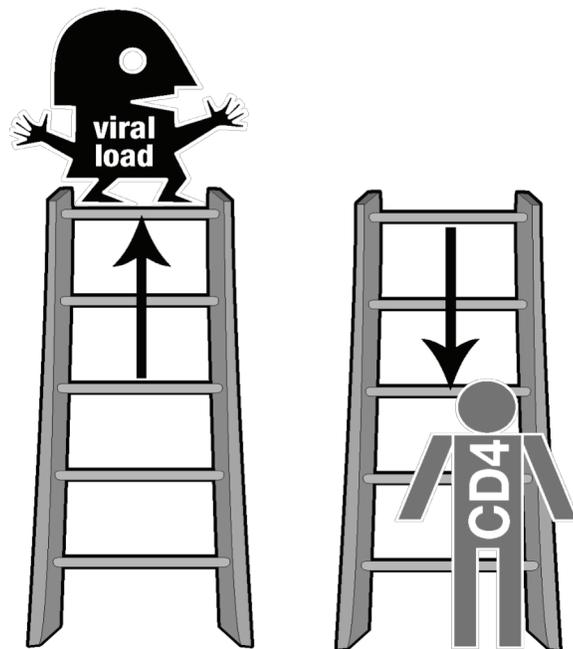
- Successful treatment with HIV medication can reduce the viral load to below 50/75/400 copies (depending on the test used), to an undetectable level.
- As the viral load goes up the number of CD4 cells goes down. As the viral load goes down the CD4 goes up.

- When you take your medications in a timely way, the viral load drops quickly but it can take months for the CD4 count to build. It takes longer to build your CD4 count if your CD4 count is really low (less than 100) or if you have had a low CD4 count for a long time.

Checkpoint:

Make sure that your patient has understood the main points of what has been discussed so far. Explore how much they have understood by asking the following questions:

- In what direction do you want your CD4 cell count to go (up/down)?
- In what direction do you want your viral load to go (up/down)?
- How do medications help to prevent you from getting sick from HIV?



Graphic source: Francois-Xavier Bagnoud Center at the University of Medicine and Dentistry of New Jersey (UMDNJ)

Turn to Page 31 of the Care Coordination Workbook: Your CD4 Count and Viral Load.

Directions for Tool: Your CD4 Count and Viral Load

Now that you have finished your basic review and explanation, you can discuss what CD4 cell count and viral load mean to your patient.

Ask: Do you know what your last CD4 count was? Has it been getting higher or lower?

Ask: Do you know what your last HIV viral load was? Has it been getting higher or lower?

Tell your patient that you have brought records of their recent CD4 count and viral load tests. **Ask** if it would be okay to bring them out and look them over.

Say: This is a chart that you can use to keep track of your CD4 and viral load. It is important for you to know what your CD4 and viral load are so you can talk to your doctor if your CD4 gets close to or below 200 or if your viral load gets very high. It is also important for you to be able to see your progress as we work together to get your CD4 count as high as possible and to get your viral load to an undetectable level.

Write your patient's old lab results and the dates the tests were done into the tool, starting with the oldest, and draw arrows to signify the direction of the trend. Use a ☺ to indicate positive trends in VL and CD4. The most recent result should be recorded last, so your patient can add more results in the future.

Ask: Can you think of personal goals you have for your CD4 count and viral load?

Write these goals on the goal lines on the tool.

Examples of goals: undetectable viral load, CD4 higher than 200, etc.

Say: You can bring this chart with you to your appointments to add new results, or to discuss with your doctor.

Turn to Page 32 of the Care Coordination Workbook: CD4 and VL Journal.

Directions for Tool: CD4 and Viral Load Journal:

Many patients may also find it useful to have a visual representation of their CD4 and viral load trends.

1. Plot each new lab result on the separate CD4 and viral load graphs.
2. Label each point on the graph with a letter, going from A to Z, and record notes that correspond with each data point in the CD4 and viral load journal.

My CD4 and Viral Load Journal

Point	Notes related to my CD4 and viral load results
A	
B	
C	
D	
E	
F	
G	
H	
I	
J	
K	
L	

Conversation F: What is an Opportunistic Infection?

Note to PN: If you are continuing this topic from a previous session, start with a teachback exercise of what was covered.

Objective: The objective of this conversation is to teach your patient about the opportunistic illnesses that can occur when people have weakened immune systems. This is your chance to explain the risks of having a low CD4.

Turn to Page 30 of the Care Coordination Workbook: Sites of Possible Infection.

Directions for Tool: Sites of Opportunistic Illness

Use the body map in the Care Coordination Workbook to draw the places on the body that can be affected by opportunistic infections.

Ask: What is an opportunistic infection?

Instructions to PN: After a discussion of your patient's ideas, review the information below:

- We carry many germs in our bodies. We are also at risk for developing certain types of cancers. When our immune system works, it controls these germs and cancers. HIV weakens the body's immune system so the body is open to infections or cancers that would normally not make them sick. These infections or cancers that take advantage of a weak immune system are called **opportunistic illnesses**, or OIs. They are opportunistic because they take the opportunity to attack the body and make you sick if the immune system becomes weakened by HIV.
- Many of these illnesses are very serious, and need to be treated. By keeping the immune system healthy (with ART) and by taking preventative medications (also called prophylactic medications), a person with HIV can avoid opportunistic illnesses.

Instructions to PN: Review the Opportunistic Infections listed below. It may not be necessary to go in depth with each OI; tailor the discussion to your patient.

Candidiasis (Thrush):

- Thrush is a fungal or yeast infection of the mouth, throat or vagina. Yeast can infect your mouth or throat or esophagus (the tube that connects your mouth to your stomach). You will see white fuzzy areas on your tongue and mouth that can be quite painful and make it difficult to swallow. When yeast infects the vagina, it causes an itchy white creamy discharge.
- People who get thrush or yeast infections frequently might need medication called Fluconazole or Diflucan to help prevent it.

Cytomegalovirus (CMV):

- A virus related to herpes that can cause disease all over the body (the bowels, the liver, the adrenal gland).
- AIDS patients with really weak immune systems can get an infection in the back of the eye (retinitis) that can cause blindness. **It's really important for people living with AIDS to see an eye doctor at least once a year.**
- You may need Ganciclovir or Foscarnet to treat the CMV once you are infected or to prevent CMV from recurring once you are better.

Herpes simplex viruses:

- Can cause oral herpes (cold sores) or genital herpes (with painful blisters and ulcers on penis or vaginal area). For people with HIV, the outbreaks can be much more frequent and more severe than in those without HIV.
- People who break out with herpes a lot might need medications like Acyclovir or Valtrex every day to help prevent the breakouts. These same medications can be used in higher doses to treat herpes if it is active in your body.

Mycobacterium avium complex (MAC or MAI):

- A bacterial infection (similar to tuberculosis) that can cause recurring fevers, malaise or general sick feeling, anemia, night sweats, problems with digestion, and serious weight loss.
- Typically affects people whose immune systems are really weak (CD4 less than 75).
- People with CD4 less than 75 usually take a medicine called Zithromax once a week to help prevent the MAC infection.
- 3-4 different drugs are used together to treat people with MAC. They work best with ART, which is needed to increase CD4 and strengthen the immune system.

Pneumocystis pneumonia (PCP):

- Can cause a fatal pneumonia (lung infection).
- Causes shortness of breath and sometimes fever or cough or chest pain.
- Usually affects people with CD4 counts less than 200; those who qualify should take an antibiotic to prevent PCP (Bactrim or Dapsone by mouth or inhaled pentamidine).

Toxoplasmosis (Toxo):

- A parasitic infection of the brain that can cause stroke or seizure-like symptoms.
- Caused by a parasite that is everywhere, most commonly in raw or undercooked meat and in cat feces.
- Most often affects people with CD4 counts less than 100 who should take a prophylactic medication to prevent toxo. This is high dose Bactrim or (Dapsone + Pyremethimine + folinic acid) or Atovaquone or Mepron.

Tuberculosis (TB):

- A bacterial infection that attacks the lungs and other parts of the body, such as the bones or the brain (meningitis).
- Ask your doctor for a yearly PPD skin test (a test that checks if you have been infected with TB).
- People with positive PPD test will receive medications to fight TB for up to a year.

Lymphoma:

- A cancer of the white blood cells which can occur in the bone, abdomen, liver, brain or other parts of the body.
- First signs of lymphoma: swollen lymph nodes, fever, night sweats, and weight loss.
- There is no prophylaxis against lymphoma.
- People who develop lymphoma are treated with chemotherapy and radiation therapy.

Cervical cancer (for women only):

- Cancer of the cervix, the portion of the uterus inside a woman's vagina.
- Caused by infection with the human papilloma virus (HPV).
- Women with HIV are at higher risk of getting cervical cancer and should be **screened at least once a year with a pap smear**. Early detection and treatment of HPV infections can prevent cervical cancer.
- A vaccine called Gardasil can help prevent HPV infections. Talk to your doctor about getting this vaccine.
- Once the HPV infections turn into cancer, women may need to have their uteruses removed.
- Smoking can increase the risk of HPV infections turning into cancer.
- Building up your CD4 count and immune system reduces the risk of HPV infections turning into cancer.

Ask: What can you do to avoid opportunistic infections?

Feedback: Review the concepts below, as needed:

- It is important to take your ART because it protects your immune system and helps prevent many serious OIs.
- Additional medications include ones that are prophylactic and can help prevent certain OIs (like Bactrim or Zithromax) if your immune system is weak.
- You can also avoid getting certain infections by getting regularly screened (i.e., doing yearly pap smears or PPD tests) or getting vaccinations against things like the flu or Hepatitis B.
- Finally, healthy eating, exercise and having good hygiene can help you avoid certain types of illnesses.

Note to PN: Remind your patient to talk to their doctor if they are experiencing any symptoms that could be related to an OI.

Conversation G: How is HIV Transmitted?

Note to PN: If you are continuing this topic from a previous session, make sure to start with a teachback exercise of what was covered.

Objective: The objective of this conversation is to help your patient understand the ways in which HIV is transmitted, and to discuss ways in which the risks of HIV infection can be reduced. You should also clarify ways in which HIV is not transmitted.

Turn to Page 28 of the Care Coordination Workbook: How is HIV Transmitted?

Ask: How is HIV transmitted?

Feedback: Review the information below with your patient, as needed:

- A person can get HIV from anyone who's infected. There is no way to tell if a person has HIV by the way they look. A person may have HIV and not look sick at all. The only way to know for sure if a person has HIV is by blood test results.
- The fluids that can carry HIV are blood, breast milk, vaginal fluids, and semen and pre cum (can be remembered as **Better Be Very Safe**)

A person can get HIV through:

- Unprotected sexual intercourse with an HIV-infected person. This includes vaginal or anal intercourse

Note to PN: Make sure that your patient knows what is meant by “vaginal” and “anal” intercourse.

Say: Did you know that certain types of sex are riskier than others? Anal sex is the most risky in terms of getting or giving HIV.

Review any of the following information that is appropriate for your patient:

- **IMPORTANT NOTE FOR MEN:** If you have HIV and you have anal sex with another man who does not have HIV, it's safer if he penetrates you than if you penetrate him. That way he is not exposed to your semen, one of the fluids that carry HIV. It's always riskier to be the bottom than the top in terms of getting infected. The person on the receiving end is on the bottom and the person doing the penetration is the top.
- During anal sex, using lots of water-based lube helps reduce rips or tears in the rectum that make it easier for HIV to get into the blood. It is best to use latex or polyurethane condoms. This way you can have sex without worrying about getting or giving HIV to someone else.
- **DO NOT USE OIL-BASED LUBE.** Oil-based lube, like massage oil or Crisco or Vaseline, can make little holes in the condom that you might not be able to see, but will make the condom ineffective.
- Vaginal sex is safer than anal sex, but many people still get HIV through vaginal sex. In order to reduce the risks of getting or giving HIV, use latex or polyurethane condoms and **LOTS OF WATER-BASED LUBE** (NOT oil-based lube). Lube can help reduce the little rips or tears that happen inside the vagina or on the penis during sex. These tears allow the virus in the pre cum or cum or vaginal fluid into the blood.
- Oral sex has the lowest risk of HIV infection, but HIV can still spread from person to person with oral sex. Usually the risk is highest if an HIV-positive man comes in the mouth of an uninfected person who has little cuts or bleeding in their mouth (after brushing your teeth, we all get little tears and cuts). Using condoms or dental dams can help reduce this risk.
- Intercourse while a woman is having her period, or during outbreaks of genital sores or lesions (caused by herpes and other sexually transmitted infections) can increase the risk of HIV transmission.

Assessment of patient's ability to negotiate safer sex options: Now that you have covered these safer sex options, it is important to assess whether or not your patient can negotiate these options with a partner. Ask your patient the following questions:

- Keeping in mind the safer sex options discussed, what changes, if any, do you think you could realistically make to the ways you have sex?
- What are your major barriers to making some of these safer sex changes?

If your patient's responses indicate that more training is needed around negotiating safer sex options, make sure to do the **Harm Reduction – Sexual Behavior Topic (Topic 12)** with your patient.

Refer to visuals on Page 28 of the Care Coordination Workbook.

Say: A person can also get HIV by:

- Sharing drug injection equipment (needles and/or works) or being accidentally stuck by needles or sharp objects contaminated with HIV- infected blood;
- Infected blood used in transfusions, and infected blood products used in the treatment of certain diseases and disorders (like hemophilia, a disease that prevents blood from clotting). It is very rare to get HIV from blood transfusions in the United States because blood banks carefully screen all blood for HIV (and other diseases like Hepatitis B and C);
- Pregnancy, childbirth and/or breastfeeding, where the virus is passed from mother to child;
- Transplanted organs from infected donors.



Image source: *The Body: A Multimedia HIV and AIDS Information Resource*. Retrieved from <http://www.thebody.com/index.html> on November 5, 2006

Explore: This is a good point to stop and talk with your patient about risky behaviors that they engage in, and ways in which they can minimize the risk of spreading HIV to others, or of getting re-infected. You can ask:

What do you do to protect yourself?

If your patient does not think he/she needs to protect herself against HIV because he/she already has HIV, take this opportunity to discuss HIV re-infection and other STIs.

What do you do to avoid passing HIV to someone else?

If your patient has not disclosed their status to others who are at risk of being infected by them, discuss ways in which they can have safer behavior without outing themselves.

Turn to Page 28 of the Care Coordination Workbook: How is HIV Transmitted?

Ask: What are ways in which HIV is NOT transmitted?

Say: HIV is not transmitted by casual contact (because none of the four fluids are involved).

Refer to visuals on Page 28 of the Care Coordination Workbook.

Review the information below as needed :

You **cannot** get or transmit HIV by:

- Coughing or sneezing
- Kissing
- Shaking hands
- Drinking from a public water fountain
- Being bitten by an insect
- Going to a public bath or pool
- Working or going to school with a person who is HIV-infected
- Eating food prepared by a person who is HIV-infected
- Sharing cups, glasses, plates, or other utensils
- Touching or hugging
- Using a public toilet
- Using telephones



Wrap Up

Say: Today we talked a lot about the way HIV affects your body, how your ART can help keep you healthy and ways that you can protect yourself from re-infection.

Ask: In your own words, what did you learn today?

Ask: What is different about the immune systems of people With HIV?

Ask: How do you think your ART can impact your life and health?

Ask: What's most important for me to know about you and what we talked about today?

Ask: What questions came up for you that we can review for next time?

Say: You can continue to track your CD4 and viral load using the tools in your Workbook

Emphasize that understanding HIV is an ongoing process and that they may ask you or their providers questions at any appointment.

Topic 8: Identifying and Building Social Support Networks

Learning objectives

After completing this topic, the patient will be able to:

- Identify some of the messages they are receiving from their community and how they affect them
- Map their non-Care Coordination Program social support network and identify positive versus negative influences
- Practice the language they want to use in talking about HIV
- Contact identified support people

Preparation

- Bring Care Coordination Workbook.
- Bring pens and highlighters of different colors.
- Review your notes on this patient from the last topic you completed together, and identify any areas of confusion that need review.
- Review the conversations and PN instructions for this topic.

Topic Overview

Conversation	Materials & tools
Review previous topic	
A: Understanding Social Support	
B: Community Influences	Tool: Talking to Others (Wkbk. page 37)
C: Disclosure and Networks of Social Support	Tool: My Support Network (Wkbk. page 34)
D: Important Contacts	Tool: Contacts (Wkbk. page 39)
Wrap Up and Topic Feedback Form	

Review

Let's go over what we talked about last time.

Review any areas that were particularly challenging for your patient during your last session together. Ask your patient to:

1. Demonstrate a skill that was learned from last session's discussion;
2. Explain one of the key points from the last session.

Intro to topic:

This topic will help your patient to assess their social supports and think about ways to strengthen their social support network. You will help your patient identify people who provide support, and emphasize people who are not Care Coordination Program staff. You and your patient will start planning how to access and use these social supports in times of stress.

Conversation A: Understanding Social Support

Objective: The objective of this conversation is to help your patient understand how a social support network can help them handle their HIV and medications.

Different people handle their HIV in different ways. Some may feel that it is a big secret that they don't want to share with anyone, and will try to deal with it all on their own. Others tell many different people and are willing to ask for help from others.

How have you been dealing with your HIV? Have you dealt with it mostly on your own, or with the help of friends and family?

Ask: What has helped you to reach out to the people whom you have asked for help?

Ask: What has been a barrier to your asking for help from people?

Feedback: Make sure to affirm and validate the patient's experiences. Then, go over the information below:

Say: Building a network of social support is something that happens over time as someone becomes more comfortable talking about their illness and is able to tell others and ask for help. Building strong social supports is very important because life is full of surprises, and if something happens that you weren't expecting, you want to have people who will help you out and help you to keep taking your medications. It is also nice to have people who appreciate you and with whom you feel that you can be yourself.

Conversation B: Community Influences

Objective: The objective of this conversation is to identify how community influences affect the way your patient feels about themselves and their HIV. Your patient will also have the opportunity to discuss how they want to talk about their HIV with others.

Ask: How do you define your community?

Ask: What kinds of people are in it?

Ask: When and how do you usually interact with your community? (Some examples: at the grocery store, at your kids' school, etc.)

Turn to Page 37 of the Care Coordination Workbook: Talking to Others.

Instructions for PN: To help your patient identify how their community and their beliefs affect them and the way they deal with HIV, use the tool Talking to Others.

1. Fold the tool in half and ask the patient to fill in the section

“How I talk about my illness.”

- Tell your patient that there is no wrong answer to this question.
- They should say any words, phrases, or other thoughts that come to mind.

2. When your patient has finished the first half, flip the sheet over and have them complete the section “How people in my community talk about this illness.”

- This can be a list of things your patient has actually heard, or things your patient thinks people would say.

3. Unfold the paper and compare the two sides.

4. Ask your patient the following questions:
 - What similarities are there? What differences are there?
 - How do the feelings expressed by the community affect you?
 - How do you feel about your community's feelings and knowledge about HIV?

5. Turn the sheet over to fill out the second side, "How would I talk about this illness with someone I care about?"
 - This side should provide an opportunity for positive associations to arise, even if none came up on the first side.
 - Encourage your patient to think positively during this part of the exercise.
 - Review the differences between the way your patient's community talks about HIV and the way the patient would talk about the illness with someone they care about. Tell your patient that by talking to people about their illness and speaking about it in words that they choose, the patient can help others to talk about and understand HIV in the same way they do.

Talking to Others

 How do I talk about my illness?	 How people in my community talk about this illness
CUT HERE	FOLD HERE

How to talk about my illness with someone I care about

Conversation C: Disclosure and Networks of Community Support

Objective: The objective of this conversation is to help your patient assess their current social support network and to be aware of the different influences that are in their life. This conversation will also help your patient begin thinking about new supports he/she could reach out to.

Note to PN: For patients who live solitary lives, this tool might make them feel more isolated. Be sensitive to how your patient is feeling during this discussion and take the time to acknowledge and address these feelings.

Turn to Page 34 of the Care Coordination Workbook: My Support Network.

Instructions to PN:

1. Place your patient's name in the center of the *My Support Network* tool. Explain to your patient how the tree is set up with the patient in the center and their supports located around them.
2. Have your patient name people who are supports in their life. Make sure he/she names specific people (not just agencies).
 - If your patient names you or the Care Coordination team as one of their supports, let them know that you are glad to be able to support them, but also be prepared to discuss why it is important for them to find other supports.
 - Encourage your patient to get involved in some kind of social activity, such as church, volunteering, a job or anything that involves regular contact with others.
 - If your patient struggles to name supports, some areas to consider are: family, friends, medical providers, social service and community services.
 - Ask your patient which of these supports knows about their HIV and which of them supports them with things that are HIV-related (like medications or taking care of them when they are ill or needs someone to help get their refills). Mark these supports with a * beside the name.

Disclosure

Turn to Page 37 of the Care Coordination Workbook: Talking to Others.

Ask: How did you decide who to tell about your HIV?

Ask: How have these people responded? What have the results been?

Instructions to PN: Record this in the table "People I've told about my HIV." If your patient has not told anyone,

Ask: How do you think this affects your ability to deal with HIV and medication adherence?

Instructions to PN: Talk about ways in which social support would be beneficial to your patient. Using what your patient has told you about their experiences with people he/she has disclosed their status to, help them think about ways to make constructive changes to their existing relationships (if necessary) or suggest new supports he/she can reach out to.

Ask: Who are some other people you would like to tell about your HIV?

Ask: Why did you choose _____ (name of person) as someone you might someday want to tell about your HIV?

Ask: What would be the pros and/or cons of telling these people?

Note to PN: If there are some people to whom it might be beneficial for your patient to disclose their status, encourage them to think about disclosure with these people. You should be up front about the possibility of a negative reaction from the person. Encourage your patient to have realistic expectations of what might happen after a disclosure conversation. Make sure your patient does not feel pressured to disclose to someone if they are not ready to—*disclosure is always the patient's choice*.

Instructions to PN: Now have your patient go back to the My Support Network tool on page 34 of the Care Coordination Workbook. Mark each support person + or – to indicate if that person is a positive or a negative influence in terms of their overall wellbeing. Have them use another color pen to create their “ideal” network, including people they hope to tell and to include in their network of support and minimizing negative influences they would like to reduce contact with.

- You can cross out people your patient would like to eliminate from their network; you can add names and draw bigger or smaller circles around the names already written to indicate whether or not your patient wants to increase or decrease their contact with these people.
- Discuss ways in which your patient can reduce contact with negative influences and how he/she can further engage with supports who are positive influences.
- This is a good time to talk to your patient about engaging with health care providers and using them as appropriate supports.

Note to PN: Make sure to create a key to keep track of the meanings of the different colors used.

Disclosure Role-Play

Say: It can be scary to tell someone about your HIV status because you can't always predict how people will react. It is helpful to practice the language you might want to use in telling someone about your HIV and to think of ways that you could approach the subject.

Ask: Have you ever had to tell someone something that was uncomfortable or difficult to talk about? How did you do it?

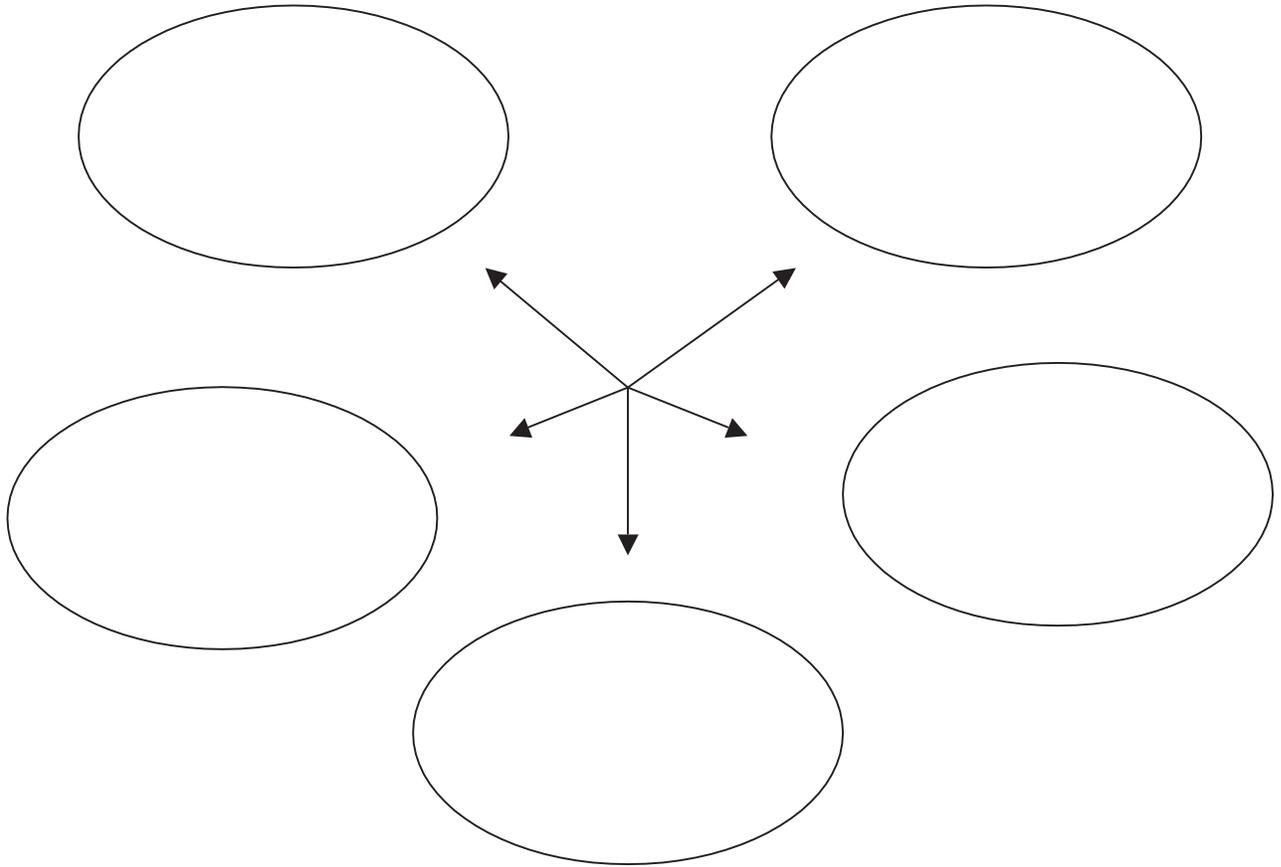
- Have you ever told anyone about your HIV? How did you do it?
- What made you open up to me about your HIV?

Instructions to PN: If your patient seems ready to think about disclosing to someone, you can suggest doing a role-play of a disclosure conversation. Make sure to discuss the potential risks of disclosure with your patient. You can either play the part of the patient, or the person your patient wants to disclose to. Ask your patient which he prefers.

Say: Many people find it helpful to tell the person you want to disclose to that you have something important to tell them so that you can set aside special time.

Say: There are never any guarantees about how someone might react to the news. Some people find that it is helpful to test the waters by talking about someone you know who has HIV or something you saw on TV about HIV so that you can see how the person reacts.

My Support Network



- family
- friends
- medical providers
- social services
- community services

My Support Network: Disclosure

People I've told about my HIV:

Name	Reason for Disclosure	Results

People I would like to tell about my HIV:

Name	Pros	Cons

Conversation D: Contact Information

Turn to Page 39 of the Care Coordination Workbook: Contact Information.

Objective: The objective of this conversation is to identify appropriate supports for different situations and circumstances and to record their phone numbers in an accessible location.

Note to PN: Some patients may not be comfortable filling out the form provided. You can encourage your patient to write down important phone numbers somewhere that is easily accessible and portable, but this tool is optional. Even if you do not fill out the tool, take this opportunity to talk with your patient about the importance of having contact information for at least a few people who could help out in an emergency.

Instructions for PN:

1. Ask your patient to identify a few (3-4) people who would be available in the case of an emergency or difficult situation.
2. Fill in information about each of the identified supports on the Contact Information form.
3. There is a personal section to this form that includes family, friends etc., You will have to rely on your patient to provide the information about these people.
4. There is also a provider section to this form. Providers include: PCP, specialists, social service providers, psychiatrists, counselors etc.
5. Go over some scenarios in which it would be a good idea for your patient to reach out to one or more of these people.

Wrap Up

Say: Today we talked a lot about the idea of social support and steps you can take to build up a support network for yourself.

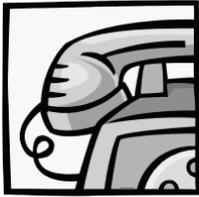
Ask: In your own words, what did you learn today?

Emphasize the supports your patient has identified, and how these people can provide support.

Ask: What's most important for me to know about you and what we talked about today?

Ask: What questions came up for you that we can review for next time?

****Refer to section of Care Coordination Workbook for a list of Resources, Page 70****



Important Contact Information

PERSONAL SUPPORT	RELATIONSHIP	PHONE #	LOCATION

EMERGENCY CONTACT	PHONE #

Topic 9: Adherence Strengths and Difficulties

Learning objectives

After completing this topic, the patient will be able to:

- Identify 3 areas of strength in adherence.
- Identify 3 areas of difficulty in adherence.
- Describe the things that can make it difficult to take ART, and be aware of feelings these things may trigger.
- Make a plan for handling each kind of difficult day identified.
- Talk through feelings that arise when an ART dose is missed.

Preparation

- Bring Care Coordination Workbook.
- Review chart progress notes for course of events.
- Review chart for information about days ART missed.
- Review your notes on this patient from the last topic you completed together, and identify any areas of confusion that need review.
- Review conversations and PN instructions for this topic.

Topic overview

Conversation	Materials & tools
Review previous topic	
A: Your ART Experience	Discussion guide: Your ART Experience (FG page 159)
B: Adherence Strengths and Difficulties	Tool: Adherence strengths and difficulties (Wkbk. page 44)
C: Difficult Days	Tool: Adherence Issues (Wkbk. page 43) Resource: Action Plans for handling common difficulties (FG page 166)
Wrap Up	

Review

Let's go over what we talked about last time. Review areas that were particularly challenging for your patient during your last session together.

Ask your patient to:

- 1) Demonstrate a skill that was learned from last session's discussion;
- 2) Explain to you one of the key points from that session.

Introduction to topic: This topic is about how your patients understand their strengths and difficulties around adherence. This topic also addresses specific times when it is difficult to take HIV medications. You and your patient will identify the things most likely to contribute to these times and develop plans for difficult days.

Conversation A: Your ART Experience

Objective: The objective of this conversation is for the patients to reflect on the positive changes they have already made around adherence and to identify the barriers still preventing their from being adherent to ART.

Say: We've been talking for a long time about ART. Let's take a few minutes to **check in** and **reflect** on where we've come from and where we are going, where you were six months ago and where you are today. Let's talk about the strengths you've developed and the things that have worked to help you take your ART. Let's also discuss what things you need to keep working on.

Turn to Page 44 of the Care Coordination Workbook: Adherence Strengths and Difficulties.

Instructions to PN: Use the “**Your ART Experience Discussion Guide**” on the next page to talk about how your patients feel about taking ART, and how they feel about their time in health promotion. Help your patient identify their **strengths**, areas where they have grown, and skills that they have built. These positive results may be related to medication adherence, but they may also include other changes of personal significance to your patient. Be sure to recognize and appreciate **all strengths**, including those not directly related to adherence or health management. Then, talk about **challenges** that your patient still needs to work on and overcome.

As **strengths or skills** acquired or developed during health promotion are mentioned in this discussion, write them down on **page 44 of the Care Coordination Workbook**. Also write down **challenges** that your patient is still struggling with. If you start a list of things that are **strengths** for your patient and a list of things that are **difficulties**, you can move fluidly into the Adherence Strengths and Difficulties tool, which follows this conversation.

Your ART Experience Discussion Guide

Note to PN: The following questions should guide your discussion, but think of them as a place to start. If the discussion starts going in a direction that is personally meaningful to your patient, follow the discussion.

- What was it like when you first started ART? What was going on with you then?
- What was it like when you first started health promotion?
- How did you feel, physically, emotionally and mentally?
- What were your thoughts about your health?
- How were you taking your HIV medicines?
- What was your housing, food and social services situation like?
- What were your thoughts about the Care Coordination Program? About the staff members you met?
- Have you noticed any changes in your physical, emotional or mental health?
- How have your thoughts about your health changed?
- What is different about taking your medications now from when you first started?
- How did your adherence change?
- What changed it?
- What types of things has Care Coordination Program done for you?
- How has health promotion contributed to change?
- What role did your relationships with people at Care Coordination Program play?
- What might be good about not being on ART?
- What kind of day makes it hard to take your pills now?
- Are there other things about ART that you would like to talk about?

Conversation B: Adherence Strengths and Difficulties

Objective: This conversation will help your patient identify adherence strengths and difficulties, and it will also help you to understand how your patients perceive their strengths and difficulties. You can use information about each patient's strengths and skills to anchor your conversations about adherence.

Turn to Page 44 in Care Coordination Workbook: Adherence Strengths and Difficulties.

Instructions to PN: If you began listing strengths and difficulties during Conversation A: Your ART Experience, continue expanding that list now.

Say: During our last conversation about your ART experience, you mentioned the following strengths: [fill in what patient said].

Ask: Am I correctly understanding the strengths you identified?

Instructions to PN: Note any corrections your patient makes to your summary, and adjust your understanding.

Ask: Tell me about other skills that you have learned or improved upon during health promotion.

Ask: What's good about you? Tell me something that you feel the most proud of.

Ask: When I first met you, HIV wasn't at the top of your list, but now that's changed. Tell me about what helped you get there.

Instructions to PN: List skills your patient identifies on the **Strengths** side of the tool.

Say: Let me see if I understand the strengths you identified. [List all the **strengths** your patient identified that you recorded on the tool, and make any changes they request.]

Instructions to PN: When you hear a strength or skill being used during this discussion, highlight it and add it to the **strengths list**. Your patient may not recognize these as strengths so your perspective here is valuable.

Say: During our last conversation about your ART experience, you mentioned the following things are still difficult for you: [fill in what patient said].

Ask: Am I correctly understanding the difficulties you identified?

Instructions to PN: Listen and watch your patient carefully as you summarize to note any corrections they make.

Ask: Tell me about other difficulties or barriers that continue to be a struggle.

Instructions to PN: List difficulties your patient identifies on the **Difficulties** side of the tool.

Say: Let me see if I understand the **difficulties** you identified. [List all the **difficulties** your patient identified that you recorded on the tool, and make any necessary changes.]

Say: Let's see how your skills and strengths might help you with your difficulties.

Ask: How have you used your skills and strengths when facing difficult situations in the past? Can you think of a specific time you used a skill on this **strengths** list?

Ask: Can you think of a specific time you faced one of these **difficulties**? How did you handle that situation?

Instructions to PN: Help your patient identify strengths you recorded that can help with overcoming difficulties you wrote down on the Adherence Difficulties side of the tool.

Note to PN: Let your patients drive this part of the discussion and identify the barriers that are most important to them. There are no right or wrong answers here, and nothing that absolutely must be included. You may feel that there are barriers the patient is not addressing. If this happens, remember that this discussion is your opportunity to understand how your patients understand their life experiences. Guard against trying to educate your patients about how you understand their barriers.

Adherence Strengths and Difficulties

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

Conversation C: Difficult Days

Objective: The objective of this conversation is to identify some of the things that happen on days when the patient doesn't take ART, and to make a plan to overcome those difficulties.

Say: Everyone has days where they don't want to do things they know they should. Some examples of this include exercising, running errands, paying bills.

Say: For lots of people this is also true for taking ART.

Ask: How do you feel about taking your medications?

Ask: What are the main reasons that you do not take your medications or that it's hard to take your medications?
[Ask for examples.]

Ask: What happens on days that you don't take ART?

Ask: How do you feel the day after you have missed your medications?

Ask: What makes it hard for you to take your medications?

Ask: What kinds of things would make it easier to take your medications?

Note to PN: Some patients may not relate to these questions immediately. Patients may not readily volunteer information of difficult days given that they may elicit feelings of shame, guilt and fear associated with prior experiences. In these cases you may change the wording, ask a follow up question, or approach the question from a different angle.

Turn to Page 43 of the Care Coordination Workbook: Adherence Issues.

Instructions to PN: On the “Issue” side of the tool, write down any of the barriers to adherence that your patient mentioned.

Ask: Are there any other issues that make it difficult for you to take your medications?

Instructions to PN: Break down each issue mentioned into smaller issues if possible.

Ask: What are some ways that you could overcome this issue?

Instructions to PN:

1. **Discuss** all possible options for overcoming each issue.
2. **Discuss** the pros and cons of each option.
3. **Use** information about options to develop a plan with your patient that states what they will do to overcome each issue.
4. **Write** the steps of the plan in the “Plan” column of the **Adherence Issues tool**.
5. **Break** the plan into manageable steps.
6. **Encourage** the patient to try the plan for a set period of time.
7. **Refer** back to this tool regularly with your patient to assess whether the plans are working. If they are not working, then **change** the plans as needed to make them work better. You may want to **integrate** some or all of the plans discussed through this tool into the CCP.

Note to PN: Make sure you think about manageable steps that your patient can complete. For example, if the issue is “oversleeping on weekends,” a plan might include getting an alarm clock at the store, setting the alarm on Friday, and putting it too far away from the bed to press the snooze button. Steer away from steps that are vague or too large to be easily accomplished, such as not drinking on Friday, or making it a priority to get up on time.

Resource: Action Plans

Forgetfulness

- Use a pill box.
- Assign a friend, family member or residential employee to assist with medications.
- Use the Medication List tool and/or the Daily Routine Chart tool to keep track of when and how medications should be taken.
- Identify routines for patients throughout the day (e.g., after brushing teeth or while watching television).

Patient misplaces/loses pills

- Use a pill box.
- Keep pills in one place (e.g., bathroom cabinet/bedroom drawer) at all times.

Patient feels like medications don't help or has no desire to take the medications

- Explore the feeling with the patient.
- Refer back to the “Your Patient's Perspective of Treatment” tool in Topic 5. If you have already completed this tool, you may want to go over it together again. If you have not already completed the tool, this may be a good time to do it.
- Ask questions like, “Tell me more about what you think about that.”
- Don't try to solve this as a problem, start to develop an understanding and awareness of what the patient's experience is.

Side effects

- Encourage your patient to discuss these side effects with their primary care provider.
- Offer to participate in this discussion with the doctor if they think that would be helpful.

Too many medications

- Encourage your patients to discuss pill burden with their primary care provider.

Adherence Issues

Issue:

Plan:

Support types needed:

Supporter names:

Wrap Up

- Say:** We've talked about a lot today!
- Ask:** In your own words, what did you learn today?
- Ask:** What did you learn about the things that can make it difficult for you to take your medications?
- Ask:** What is one new thing you will try to overcome the adherence barriers we discussed today?
- Ask:** What questions came up for you that we can review for next time?
- Ask:** What's most important for me to know about you and what we talked about today?
- Say:** Thank you for your honesty and openness in today's discussion.

Topic 10: Medical Appointments and Providers

Learning objectives

After completing this topic, the patient should be able to:

- Put together a list of medical providers and their contact information.
- Demonstrate how to schedule appointments
- Make arrangements for transportation to get to scheduled medical, social or other ancillary appointments.
- Identify barriers that may prevent patient from attending scheduled appointments
- Make a plan to prepare for appointments
- Prepare questions to ask to Primary Care Provider

Preparation

- Review CCP Logistics for Navigator to review patient's preferences.
- Bring Care Coordination Workbook.
- Bring a copy of **CCP Contact Information Form**.
- Bring a calendar.
- Review your notes on this patient from the last topic you completed together, and identify areas that need review.
- Review conversations and PN instructions on this topic.

Topic overview

Conversation	Materials & tools
Review previous topic	
A: Appointment logistics	Tool: Preparing for Your Appointment (Wkbk. page 47)
B: Communicating with providers	<ul style="list-style-type: none">• Tool: Pre-Visit Form (Wkbk. page 47)• Discussion Guide: Communicating with Providers (FG page 174)
C: Keeping track of medical information	Tool: Post-Visit Form (Wkbk. page 49)
Wrap Up	

Review

Can you tell me what you liked best about our last session or what you found most helpful? Review any areas that were particularly challenging or relevant for your patient during your last session together. Ask your patient to:

- 1) Demonstrate a skill that was learned from last session's discussion;
- 2) Explain one of the key points from that session.

Introduction to topic: In this topic you will discuss with your patient how to make and keep appointments as well as how to communicate effectively with providers. Patients have a wide range of skills in this area. Evaluate how your patient is doing based on your experiences with them and tailor the discussion appropriately. The topic is divided into three conversations: appointment logistics, preparing for appointments, and keeping track of medical information.

Conversation A: Appointment Logistics

Objective: The objective of this conversation is to build your patient's capacity to make appointments, keep track of providers' contact information, and arrange transportation to and from appointments.

Turn to Preparing for Your Appointment on page 47 of the Care Coordination Workbook.

Instructions to PN: Fill out logistical information for your patient's next medical appointment together on the top half of the Pre-Visit form as you discuss the following.

Say: This form was made to help you manage the logistics of making and getting to and from appointments. There are several copies of this form in your Care Coordination Workbook. You can use these forms in preparation for appointments. The form is designed to be brought to the appointment and reviewed with the provider.

Say Let's fill out the form as practice using an upcoming appointment as an example.

Ask: What happens when you have an appointment? How do you keep track of the appointment? Do you have a calendar?

Note to PN: If your patient does not have a calendar, consider providing one.

Ask: Do certain days of the week or times of day work better for you for appointments than others?

Ask: Where do you keep your provider's contact information?

Ask: How do you plan to get to your next appointment?

Ask: Do you usually go alone or with a friend or family member?

Ask: Where do you keep your medications and insurance cards?

Ask: Do you need a babysitter or need to make other arrangements while you are away at the appointment?

Ask: What do you need to take with you to keep track of information at the appointment (e.g., the Care Coordination Workbook, a small notebook)?

Ask: Do you need an interpreter?

Ask: How are you going to get to and from the appointment? Do you have a car, take public transportation, or have a friend or family member who can give you a ride? Are you eligible for transportation services? If so, are you enrolled in them? Do you have the number for the service? How many days before the appointment do you need to call to set up a ride? How will you remember to call? Where do you need to meet after the appointment for pick-up?

Patient ID:

Doctor/Provider:

Date:

Time:

Location:

How to get there?

Access-A-Ride

PN Pickup

NYC MTA

Family/Friend

Other

Is the PN Accompanying? Yes No

Will you need an interpreter? Yes No

Conversation B: Communicating with Providers

Objective: The objective of this conversation is to practice using the Pre-Visit form to make a prioritized list of the issues the patient wants to discuss with their provider. This conversation will also help the patient learn how to improve communication with the provider. This conversation helps your patient ask hard questions and build confidence in interacting with their provider.

Note to PN: This conversation may be especially useful with patients who feel challenged asking questions of their doctors. Note how your patient understands interactions with their providers. Are there any discrepancies between how your patient views these interactions and how you see them, having accompanied and observed your patient's appointments? Focus on your patient's perspective, even if it is different from your own.

Turn to the form on Page 47 of the Care Coordination Workbook.

Discuss the reasons for filling out the form with your patient:

For many people, filling out the Pre-Visit form improves confidence, helps make sure that the issues that are most important to you are discussed during your visit, and that you don't forget to talk about important details because they are written down.

Say:

Let's practice filling out the bottom half of the form together, using your next appointment as an example.

Ask:

What issues are you dealing with right now that you would like to discuss with your provider?

Ask: Of all of these issues you mentioned, which ones are the most important? Which ones are the least important?

Ask: All questions are good questions! What questions do you have for each of these issues?

Pre-Visit Form Continued

Questions and answers for your provider		
Q:		
A:		
Q:		
A:		
Q:		
A:		
Q:		
A:		

Ask: Are there any issues that you wrote down (or didn't write down) on the Pre-Visit Form that you find difficult to discuss with your provider?

Ask: If you are worried about your health, how do you talk about it with your doctor?

Ask: What are some things that will keep you from talking with your doctor about things you may worry about?

Ask: How do you and your doctor decide what to do about your health?

Ask: What happened at your last appointment with your doctor? What types of things were discussed? Were any decisions made? How long did the appointment last? Did you have any questions before or after?

Ask: During your appointments, who talks more: you or your doctor?

Ask: How do you feel about that?

Ask: How does it feel to ask questions during an appointment?

Say: Let's try a role-play to help you feel comfortable talking about these types of issues at the doctor's. Pretend I am the doctor and you are the patient. Pretend I say to you: 'Hi, _____, how are you? I am a little busy today, so let me get right to your exam.' What might you say to your provider in this situation if you still have things to discuss?

Some other topics you might want to discuss with your patient during this conversation include:

- The patient and the provider are both parts of the same team.
- The provider doesn't see the patient every day and doesn't know all that's going on, so it's important for the patient to tell the provider things that may be relevant to their health and to raise any questions or concerns.
- If the patient doesn't give the provider certain information (such as side effects or consistently missed medications), the provider might not know that something is wrong.
- It is important for patients to question their providers on anything they don't understand or agree with.
- Decisions are ultimately made by the patient, not the provider.

Conversation C: Keeping Track of Medical Information

Objective: The objective of this conversation is to help your patient manage and understand the information, decisions and recommendations generated by a medical appointment in order to become a more active participant in their medical care.

Turn to Page 49 of the Care Coordination Workbook: After Your Visit.

Instructions for PN: Practice filling out the After Your Visit Form together, using the patient's most recent doctor's visit as an example.

Post-Visit Form

Before you leave your appointment, make sure you ask...

Do you need any medications refilled this month?

Your next appointment is with Doctor:

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 there were any changes, please list them:

Were any tests done or ordered? Yes No

If there were tests done, please list them: _____

Wrap Up

- Say:** We've talked about a lot today!
- Ask:** In your own words, what did you learn today?
- Ask:** What did you learn about communicating with your providers?
- Ask:** Are there any new things that you will try to do after your next doctor's visit?
- Ask:** What questions came up for you that we can review for next time?
- Ask:** What's most important for me to know about you and what we talked about today?

Topic 11: Health Maintenance

Learning objectives

After completing this topic, the patient will be able to:

- Explain the role of their doctor(s)
- Explain what kind of support they can expect from people in the health care field
- Maintain a journal of health maintenance activities

Preparation

- Bring Care Coordination Workbook.
- Review your notes on this patient from the last topic you completed together, and identify any areas of confusion that need review.
- Review the conversations and PN instructions in this topic.

Topic overview

Conversation	Materials & tools
Review previous topic	
A: Intro to Health Maintenance	
B: Building Patient-Doctor Relationships	
C: Routine Questions and Tests at the Doctor's Office	
D: Appointment Tracking	Health Maintenance Appointment Tracker tool (Wkbk. page 45)
E: Roles of Different Service Providers	Tool: Contacts Information (Wkbk. page 39)
Wrap Up	

Review

Let's go over what we talked about last time. Review any areas that were particularly challenging for your patient during your last session together.

Ask your patient to:

- 1) Demonstrate a skill that was learned from last session's discussion;
- 2) Explain one of the key points from that session.

Introduction to Topic: In this topic, you and your patient will discuss how your patient can maintain their overall health and wellbeing by attending regular appointments with different health care and service providers. You will discuss what happens during a regular follow-up doctor's appointment as well as the roles of their service providers, including specialty doctors, dentists, eye doctors, case managers and social workers.

Conversation A: Introduction to Health Maintenance

Objective: The objective of this conversation is to help your patient think about ways in which they can take steps to stay healthy and prevent illness.

Ask: What does being healthy mean to you?

Say: People's minds and bodies are made up of many parts. In the same way that cars require regular maintenance and tune-ups to keep them running smoothly, our bodies also require regular visits and check-ups with doctors to keep us healthy. If you take the time to take your car into the shop every few months for an oil change and a check up, the chances that your car will keep running smoothly for a long time are much greater than if you never change the oil or get a check up. In the same way, by putting in some extra time to take care of ourselves on a regular basis, we can reduce our chances of getting ill and increase our ability to recover more quickly if we do get sick.

Conversation B: Building Patient-Doctor Relationships

Objective: The objective of this conversation is to help your patients understand the role that their doctor can play in helping them achieve and maintain good health and adherence.

Ask: How do you feel about your primary care doctor and/or your HIV doctor?

Ask: Do you feel comfortable telling your doctor about things going on in your life that might be affecting your health or your ability to take your meds?

Feedback: Respond to what your patients share with you, and if relevant, validate some of the difficulties they might face around interactions with their providers.

Say: One of my most important roles as a Patient Navigator is to help you develop good relationships with your doctors. Your doctors are on your side, trying to do what is best for you, and the more we can do to help them help you, the better they can serve you. Your doctors are a great source of information and can answer any questions you have related to your medications, your health and anything else related to your overall mental and physical wellbeing. It may take some time for you to feel comfortable with your doctors, but together we can work on how to develop that relationship. Because everyone has very different life circumstances and lifestyles, the best way for you to be healthy and to be adherent to your meds is to work with your doctor and PN to develop a plan that fits your life. An important part of staying healthy while living with HIV is visiting your doctor regularly. These regular visits will also help you to increase your comfort level with your doctor.

Ask:

Why do you think it's important to go to your doctor's appointments regularly and to build a good relationship with your doctor?

Fill in gaps in understanding

1. Going to appointments regularly will help your doctor stay updated about your health.
2. It will help you and your doctor understand and trust each other. Once this happens, your doctor will be better able to respond to your needs.
3. The more regularly you see your doctor, the safer and more comfortable you can be with them.
4. Your doctor can be a strong support around adherence once you are comfortable speaking to them openly about things that might make taking your meds hard at the moment. Your doctor can work with you to try different regimens and find something that works for you and fits your lifestyle.

Conversation C: Routine Questions and Tests at the Doctor's Office

Objective: The objective of this conversation is to help your patient understand what is going on during a doctor's visit and the reasons why certain tests or procedures are done.

Say: We're going to go over a list of many of the important questions that doctors will ask and the tests they will perform during regular follow-up appointments every three months. These tests are typically performed by your primary care doctor (PCP) or HIV doctor.

Ask: Do you know what a PCP is?

Fill in gaps in understanding: The PCP should know the most about all of your health needs. PCPs follow lab work and can refer you to specialists when needed. Your PCP could also be a nurse practitioner or a physician's assistant.

Note to PN: Your patient is probably familiar with many of these questions and tests that occur during regular follow-up appointments. Ask your patient to describe in their own words the different parts of a doctor's appointment that they are familiar with. **Go over the following information together, skipping the topics that your patient is already familiar with.**

Taking a general history

Your doctor will ask how you are feeling and if there are any new problems. It is a good idea to tell your doctor about side effects you are having, drug related discussions or concerns about your mood or spirits.

Performing a physical exam

Common questions and observations made during this exam include:

- Has the patient been regularly losing weight?
- Does the person have a low-grade fever that may indicate an infection?
- Are there signs of thrush?
- Are there new rashes that could represent a drug reaction?

Doing analysis and procedures

Some common analysis and procedures that your provider may use to monitor your health include:

- Drawing blood to analyze CD4 levels and viral load (usually every three months)
- Drawing blood to analyze any resistance to medications (to see if the treatment is effective)
- Analysis to monitor possible long-term side effects of medications, such as abnormal liver functions or lactic acid

Ask: Do you have any questions about any of the items above?

Say: It is really important to go to all your quarterly HIV doctor or PCP visits. These routine tests and questions are important for detecting illnesses, for making sure that the current ART regimen is effective and for managing side effects.

Performing a pap smear (for people with a cervix)

The Pap smear is a test done by removing cells from the cervix with a swab.

- The cervix is a tube-like extension of the uterus that connects the uterus to the vagina.
- A virus called human papilloma virus (HPV) can infect the cells of the cervix and cause cancer. HPV is sexually transmitted.

- All women should have pap smears every year because you do not have to be living with HIV to be at risk for HPV.
- Women living with HIV typically have pap smears every 6 months. If the first two smears are normal, the test is done every 12 months after that.
- Women living with HIV are at a higher risk of developing cervical cancer.
- There is a new HPV vaccine called **Gardasil**. It is a good idea to talk to your doctor about getting this vaccination.

Test for Tuberculosis (TB)

One of the most common infections associated with HIV is TB.

- TB is a slow growing infection caused by bacteria called the *Mycobacterium tuberculosis*.
- Although TB can grow almost anywhere in the body, the most common site of infection is the lung.
- People living with HIV are more at risk for developing TB because HIV weakens the immune system.
- People living with HIV and who have TB need to be treated with antibiotics to eliminate the bacteria from their system.
- Doctors screen for TB with a test called a PPD every year, or until a patient receives a positive result.
 - The doctor injects a small amount of liquid under the skin.
 - Two days later, the patient comes back to have the test “read” by a nurse.
 - If the site of the injection is red and hard, then the person has been exposed to TB.

Hepatitis B and C screening

- Hepatitis B and C are viruses that enter the body and attack the cells of the liver.
- Both are passed from one person to another through the blood, like HIV.
- Hepatitis B and C can cause an acute infection of the liver with symptoms of nausea, vomiting, abdominal pain and yellowing of the skin.

- The viruses can also cause **chronic** infections of the liver, which can lead to liver scarring and even to liver cancer.
- The doctor can take yearly blood tests to see if a patient is carrying Hepatitis B or C. There are vaccines that can protect against Hepatitis B, but there is no vaccine for Hepatitis C.
- There are also medications that can help treat both Hepatitis B and C, if a patient has either virus.

Screening for opportunistic infections

The doctor will also screen for common opportunistic infections such as toxoplasmosis and CMV.

- Patients might have to add extra medications into their regimen in order to treat any opportunistic infection they might have.

Screening for STIs

Treatment of STIs is important because they increase the risk for HIV transmission.

Ask: Can you think of examples of STIs?

Fill in gaps in understanding: Some common STIs include herpes, gonorrhea, chlamydia and syphilis.

Providing vaccines

The doctor or nurse can give you vaccines to help you avoid common infections that can be made more serious by HIV.

Ask: Can you think of any examples of vaccines?

Fill in gaps in understanding: Some common vaccines include those against the flu, some types of pneumonia, hepatitis A and B and tetanus.

Screening for diseases unrelated to HIV

- People with HIV can have health problems that are common for anybody, such as high blood pressure or diabetes.
- Conditions such as high blood pressure or diabetes can lead to serious health problems like heart attack and stroke.

In addition to seeing a medical doctor, you may need regular appointments with the dentist, eye doctor and podiatrist.

Dental appointments once a year

The dentist will make sure that teeth and gums are clean and healthy, and that the mouth does not serve as a source for infections.

Eye appointments once a year

The eye doctor will check your eyesight to make sure that your eyes are not damaged either by medications or infections.

Podiatrist (foot doctor) as needed

The podiatrist will check your feet and treat any infections that may be present.

Conversation D: Appointment Tracking

Objective: The objective of this conversation is to equip your patient to keep track of all the annual appointments they have attended and to help remind them which regular appointments they should attend on an annual basis.

Turn to Page 45 of the Care Coordination Workbook: Health Maintenance Appointment Tracker.

Say: It might seem overwhelming to remember to go to all these appointments and to get all these tests done, but this resource can help you stay organized. In addition, many of these regular tests and check-ups will be done at your quarterly HIV appointment, so it is very important to make sure to attend these appointments.

Say: After each doctor's appointment, you can refer to this Appointment Tracker (Workbook, page 45). For each test or type of appointment that was attended, write down the date of the appointment under "Date of Last Appt."

Say: For annual appointments, the "Date of Next Appt." will be one year from the date of your last appointment. Write down this date to serve as a reminder for when to schedule your next visit. If you already scheduled your next visit at the end of your previous appointment, write it on this card and circle it so you know this appointment has already been scheduled.

Conversation E: Roles of Different Service Providers

Objective: The objective of this conversation is to inform your patient of the different service providers that may be available to your patient in the hospital, community health center or medical practice that your patient visits, and to explain the roles of each provider.

Instructions to PN: Go over the following list of types of providers with your patient and answer any questions they have.

Specialist (specialty doctors)

- This doctor helps with specific problems that you have. Specialty doctors do not know about your various health problems but they help you with specific health care problems.
- Some examples include:
 - Endocrinologists help manage diabetes, thyroid disorders, etc.
 - Gynecologists help with women's health and reproductive issues.
 - Rheumatologists help with arthritis and other diseases of the muscles and joints.

Care Coordinators

- These people manage your social service needs as they relate to HIV.
- This person might help you find housing or connect you to services that help heat your home, pay bills, find transportation, etc.

Social Workers

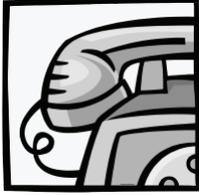
- These are the people who help get the things you need that are not just about health and health care.

- Some social workers also provide support for your emotional and mental health issues, such as depression and anxiety, by offering individual, family or group therapy for you and/or your family.

Activity: Turn to Page 39 of the Care Coordination Workbook: Contact Information.

Instructions for PN:

1. Work with your patients to identify all of the providers who help them with maintaining their health. Bring up people like their case manager, social worker and others, as relevant to your patients.
2. Make sure the contact information for each provider connected to your patient is listed in the Contact Information chart (it should have been filled in during Topic 8). If any providers have been omitted, add them to the chart and encourage your patients to reach out for help from their providers when they have questions or concerns.
3. Review a few scenarios with your patients to make sure they understand who to contact when and for what kinds of things. For example, you could ask, “Who would you talk to if you were feeling really down and depressed?” Or, “Who would you call if you needed help with housing?”
4. Ask your patients if they would like a referral to any of the providers discussed. Also take the time to discuss any referrals you would like to make to additional providers, such as mental health or substance abuse therapists.



Contact Information

PRIMARY CARE PROVIDER	PHONE #	LOCATION
OTHER HEALTH CARE PROVIDERS	PHONE #	LOCATION
COMMUNITY SUPPORT SERVICES	PHONE #	LOCATION
OTHER SUPPORTERS	PHONE #	LOCATION

Wrap Up

- Say:** We've talked a lot about how important it is for you to work on building a strong relationship with your doctors and also identified several different providers who can assist you with different issues.
- Ask:** In your own words, what did you learn today?
- Ask:** Did any of the conversations that we had today make you think about changing anything that you've been doing so far to take care of yourself? If so, what?
- Ask:** What's most important for me to know about you and what we talked about today?
- Ask:** What questions came up for you that we can review for next time?

Topic 12: Harm Reduction – Sexual Behaviors

Learning objectives

After completing this topic, the patient will be able to:

- Define “Harm Reduction”
- Explain why safer sex is important for people with HIV and their partners
- Discuss the risks associated with various sexual behaviors and how to reduce those risks
- Come up with a personal plan for safer sex practices
- Demonstrate how to use condoms

Preparation

- Bring Care Coordination Workbook
- Bring a least two different color pens/markers
- Bring male condoms, lubricants, and the penis model
- Review the Prevention with Positives Screen in the patient's file
- Review your notes on this patient from the last topic you completed together, and identify any areas of confusion that need review
- Review the conversations and PN instructions for this topic

Topic overview

Conversation	Materials & tools
Review last topic completed	
A: What is Harm Reduction?	
B: Risky Sex and Possible Harms	Tool: Harm Reduction Body (Wkbk. page 51)
C: Safer Sex	
D: Why Safer Sex is Important for People with HIV	Tool: “But why?” (Wkbk. page 52)
E: My Sexual Behaviors	Tools: Risk continuum (Wkbk. page 53)
F: Condom Demonstration	Condoms, penis model
Wrap Up	

Review

Let's go over what we talked about last time. Review any areas that were particularly challenging for your patient during your last session together.

Ask your patient to:

1. Demonstrate a skill that was learned from last session's discussion;
2. Explain one of the key points from that session.

Information for PN: This topic will first introduce the topic of "Harm Reduction" and then shift to the specific topic of Safer Sex. First, the patient and the PN will discuss why safer sex is particularly important for people with HIV and their partners. Next, the PN will ask the patient to write down their present or past sexual practices on a continuum of safer to riskier behaviors. These sexual behaviors will then be discussed further, to see if there are ways to make them safer. A condom demonstration will follow. These activities and discussions will serve as the basis for your patient's personal plan for safer sex.

Note to PN: This topic of Sexual Behaviors is a very personal and potentially uncomfortable subject. To make the conversation as comfortable and natural as possible:

1. Be aware of your environment (i.e., public vs. private space, sit in the living room vs. in the patient's bedroom, etc.);
2. Acknowledge when your patient looks uncomfortable;
3. Lighten up the conversation when necessary;
4. Tailor the discussion and the completion of the tools around your patient's comfort level;
5. Demonstrate a high level of ease in talking about sex and related topics;
6. If you notice that your patient continues to appear uncomfortable despite your efforts to normalize the conversation, you can talk about sex "in general," as opposed to individual sexual practices. (For example, use "some people" instead of "you"). You can also use impromptu cues like casually "discovering" condoms in your bag and asking your patients if they would like one, and start the conversation from there.

Explain to your patient that this topic focuses on the highly personal topic of sexual behavior.

Conversation A: What Is Harm Reduction?

Objective: The objective of this conversation is to introduce the idea of harm reduction as an approach that allows you to work with your patients to make small and manageable changes in their behaviors that can reduce health risks.

Ask: What is “Harm Reduction”? Have you ever heard of this term? What do you think it means?

Feedback: Add in any parts of the **definition** your patient may have left out, such as:

- A practical set of strategies that reduce the negative results of a particular behavior (i.e., engaging in unsafe or risky sexual behaviors, etc.)
- Harm reduction helps people change a behavior a little bit at a time. It does not ask people to completely stop the behavior in question (i.e., sex or drug use).
- Strategies that meet people “where they’re at.”
- A provision of resources and strategies to protect you and others.

Say: I’m not here to tell you to stop doing anything but to help you pay attention to the harm and risk you may be in due to some behavior or circumstances, and to help you figure out what you want to do about that.

Conversation B: Risky Sex and Possible Harms

Turn to Page 51 of the Care Coordination Workbook: Harm Reduction Body.

Objective: The objective of this conversation is to have your patient identify harms associated with unsafe or risky sexual behaviors and to begin brainstorming strategies that would reduce those harms.

Note to PN: It is very important to let the patients lead this activity so that you can gain a better understanding of how they perceive the harms associated with risky sexual behaviors. Later, other conversations on this topic will provide you with a chance to share more ideas and information with the patient.

Say: Sex is an important part of many people's lives, but it comes with different risks that are not always obvious. The good news is that many of these risks can be reduced by small changes that you can make in your sexual practices. Today we'll talk about some of these things.

Say: If you feel uncomfortable at any time, just let me know and we can talk about this in a different way, or talk about this later when you feel more comfortable.

Turn to Page 51 in the Care Coordination Workbook: Harm Reduction Body Map.

Instructions for PN:

1. Ask your patients to list some sexual acts and behaviors that they are familiar with or engage in. You can add behaviors that your patients may have missed.
2. Ask how these behaviors may harm one's body. Use one color pen or marker to write these ideas on the body map and then draw arrows to the relevant body parts in the drawings.
3. Then, use a different color pen or marker to brainstorm strategies to reduce the harms that your patients just identified. These ideas should come from the patients, not the PN.

Conversation C: Safer Sex

Objective: The objective of this conversation is to introduce the idea of safer sex and to help your patients understand why sex that allows someone else's semen, blood or vaginal fluids to enter their body is risky.

Note to PN: Use simple language as much as possible. If you use medical or technical words during this discussion, make sure to thoroughly explain things in plain language.

Say: We've discussed how some sexual behaviors can be risky and can affect different parts of your body. But there are ways to still enjoy sex while reducing these risks. Safer Sex is any sexual practice that does not let someone's semen, blood or vaginal fluids get into somebody else's body.

Ask: Why do you think sex that does **not** let semen, blood or vaginal fluids get into someone's body is safer than sex that **does** let these fluids get into someone's body?

Feedback: Build upon the ideas your patient may have mentioned and go over the points below that were not brought up:

- These fluids often contain high concentrations of certain bacteria or viruses that cause disease. When fluids from an infected person get into the body of another person, that person may also get infected. Diseases like genital herpes, genital warts, HIV, Chlamydia, gonorrhea, syphilis, hepatitis B and C, and others are transmitted by the exchange of fluids between two people.
- Diseases that can be transmitted by the exchange of semen, blood, or vaginal fluids are called sexually transmitted diseases (STDs) or sexually transmitted infections (STIs) because these fluids can enter a person's body during sex and cause infection.

Ask: Which parts of the body could allow for HIV transmission during sex?

Feedback: Build upon the ideas your patient may have mentioned and go over the points below that were not brought up:

- The parts of the body where HIV could enter the body/bloodstream during sex are the anus and rectum, vagina, penis and the mouth.
- You can protect these parts from contact with HIV-infected fluids.
- Condoms for the penis and vagina create barriers against these fluids.
- Dental dams can be used during oral sex.
- HIV cannot go through the skin unless there are open sores or bleeding cuts.

Conversation D: Why Safer Sex is Important for People with HIV

Turn to Page 52 of the Care Coordination Workbook: But Why?

Objective: The objective of this conversation is to have your patients come up with their own reasons why safer sex is important for people with HIV.

Directions for Tool: But Why?

1. Use the central assertion that safer sex *is* important for people with HIV and their partners and ask, “but why?”
 2. Write the reasons your patient provides about **why** safer sex is important around the center circle on page 52 of the Care Coordination Workbook, and circle those reasons. Put arrows from those reasons to the center circle.
 3. Backtrack from each of those reasons asking “but why?” and writing why those reasons are true. Again circle those ideas and make arrows toward the center.
 4. Continue the exercise until the patient and the PN have explored many reasons WHY safer sex is important for people with HIV and their partners.
- Make sure that the topic of pregnancy is reviewed –
 - Safer sex can prevent HIV as well as unwanted pregnancy
 - There is the risk of mother-to-child transmission of HIV, so HIV+ couples wanting to have a child should consult their doctors
 - Other issues that may be beneficial to include, if the patient did not think of them, are:
 - Re-infection among people who are already infected and the complications that re-infection causes for treatment;
 - HIV-negative people becoming infected with HIV;
 - Sexually Transmitted Infections (STIs) are particularly dangerous for people with compromised immune systems;

- o Staying adherent to medication when pregnant reduces the risk of mother-to-child transmission;
- o The importance of speaking to a physician about concerns about sexual health.

Note to PN: Emphasize re-infection and make sure that your patient understands the concept.

Note to PN: Many of the subjects that are brought up during the course of this discussion may be long-term issues that can be re-visited in later sessions. It is a good idea to make note of topics that may require follow-up.

BUT WHY?



**Safer Sex is Important
For People with HIV and
Their Partners**

Conversation E: My Sexual Behaviors

Objective: The objective of this conversation is to help your patient assess how risky their previous or current sexual behaviors were/are and to come up with ways in which they can reduce some of the risks of their behaviors.

Note to PN: If the patients get embarrassed or uncomfortable, suggest talking about sex “in general” instead of the sexual behaviors that they practice personally.

Turn to Page 53 of the Care Coordination Workbook: Risk Continuum

Instructions for PN:

1. Explain to the patient that “sexual behaviors” should be defined broadly in this activity. Rather than only considering penetrative sex, have the patient think about anything that is sexually exciting or arousing.
2. Write the patient’s sexual behaviors along the continuum, wherever the behavior fits, from “High Risk” to “Low Risk,” on Page 53 of the Care Coordination Workbook.

Examples of sexual behaviors may include:

- Having sex while under the influence of alcohol or recreational drugs
 - Vaginal sex
 - Anal sex
 - Oral sex
 - Masturbation
 - Rimming (Oral-Anal Contact)
 - Fisting
 - Kissing
3. After listing your patient’s previous or current sexual behaviors, switch to a different color pen or marker. Ask your patients to think about the risks associated with each of these behaviors.
 4. Then ask them to think about ways to reduce these risks. Have the patients lead this brainstorming, only adding suggestions after they have given their

Ideas or when they get stuck. Write the new ideas next to each behavior, in the new color pen/marker.

5. Be sure to also go over this the following list of **examples of ways to reduce risks associated with sexual behaviors:**

- Talking to your partner(s) and setting limits ahead of time
- Not having sex while drunk or high
- Using latex condoms with water-based lubricants for vaginal and anal sex, and using latex condoms without lubricants for oral sex with a penis
- Having latex condoms and water-based lube (**PN should offer patient condoms and lube**)
- Using latex dental dams, plastic wrap, latex gloves and finger cots as barriers
- Not sharing sex toys unless they are cleaned or have a fresh condom on
- Reducing your number of sexual partners

6. Put a circle around reduced risk behaviors that the patients intend to practice as part of their personal plan for safer sex practices.

Skill-Building – Negotiating Safer Sex Options

Note to PN: Following your discussion about safer sex options, it is very important to assess how many of these safer behaviors your patients are actually able to adopt given their circumstances and their level of empowerment in their sexual relationships.

Ask: How hard or easy do you think it will be for you to make changes to your sexual behaviors?

Ask: What things might get in the way of your being able to change your behavior?

Feedback: Address the concerns your patient has expressed. If your patient is concerned with not being able to make specific changes due to resistance from a partner, suggest practicing a conversation together.

Say:

It might be difficult to talk to your partner about safer sex options if you never had a conversation like this before. But the more you know about safer sex options and the more convinced you are that protecting yourself is worth standing up for, the easier it can be. Some important things to remember when talking to your partners about safer sex practices are:

- Think about a good time to bring up this conversation. It is not a good idea to wait until right before sex, as it is easy to get caught up in the moment if you have not set boundaries beforehand.
- Listen to your partner and respond to their concerns with “I”-focused statements. Talk about why *you* want to use condoms or other safer sex options instead of blaming or accusing your partner.
- Admit that using a condom may feel different, but you can make it a fun challenge for you and your partner to be creative in thinking of ways to make safe sex pleasurable.
- Be consistent in using safer sex practices. If you give in “just this once,” your partner may feel that you will always give in under pressure.
- Make this decision about both you and your partner — safer sex protects both of you from unwanted pregnancy and STIs. Many people have STIs without even knowing it, so it is never a good idea to take the risk of unprotected sex.

Instructions for PN: After you have discussed these points, ask your patients if they want to practice a negotiation conversation with you. You can play the role of the patient and the patient can play the role of the partner. This way you can model how to respond to a partner’s potential objections to using a condom or other safer sex practices. When your patient is more comfortable, switch roles.

Risk Continuum

High Risk/ Very Risky Behavior



Lower Risk/ Safer Behavior

Conversation F: Condom Demonstration

Objective: The objective of this conversation is to discuss any ways in which your patient could increase the effectiveness of a condom through proper application techniques.

Ask: Have you ever used a condom?

Ask: Could you show me how to apply a condom and explain each step?

Use the penis model for the demonstration.

Feedback: After the patient is done, the PN should do the demonstration, emphasizing anything that the patient may have missed. During the PN demonstration, be sure to discuss the following:

1. Check expiration date. Throw away condoms that have expired, been in a very hot environment (e.g., left in a car on a hot day), carried in a wallet or washed in a washer.
2. The penis should be hard before putting the condom on.
3. Open the package carefully by pushing the condom away from the corner that you tear.
4. If the penis is uncircumcised, pull the foreskin back first.
5. Make sure the condom is right side out. Throw the condom away if you start putting it on inside out, and get a new one. (You should show the patient the difference between the sides.)
6. Hold the top half-inch of the condom between your fingers when you roll it down. This keeps out air bubbles, which can cause the condom to break. It also leaves space at the end for the cum.
7. Roll the condom all the way down to the base of the penis, near the testicles.

8. Use water-based lubricant. Put the lube on after you put the condom on (putting lube on first could cause the condom to slip off).
 - Keeping condoms lubricated reduces the chance that the condom will break.
 - Lubing is especially important during anal sex.
9. Hold on to the condom near the testicles when pulling out to avoid spilling the cum. Try to pull out when the penis is still hard. Take the condom off only after withdrawing from the partner.
10. Throw out the used condom. Use each condom only once. Never use the same condom for vaginal and anal sex.

Ask patients if they would like to demonstrate how to put on the condom again. The patients should explain each step in their own words, being sure to include any new information shared by the PN.

Offer your patients condoms and let them know that they can always ask you for condoms.

Wrap Up

Say: We've talked a lot about safer sex behaviors and their importance to people with HIV. Thanks for being open to discussing this personal topic with me.

Ask: In your own words, what did you learn today?

Ask: Explain to me one of the strategies you learned today that can reduce the risks associated with sex.

Ask: What's most important for me to know about you and what we talked about today?

Ask: What questions came up for you that we can review for next time?

**** Note to PN:** If your patients express any concerns that lead you to believe they might be in an abusive relationship, go over Topic 14: Harm Reduction – Safety in Relationships with them next.

Topic 13: Harm Reduction – Substance Use

Learning objectives

After completing this topic, the patient should be able to:

- Understand the principles of “Harm Reduction”
- List strategies for reducing health risks while using substances
- Plan strategies for staying adherent to ART while using substances
- Know how to access available resources

Preparation

- Bring Care Coordination Workbook.
- Review notes about substance use in patient's file.
- Discuss the patient's history of substance use and previous coping strategies with your supervisor, and/or other relevant caseworkers.
- Review the substance use and needle use sections of the Intake & Assessment, Reassessment, and Prevention with Positives Screen in the patient's file.
- Review your notes on this patient from the last topic you completed together, and identify any areas of confusion that need review.
- Review conversations and PN instructions for this topic.

Topic Overview

Conversation	Materials & tools
Review last conversation completed	
A: Assessment	
B: Introduction to Harm Reduction	
C: ART adherence and substance use	
D: Substances commonly used and strategies for reducing risk	Substances Chart (Wkbk. page 54)
E: Relationships and Substance Use	
F: Substance Use and HIV Transmission	
G: Create a Harm Reduction plan	Risk Continuum (Wkbk. page 53)
Wrap Up	

Review

“Let’s go over what we talked about last time.”

Review any areas that were particularly challenging for your patient during your last session together. **Ask your patient to:**

1. Demonstrate a skill that was learned from last session’s discussion;
2. Explain one of the key points from that session.

Conversation A: Assessment

Objective: The objective of this conversation is to assess whether your patient is ready to discuss substance use harm reduction with you.

Try hard to discuss this topic with:

- Patients who you know are actively using and are open with you or others at your Care Coordination program about it
- Patients you suspect are using but are not open about it

Try to discuss this topic with:

- Patients in short-term recovery (less than two years); however, use caution with those in recovery to make sure discussing this topic will not be a trigger for them.

Try less hard to discuss this topic with:

- Patients who are open about being in long-term recovery (more than two years)
- Patients who you do not suspect use currently or within the past two years
- Any patient who is reluctant and won’t engage with you about substance use

Instructions to PN: Discuss the following points with your patient. If patient is open to discussing substance use with you and it does not seem that doing so would be a trigger, then continue with the other conversations on this topic.

For patients who are using or who you suspect are using

Say: In your annual Assessment or Reassessment, you expressed a history of substance use, so today we're going to work on that.
(if appropriate):

Say: I work with people who use every day. I'm not so concerned about whether you're using or not. I want to be as supportive as possible. My focus is about health and safety, not so much whether you use or not.

Say: This topic can be helpful to everyone, whether they use substances or not. Many people know somebody who uses substances and so knowing about ways to reduce harm with substance use can be helpful for everyone.

Say: I have these conversations with everybody, and I learn something different from everybody I talk to about this, so I want to learn from you.

For patients in recovery

Say: Some people who are in recovery find it helpful to discuss different harm reduction techniques or to discuss emotional issues they feel about their substance use history so that these feelings don't interfere with recovery. Other patients find it helpful to learn about harm reduction if it relates to someone they know who is using drugs or alcohol.

Ask: Would it be helpful for you to talk about any of these things?

Say: I know you're in recovery. Some people in recovery feel comfortable talking about substance use. Others do not. How do you feel about it?

Ask: Do you think talking about this might be a trigger for you?

If patient says yes, do not discuss this topic with them now.

If patient is unsure,

Ask: Can you help me understand what might be a trigger for you?

Ask: How have you been able to stay clean for so long? What have you tried? What has worked? What has not worked?

Note to PN: If you proceed to discuss this topic with patients in recovery, be careful to frame your conversations in a way that supports their recovery and abstinence from substances. Be careful **not** to give your patients the impression that substance use isn't harmful as long as it is "safe."

For all patients

Say: I like talking about this with all of my patients. This is not about you in particular; this is general information not only for users, but for people who have any experience with using or know somebody who uses.

Say: If at any point in this discussion, there are areas that you are not comfortable talking about, please let me know and we can always stop and come back to this conversation later when you feel more comfortable.

Note to PN: Even if you discuss this topic with your patient, some of the conversations may not be relevant to all patients.

You do not need to take notes during these conversations, unless you want to and your patient is comfortable with it. However, be sure to document in your progress note what you learn about your patient as well as what you think your patient learns during these conversations.

Conversation B: Introduction to Harm Reduction

Objective: The objective of this conversation is to help your patient understand the principles of harm reduction.

Ask: When you hear “Harm Reduction,” what does it mean to you?

Fill in gaps in understanding: The main goal of substance use harm reduction is to **reduce** drug-related harm and develop strategies that fit a person's lifestyle to promote “safer” use. In addition, its goal is to promote adherence to ART medication when using substances. **Harm reduction is:**

- A practical set of strategies that reduce the negative consequences of substance use
- A non-judgmental provision of services or resources.
- Strategies that meet people “where they’re at”
- NOT asking people to completely give up the behavior

Ask: What does substance use mean to you?

Summarize to check for understanding: So you're saying that substance use means [fill in what patient said].

Fill in gaps in understanding: **Substance use** means using a substance for pleasure that may cause harm to your health and well-being. In addition, a substance can be originally used for treatment purposes (e.g., prescriptions for pain) but can then be misused.

Ask: What does drug dependence mean to you?

Fill in gaps in understanding:

Some people who begin using substances may find that that they need to use more of a drug to achieve the same effect as when they started. This could result in dependence. If people use large amounts of a drug for a long time, continue use despite negative consequences, and feel unable to quit using, either because of overwhelming craving or because of withdrawal symptoms, they might be dependent.

Conversation C: ART Adherence and Substance Use

Objective: The objective of this conversation is to help the patient think about how using substances can impact someone who is on ART.

Say: Different drugs and alcohol react differently in each person. When a person is taking ART, the reactions to drugs and alcohol can be more extreme.

Ask: What does the term “**drug interaction**” mean to you?

Fill in gaps in understanding: When foreign substances such as recreational drugs and ART are used at the same time, the body can get overwhelmed and have a negative reaction.

Say: ART medications can affect how drugs and alcohol work, and drugs and alcohol can affect how ART medications work. For example: if a patient is using crack and ART, major health problems might arise such as difficulty breathing. The same person may not experience this if using crack or ART separately. This is why harm reduction is important to discuss.

Say: Some substances will reduce the effectiveness of ART, which could lead to becoming sicker, or to the development of drug-resistant virus.

Say: Some ART medication could magnify the effects of “street drugs,” increasing the risk of fatal overdose.

Ask:

What are some ways that substance use can affect adherence?

**Complete
what patient
says:**

Some people might have more trouble remembering to take their pills when they are using substances; other people become paranoid and afraid of taking their pills when they are using. Some patients' treatment is interrupted when they use substances because the combination of drugs or alcohol and ART makes them feel sick.

Conversation D: Substances Commonly Used and Strategies for Reducing Risks (discretionary)

Objective: The objective of this conversation is to discuss detailed information on specific substances, their impact on general health, and their impact when used in combination with ART. You will also discuss terminology (or “street names”) for drugs so that you and your patient are on the same page.

Note to PN: Before you have this conversation, it will be important for your patient to first understand the general concepts of harm reduction, substance use, and drug interactions and its impact on adherence. So, **make sure to have this conversation after you have already completed conversations A, B, and C.**

Note to PN: If your patient is not actively using, go over this chart if patient expresses an interest in it; otherwise, patient can just keep it as a reference. Check in with patients in recovery to see if this conversation might be a trigger for them, and if it might be then don't have this conversation now.

PN instructions: Go over the Substance Use Chart with your patient, focusing on the drugs that are currently used by your patient. Consider also discussing drugs formerly used by the patient, drugs used by the patient's partner or other people the patient knows, or any other substances the patient expresses an interest in learning about. You do not need to go over the whole chart if it is not all relevant to your patient.

Turn to Pages 54-55 of the Care Coordination Workbook: Substances Chart.

Ask : Could you please look at this Substance Chart and read the different names used for the drugs?

Ask: Which of these drugs do you know about?

Ask: Which of these drugs do you use or have previously had experience using?

Ask: Which of these substances does somebody you know use?

Ask: Can you mention one drug you are familiar with?

For that drug, ask: Tell me about that drug. What do you call it?

Ask: What are the different ways it can be taken?

Complete what the patient says with information from the chart.

Ask: How does this substance impact a person's behavior and health?

Complete what the patient says with information from the chart.

Ask: Do you know if this substance interacts with ART?

Complete what the patient says with information from the chart. Be sure to also discuss how potential health consequences such as reduced appetite and insomnia may also impact ART adherence.

Substances Chart*

Recreational Drug Name (and Street Names)	How it enters the body	Potential health consequences	Interactions between Recreational Drugs and Antiretroviral Agents/Other Prescription Drugs
<p>Marijuana or THC (<i>Blunt, dope, grass, herb, joints, Mary Jane, pot, skunk, weed, "Tabaco," ganja, tree, T</i>)</p>	<p>Swallowed, smoked, eaten</p>	<p>Euphoria, 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</p> <p>Health benefits: increased appetite, reduced nausea and pain</p>	<p>Interaction with: Protease Inhibitors (PIs) Sustiva (stocrin, efavirenz) – no actual drug interactions, but may cause a false positive marijuana test.</p> <p>Potential Results: PIs can increase marijuana levels: smoked marijuana may lower PI levels. Lower levels of marijuana may be needed for medicinal purposes if PIs are being used.</p>
<p>Benzodiazepines (<i>Ativan, Halcion, Librium, Valium, Xanax, candy, downers, sleeping pills, "pastillas," beans, the mix, klanopins called k, sanipex called zenys</i>)</p>	<p>Swallowed, injected</p>	<p>Sedation, drowsiness, dizziness, decreased breathing, death</p>	<p>Interaction with: Kaletra (Aluvia, lopinavir/ritonavir), Norvir (ritonavir) and other Protease Inhibitors (PIs), other ART medications, alcohol and other sedatives.</p> <p>Potential Results: Many PIs can increase the concentration of benzodiazepines in the body, making them more dangerous.</p>
<p>PCP and analogs (<i>Phencyclidine, angel dust, dust, crank, pick-me-up, space, boat, hog, love boat, peace pill</i>)</p>	<p>Injected, swallowed, smoked</p>	<p>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</p>	<p>Interaction with: Protease Inhibitors (PIs).</p> <p>Potential Results: PIs block degradation of PCP, so PCP can be much more toxic if a patient is also taking PIs.</p>

<p>LSD (<i>Acid, acido, blotter, boomers, cubes, microdot, yellow sunshine, purple haze, "Lucy-in-the-sky-with-diamonds," best trip, trippn</i>)</p>	<p>Swallowed, absorbed through mouth or tissues</p>	<p>Altered states of perception and feeling, nausea, chills, sweating, persistent perception disorder (flashbacks)</p>	<p>Interaction with: Protease Inhibitors (PIs) and Nonnucleoside reverse transcriptase inhibitors (NNRTIs).</p> <p>Potential Results: PIs and NNRTIs could potentially cause build up of LSD in the body, leading to increased toxic effects.</p>
<p>Ecstasy (<i>E, Molly, happy, X</i>)</p>	<p>Swallowed</p>	<p>Euphoria, confusion, sleep problems, anxiety, blurred vision, brain damage, depression, paranoia, nausea, chills, sweating, liver damage, seizures, kidney damage</p>	<p>Interaction with: Protease Inhibitors (PIs), especially Kaletra (Aluvia, lopinavir / ritonavir) and Norvir Kaletra (Aluvia, lopinavir/ ritonavir) and Norvir (ritonavir) Selective serotonin reuptake inhibitors (SSRIs).</p> <p>Potential Results: Using certain ARTs with ecstasy could result in life threatening effects such as heatstroke, dehydration, and loss of consciousness. PIs may lead to increase in Ecstasy levels.</p>
<p>Opiates</p> <p>Heroin (<i>Brown sugar, dope, skunk, smack, junk, dogfood, manteca, manterian, estofa, tecata, chiva, caballo blanco</i>)</p> <p>Codeine (Tylenol with Codeine; <i>Captain Cody, Cody, packs, CD, the big bean</i>)</p> <p>Morphine (pins and needles)</p>	<p>Injected, smoked, snorted</p>	<p>Pain relief, euphoria, drowsiness/nausea, constipation, confusion, sedation, respiratory depression and arrest, and death.</p>	<p>Interaction with: Kaletra (Aluvia, lopinavir/ritonavir) Norvir (ritonavir) Inhibitors.</p> <p>Potential Results: Heroin could make an HIV+ person sicker. Ritonavir decreases the effectiveness of codeine.</p>

<p>OxyContin (oxies) Vicodin (V beans) Percocet (perks, pick me up) Demerol (DI) Fentanyl</p>			
<p>Cocaine (Blow, bump, C, candy, Charlie, coke, crack, flake, rock, snow, toot, perico, basico, snow, fish scale, pasta, esqueleto)</p>	<p>Injected, smoked, snorted</p>	<p>Increased heart rate and blood pressure, increased mental alertness, rapid or irregular heart beat; reduced appetite, weight loss, heart failure, nervousness, insomnia</p> <p>Also: long-term snorting can damage nasal membrane</p> <p>Smoking hot crack pipes can result in lip blisters/burns, which increase the risk of infections, especially during oral sex</p> <p>If you use vinegar, lemon, or other "organic" acid to make your crack injectable, you can get serious infections. Use ascorbic acid instead.</p>	<p>Interaction with: Protease inhibitors (PIs) Nonnucleoside reverse transcriptase inhibitors (NNRTIs) [especially Viramune and Viramune XR (nevirapine), Sustiva (stocrin, efavirenz), and Atripla (efavirenz + tenofovir + emtricitabine)].</p> <p>Potential Results: Cocaine is known to be toxic to the immune system and could reduce CD4 cells making an HIV+ individual 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.</p>
<p>Methamphetamine (Crystal meth, Crank, crystal speed, Tina, tweak, ice, white snow, the diet, the thinning, the scar)</p> <p>"Strawberry quick" (a mix of ecstasy, cocaine, and methamphetamine)</p>	<p>Swallowed, snorted, smoked, injected</p>	<p>Euphoria, increased energy and attentiveness, diarrhea, nausea, loss of appetite, insomnia, tremor, compulsive fascination with repetitive tasks, talkativeness, irritability, panic attacks, having very</p>	<p>Interaction with: Kaletra (Aluvia, lopinavir/ritonavir) Norvir (ritonavir) Rescriptor (delavirdine) Selective serotonin reuptake inhibitors (SSRIs)</p> <p>Potential Results: Methamphetamines can increase levels of ritonavir in the body to more toxic levels.</p>

		long sex sessions, sexual craving (in the long term, combined with impotence resulting in preference for being the "bottom")	
Alcohol	Swallowed	Slurred speech, loss of inhibition, unsteady gait, hypothermia, impotence, memory loss, coma, death. Chronic use can cause hepatitis, pancreatitis, liver failure, and memory problems.	Interactions with: Agenerase (amprenavir) Alcohol use while taking ART 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 the condition get 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 also increases the risk of thrush and oral hairy leukoplakia (whitish mouth sores) as well as Mycobacterium avium complex (MAC). Smoking while taking some ART can worsen hepatitis. Those who smoke are more likely to experience side effects of HIV medications, such as nausea and vomiting.

Source: National Institute on Drug Abuse "Commonly Used Drugs," website: <http://www.nida.nih.gov/DrugPages/DrugsofAbuse.html> and Clinical Manual for Management of the HIV-Infected Adult 2006 Edition

***Note to PN:** it is very important that the patient consults their doctor for information on specific ART medications and potential interactions with substances.

Conversation E: Relationships and Substance Use (discretionary)

Objective: The objective of this conversation is for patients to think about the ways their relationships affects their substance use, and the ways their substance use affects their relationships. It is also an opportunity for you to learn more about the patients.

Note to PN: This conversation is an opportunity for you to practice **motivational interviewing**, to help your patients think about the relationship context of their substance use in a non-judgmental way.

Ask: Who in your life uses substances?

Ask: Does your partner use substances?

Ask: Do you ever discuss your partners' substance use with them?

Ask: Do you ever discuss your own substance use with your partner?

Ask: In what ways does substance use affect your relationships?

Ask: Have you disclosed your HIV status to the people who you use substances with?

Conversation F: Substance Use and HIV Transmission (discretionary)

Objective: The objective of this conversation is to identify the transmission risks associated with substance use as well as the impact of substance use on HIV progression.

Note to PN: This conversation is recommended only for active substance users; it is not recommended for those in recovery.

Say: This conversation is intended to generate a discussion on impacts of substance use and HIV so that you are aware of the consequences and can take control and make informed decisions.

Ask: What are some ways that a person using drugs or alcohol could be putting themselves or others at risk for HIV?

Repeat to check for understanding: So what I hear you saying is that a person can put themselves or others at risk for HIV by [fill in what patient said].

Fill in gaps in patient's understanding by explaining the following three possible types of increased risk:

- 1. HIV transmission risks – Routes of administering substances**
 - The highest risk of HIV transmission due to substance use is from intravenous use.
- 2. HIV transmission risks – Route of sexual transmission**
 - The number of sexual partners might be higher when under the influence of substances.
 - Some people are paranoid when they use substances and are "not in their right mind."
 - There might be an increase in unsafe sexual practices such as: increased partners, difficulty saying no, not feeling comfortable

asking for condom use, not saying no to uncomfortable positions. Also, some substances — particularly stimulants such as coke or speed — can promote “marathon” sessions, increasing the risk of tearing the skin, which increases transmission.

- Increased HIV transmission risk means other people your patient uses with or has sex with are more at risk for contracting HIV. It is also possible that patients can put themselves at risk for **HIV re-infection or super-infection**, which means the patient is infected with more than one type of HIV virus. It is still unclear exactly what the impact of HIV super-infection is, but it *could* lead to the medications not working because of resistance.

Medical – Progression of HIV

- The combination of substances and HIV could cause the immune system to be suppressed.
- It could increase the speed of viral replication.
- It could increase the occurrence of co-infection with hepatitis B and C.
- Drug-use related infections (such as Staph and soft tissue infections) could take a particularly bad turn among the immuno-compromised.

Say:

This is a lot of difficult information to cover and discuss. But it will help to understand how these different substances work on your body so that you can **reduce** transmission risks and **reduce** the harm associated with use.

Conversation G: Create a Harm Reduction Plan (discretionary)

Objective: The objective for this conversation is to discuss strategies your patient can take to reduce risks of substance use, and to create a harm reduction plan for substance use.

Note to PN: This conversation is recommended only for active substance users; it is not recommended for those in recovery.

Please turn to Page 53 of the Care Coordination Workbook: Risk Continuum.

Instructions to PN: Together, write down the behaviors your patient engages in on the Risk Continuum. Include both the dangerous and the safer behaviors. For example, sharing needles to inject cocaine would be on the dangerous end of the risk continuum, while using clean needles, not sharing needles, or inhaling cocaine would be more toward the safer end of the risk continuum.

Ask: What are you doing now to protect yourself against the harms associated with the substances you are using?

Add any additional behaviors mentioned to the safer end of the risk continuum.

Ask: Based on all that we've talked about, what are some strategies that you would like to try to reduce the risk of HIV transmission and reduce the progression of HIV?

Add any additional behaviors mentioned to the safer end of the risk continuum.

You may wish to suggest some additional ways to reduce harm from substance abuse, including:

1. Less frequency
2. Different times of day
3. Less overall use
4. Different substances
5. Change method of use (i.e., intranasal instead of intravenous)
6. Consider not using?
7. Use with somebody to reduce risk of fatal OD
8. Use clean needles
9. Practice vein care
10. Money management to budget for daily needs
11. Change the setting (use at home in clean environment instead of in an alleyway)
12. Buy from a more reliable dealer
13. Get naxolone (Narcan) prescription
14. Use safer smoking practices
15. Go on methadone or suboxone program
16. Address mental health issues or trauma underlying drug use
17. If you are having interactions between ART and a substance you use, talk to the provider about changing the ART or the time of day the ART is taken.

Ask: What new harm reduction strategies do you think you can take right now to reduce the harm associated with each of the substances you are using?

Instructions for PN: Write down each harm reduction strategy on the safer end of the risk continuum. Discuss or even write down the pros and cons of each new harm reduction strategy that your patient is considering. Break each harm reduction strategy into manageable steps with a specific timeline.

Wrap Up

- Say:** We've talked about a lot today!
- Ask:** In your own words, what did you learn today?
- Ask:** What strategies did you come up with for reducing harms?
- Ask:** What are some steps you will take to reduce harm in your life?
- Ask:** What questions came up for you that we can review for next time?
- Ask:** What's most important for me to know about you and what we talked about today?

Topic 14: Harm Reduction – Safety in Relationships

Learning objectives

After completing this topic, the patient will be able to:

- Define “Harm Reduction”
- Identify components of safe and unsafe relationships
- Anticipate some unsafe situations that might arise and think about how to minimize the chances of these situations occurring
- Know how to minimize harm if unsafe situations do arise
- Make a personal “safety plan”

Preparation

- Bring Care Coordination Workbook.
- Bring two different color pens/markers.
- Review any notes about domestic violence in the patient's file.
- Discuss the patient's history of unsafe relationships and previous coping strategies with the Care Coordinator and/or other relevant Care Coordination staff.
- If relevant, call patient and make arrangements to cover this topic at a time and place where the abusive person will not be present.
- Review your notes on this patient from the last topic you completed together, and identify any areas of confusion that need review.
- Review conversations and PN instructions for this topic.

Topic Overview

Conversation	Materials & tools
Review previously completed topic	
A: What is Harm Reduction?	
B: Healthy Relationships	Graphic: Equality Wheel
C: Relationship Dynamics	Tool: Power and Control Wheel (Workbook page 56)
D: Identifying Safe/Unsafe Situations	Tool: Safety Strategies Flow Chart (Workbook page 57)
E: Personal Safety Plan	Tool: Personal Safety Plan (Workbook page 82)
F: Additional Resources	Material: Resources (Workbook page 70)
Wrap Up	

Review

“Let’s go over what we talked about last time.”

Review any areas that were particularly challenging for your patient during your last session together. Ask your patient to:

1. Demonstrate a skill that was learned from last session’s discussion;
2. Explain one of the key points from that session.

Note to PN: This topic can be used with anyone, not only people in abusive relationships. It can be used with women or with men. This topic should NOT be used with partners together. It should NOT be used with people who have histories of being abusive in intimate relationships. If you find out about abusive situations that your patient may be in, talk to your supervisor.

Information for PN: In this topic, the concept of “Harm Reduction” will be introduced. The patient and the PN will then apply a harm reduction perspective to the patient’s relationships. The patient and PN will reflect on the patient’s relationships, discuss strategies for staying safe in relationships and then make a personal safety plan for the patient. Adapt this topic to fit your patient’s circumstances and level of comfort. You can address a patient’s current or past unsafe relationships, or talk more generally about someone your patient may know.

Note to PN: Make sure that you and your patient will have **uninterrupted privacy** while completing this topic (i.e., the patient’s partner should not be in the house).

Conversation A: What is Harm Reduction?

Objective: The objective of this conversation is to introduce the idea of harm reduction as an approach that allows you to work with your patient to make small and manageable changes that can reduce health risks.

Ask: What is “Harm Reduction”?

Ask: Have you ever heard of this term?

Ask: What do you think it means?

Feedback: Let your patient's ideas begin the conversation. Add in any parts of the definition your patient may have left out, such as:

- A practical set of strategies that reduce the negative effects of a particular situation or behavior;
- Harm reduction helps people make small changes but does not ask people to completely stop a behavior or make an immediate big change;
- Strategies that meet people “where they're at”;
- A provision of resources and strategies to protect you and others.

Say: I'm not here to tell you to stop doing anything or to make a dramatic change in your life. My goal is to help you pay attention to the harm and risk you may be in due to some of your circumstances, and to help you figure out what you want to do about that.

Conversation B: Healthy Relationships

Objective: The objective of this conversation is to help your patient reflect on past relationships and identify some of the positive and negative aspects of these relationships.

Say: Think about some of your past and/or current relationships.

Ask: What things do you like about your relationships? What things you do you not like?

Instructions to PN: Pull out a piece of scratch paper from the back of the Care Coordination Workbook and write down your patient's answers in a chart like the one below:

Things I like	Things I don't like

Feedback: Respond to the information your patients just provided by validating some of the things they have identified as positive aspects about their relationships, as well as empathizing with some of the negative aspects of their relationships.

Refer to the equality wheel on next page.

Say: This wheel shows some other positive things that can come out of a relationship that is built on equality and nonviolence and promotes respect.

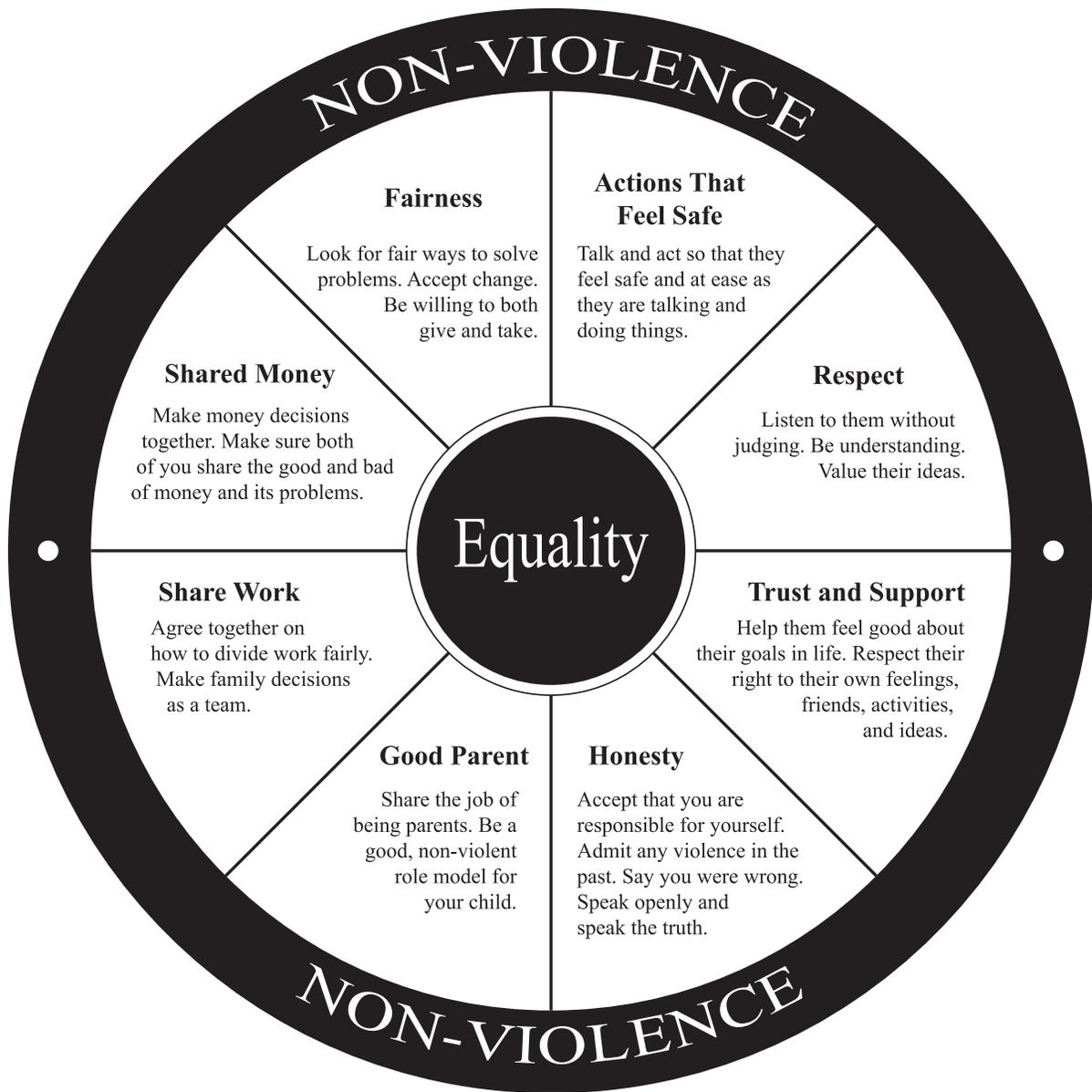
Note to PN: Read through the different sections of the wheel and ask your patients whether or not there are any parts that are characteristics of their relationship.

Ask: What do you think of the kind of relationship that is represented in this wheel?

Ask: Is this the kind of relationship that you would want for yourself?

If yes, ask: What are some things that you think are keeping you and your partner from having this kind of relationship?

Equality Wheel



Source: <http://www.gov.nl.ca/VPI/types/wheelsofpower.html>

Conversation C: Relationship Dynamics

Objective: The objective of this conversation is to help your patients identify abusive behaviors that they may be experiencing.

Note to PN: Many patients may not identify their relationships as abusive or unhealthy, even if they may appear that way to an objective observer. Be sensitive to the language your patients use to describe their partners or their relationships and try to use similar language. You don't want to minimize abusive behavior, but you also don't want to cause your patients to become defensive and guarded about this topic.

Say: Every relationship has its ups and downs, but there are some times when a relationship actually gets dangerous or unhealthy.

Ask: What are some things that make a relationship unhealthy?

Ask: Have you ever been in an unhealthy relationship like this, or do you know anyone who has?

Ask: People stay in difficult relationships for many reasons. Were there times when you put up with things you didn't like about a relationship because there were things about it that you did like or need?

Say: People sometimes take advantage of the fact that their partners need or want to stay in the relationship and don't always treat them with care or respect. They exercise negative power and control over their partners. This control can extend beyond physical abuse to other types of domination.

Turn to Page 56 of the Care Coordination Workbook: Power and Control Wheel.

Instructions for PN:

1. Go through the Power and Control Wheel with your patient. Discuss the different categories of power and control listed in the Wheel provided in the Care Coordination Workbook and go over examples of each. Encourage your patients to come up with examples as well, from their own experiences or the experiences of others. Ask your patient if they have ever experienced any of these things.
2. Write the patient's personal examples on the Power and Control Wheel in the Care Coordination Workbook.

Definitions:

Intimidation: Putting someone in fear by using looks, action, gestures, a loud voice, smashing things, destroying property

Psychological: Playing mind games

Using privilege: Treating someone like a servant, making all the "big" decisions

Isolation: Controlling what someone does, who they see and talk to, where they go

Economic: Trying to keep someone from getting or keeping a job. Making them ask for money, giving them an allowance, taking their money.

Emotional: Putting them down or making them feel bad about themselves, calling them names.

Sexual: Making someone do sexual things against their will. Physically attacking the sexual parts of their body. Treating them like a sex object.

Physical: Hitting, grabbing, using a weapon, beating, throwing, hitting, pinching, twisting arms, biting, tripping, pushing, punching, slapping, choking

Note to PN: This exercise may bring up a lot of emotions and stories.

Re-emphasize that your patient is not at fault: Sometimes people try to control their partners because they are insecure or angry and desire power. They often blame their partners to justify their actions, **but it is not the partner's fault**. Extend your support and be sure to talk with your patient about the resources available in dealing with these issues.

Conversation D: Identifying Safe and Unsafe Situations (discretionary)

Objective: The objective of this conversation is to think of practical ways in which your patients can reduce some of the risks and harms of unsafe occurrences that might arise in their relationship(s).

Note to PN: This tool may be more useful for patients who are currently in abusive relationships. It may not be applicable or useful for all patients; use your discretion in deciding whether this will be a beneficial conversation for your patient.

Turn to Page 57 of the Care Coordination Workbook: Safety Strategies Flow Chart.

Instructions for PN: Now that your patient has begun identifying the harms of being in an unsafe relationship, transition to a reflection on unsafe occurrences that the patient has experienced or that are possible in an unhealthy relationship. Use these specific situations to discuss what may have caused these harmful events to happen, and think of ways to reduce those triggers in the future.

1. First, have your patients list situations that made them (or others that they know about) feel unsafe in their current or previous relationship(s). The patients should write those things in the left column of the chart, entitled "**Unsafe Situations.**" Space the various situations down the length of the column.
2. Tell your patients it is **not their fault** that their partner gets angry or abusive, but it is important for their safety that they are able to identify the things that make their partner act in certain ways. Your patients deserve to be safe and respected, and together you can think of ways that your patients can protect themselves. Ask your patients to think of some methods of minimizing unsafe situations in the future.
3. Write each of these ideas in the "Safety Strategies" column on the right.

4. After your patients finish listing strategies that will reduce the harm of the unsafe events, ask them to draw arrows from the specific items in the left column to the strategies in the right column that could be of help.
5. Once the chart is filled in and the arrows are drawn, spend a few moments emphasizing how the patient's own ideas and strategies are empowering.

Note to PN: It is possible that the patient may mention the safest strategy would be to leave the relationship. This possibility should be thoroughly explored and the Personal Safety Plan tool can facilitate a deeper discussion of this topic.

Safety Strategies Flow Chart (discretionary)

Unsafe Situations	Safety Strategies

Conversation E: Personal Safety Plan

Objective: The objective of this conversation is to get your patients thinking about planning for potentially dangerous situations. The Personal Safety Plan will help your patients think of very concrete ways in which they can be prepared in the case of an emergency.

Note to PN: The Safety Plan is hidden in the back of the Care Coordination Workbook on page 82. Due to safety concerns, and to avoid the possibility of the tool being found by an abusive partner, **you may choose to remove it from the Care Coordination Workbook** and bring it back and forth to the patient's home to work on together. Use this tool as a discussion guide around possible safety strategies.

Say: I would like to introduce what a Safety Plan is. We are not going to fill out a personal safety plan at this time, but instead I'd like to go through it to introduce you to some safety strategies that may be useful in the future.

Say: Even if this "worst case scenario" planning doesn't feel necessary for you at this time, it is important to still review the material. You might have friends or relatives who could benefit from knowledge about safety planning.

Ask: How do you feel about that?

Say: Safety planning always involves the following:

- Learning information about your resources and rights
- Designing detailed plans to respond to threatening situations
- Creating support and connections that foster a sense of hope and empowerment
- Expanding what you are already doing to survive

Say: Safety planning is an ongoing process, while the unsafe relationship is taking place and after it is finished. A safety plan should address how to stay as safe as possible in a very difficult situation or dynamic.

Instructions to PN: Go through each of the steps in the tool and ask your patients for feedback about whether or not they could see each step being useful or relevant for their current relationship.

Ask: Are there specific steps in the Personal Safety Plan that you would like to spend more time discussing in the future?

Personal Safety Plan (1 of 3)

Step	Description	Personal Plan Notes
1	Develop an escape plan for the “worst case scenario” (e.g., make a code with neighbors to signal that they should call the police, ensure access to a phone, program phone to dial 911 or a family member for help, etc.)	
2	Identify “safe” people for support (e.g., family, friends, neighbors, health care providers, teachers, clergy, counselors, co-workers, etc.)	
3	Learn about legal rights and remedies and consider which options will help increase safety	See attached “List of Resources” The patients may wish to put some of these numbers in their cell phone (under a non- suspicious name)

Personal Safety Plan (2 of 3)

4	Identify local resources and consider which ones you might feel most comfortable accessing	See attached "List of Resources" The patient may wish to put some of these numbers in their cell phone (under a non- suspicious name)
5	Keep a bag packed with clothes and essentials, copy house and car keys and keep hidden if needed to leave quickly	
6	Put important documents and items of value in a safe place	<ul style="list-style-type: none"> • Identification • Birth Certificates • Social Security Cards • Passports, visas, work permits • School and medical records • Insurance cards/papers • Medication/prescriptions • Money, bankbooks, credit cards • Keys to house/car/office • Driver's license/car registration • Welfare information • Divorce papers • Lease/rental agreement, deed • Address book • Jewelry, sentimental items • Children's favorite toys/blankets • Photo albums, photo of abuser

Personal Safety Plan (3 of 3)

7	Attend a support group with individuals in similar situations	<i>See attached "List of Resources"</i> Patients may wish to put some of these numbers in their cell phone (under a non- suspicious name)
8	Gather as much information as possible to explore and create alternatives to the current situation	<i>See attached "List of Resources"</i> Patients may wish to put some of these numbers in their cell phone (under a non- suspicious name)

Conversation F: Additional Resources

Objective: The objective of this conversation is to let your patient know about the resources that are available to someone who might be in an abusive or otherwise unhealthy relationship.

Say: When you're in an unhealthy relationship, you will often feel alone and helpless. The reality is that there are actually many people who are experiencing and have experienced similar difficult situations. That doesn't make the situation any less serious, but it does mean that there are people who can help you and who understand some of what you are going through. There is a long list of resources that you can look through and call whenever you feel ready. I can also sit with you while you call or go with you to talk to someone who has experience with these kinds of difficult and sometimes dangerous situations.

Turn to Page 70 of the Care Coordination Workbook.

Instructions to PN: Go over the resources that are available for people in unsafe relationships in the Care Coordination Workbook. Your patient may not be ready to ask for help from any of these resources, but it is important that they know that they are not the only person who is experiencing this.

Wrap Up

Say: We've talked a lot about relationships today — things that are good and things that are sometimes harmful or dangerous in a relationship.

Ask: In your own words, what did you learn today?

Talk about strengths you saw in your patient during this session. Consider:

- Ability to talk about and share challenging issues
- Self-empowering strategies that the patient came up with for reducing the negative harms associated with being in a particular relationship
- Bravery in facing these unsafe aspects of their relationship

Ask: What's most important for me to know about you and what we talked about today?

Ask: What questions came up for you that we can review for next time?

*******DO NOT LEAVE ANY OF THIS INFORMATION WHERE A PARTNER MAY FIND IT AND RETALIATE AGAINST THE PATIENT FOR DISCUSSING THESE ISSUES! BE SURE TO TAKE THE COMPLETED TOOLS BACK TO THE OFFICE AND FILE THEM IN THE PATIENT'S CHART.*******

Resources

Health Care Provider			
	Care Coordination 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
	AIDS	National HIV/AIDS Treatment Hotline	800-822-7422
		National AIDS Information Clearinghouse	800-458-5231
		Gay Men’s Health Crisis Hotline	800-AIDS-NYC
		NIAID AIDS Clinical Trials	866-284-4107
Adult Education	NYC Department of Education, Office of Adult and Continuing Education	Bronx: 718-863-4057 Brooklyn: 718-638-2635 Manhattan/SI: 212-666-1919 Queens: 718-361-9480 Education Services: 718-557-2567 adulthoodnyc.org	
	City University of New York Division of Adult and Continuing Education	cuny.edu	

Resources

Domestic Violence and Sexual Assault Hotlines	Child Abuse and Maltreatment Register	800-342-3720
	National Domestic Violence Hotline	800-799-SAFE or 800-787-3224 (TDD)
	NYC Crime Victims Hotline	212-577-7777
	NYC/Safe Horizon Domestic Violence Hotline	800-621-HOPE (4673) 866-604-5350 (TDD) safehorizon.org
	NYC Elderly Crime Victims Resource Center	212-442-3103
	NYC Incest/Sexual Assault 24-Hour Hotline	212-267-7273
	NY State Coalition Against Domestic Violence Hotline	800-942-6906 (English) 800-818-0656 (English TDD) 800-942-6908 (Spanish) 800-780-7660 (Spanish TDD) nyscadv.org
	Safe Horizon Rape and Sexual Assault Hotline	212-227-3000
	Youthline (crisis intervention and service referral)	800-246-4646
	Events	The Positive Life Workshop (Information and support for people living with HIV)
Food and Nutrition	God's Love We Deliver	212-294-8102 or 800-747-2023 glwd.org
	Growing Up Healthy (Women and Children)	800-522-5006
	The Momentum Project	212-691-8100, x2121 themomentumproject.org
	Gay Men's Health Crisis	212-376-1263 gmhc.org
	La Nueva Esperanza	718-497-7592

Resources

Food and Nutrition	Bronx AIDS Services	718-295-5605 basnyc.org
	Iris House, a Center for Women Living with HIV, Inc.	646-548-0100 irishouse.org
	Harlem United Community AIDS Center	212-860-0820, x2644 harlemunited.org
	Project Hospitality	718-815-0800 projecthospitality.org
	Food Bank for New York City	212-566-7855 foodbanknyc.org
	Metropolitan Community Church of New York	212-629-7440 mccny.org
	HHC Health and Home Care, Behavioral Health Program	866-692-4663 (NY-B-HOME) homecarenyc.org
	HIV/AIDS Services Administration	212-971-0626
	New York State AIDS Institute, ADAP Plus	800-542-2437 health.ny.gov/diseases/aids/resources/adap/formulary.htm
	New York City Department for the Aging	nyc.gov/html/dfta
	New York State Department of Health	311 800-942-3858 health.state.ny.us
	New York City Human Resource Administration, Adult Protective Services	212-630-1853 or 311 nyc.gov/html/hra/html/services/adult.shtml
	Community Healthcare Network	866-CHN-8259 chnnyc.org

Resources

Food and Nutrition	New York State Office of Temporary and Disability Assistance	800-342-3009 otda.ny.gov
	Visiting Nurse Service of New York	212-609-1521 vnsny.org
Housing	African Services Committee	212-222-3882 africanservices.org
	AIDS Center of Queens County	718-896-2500 acqc.org
	The Ali Forney Center	212-222-3427 aliforneycenter.org
	The Bridge, Inc.	212-663-3000 thebridgeny.org
	Bridging Access to Care (Formerly Brooklyn AIDS Task Force)	718-596-3635, ext. 8 bac-ny.org
	Church Avenue Merchant's Block Association (CAMBA)	718-287-2600 camba.org
	Catholic Charities Neighborhood Services, Circle of Hope	718-338-4716 ccbq.org
	Catholic Charities Neighborhood Services, Casa Bethsaida	718-218-7890 ccbq.org
	CitiWide Harm Reduction Program, Inc.	718-292-7718 citiwidehr.org
	Bronxworks	718-365-0910 bronxworks.org
	Federation Employment Guidance Services	718-760-1205 fegs.org
	The Fortune Society	212-691-7554 fortunesociety.org

Resources

Housing	Gay Men’s Health Crisis Advocacy Helpline	212-367-1125 gmhc.org
	HASA Service Line	212-971-0626
	Haitian Centers Council, Inc.	718-940-2200 hccinc.org
	Harlem United Community AIDS Center	212-803-2850 harlemunited.org
	Housing Works, Inc.	877-296-9264 housingworks.org
	Institute for Community Living	212-385-3030 iclinc.net
	MTI Residential Services	718-492-1733
	The Osborne Association	718-707-2600, x2657 osborneny.org
	The Partnership for the Homeless	212-645-3444 partnershipforthehomeless.org
	Project Hospitality	718-448-1544 projecthospitality.org
	Safe Horizon	Bronx: 718-933-1000 Brooklyn: 718-834-6688 Manhattan: 212-316-2100 Queens: 718-899-1233 x100 Staten Island: 718-720-2591 safehorizon.org
	Services for the UnderServed	718-852-0587 sus.org

Resources

Job and Career Centers	Workforce 1 Career Center	Bronx: 718-960-2458 Bronx Hunts Point: 718-542-6777 Brooklyn: 718-246-5219/718-246-3973 (TDD) Manhattan: 917-493-7000 Queens: 718-557-6755 Staten Island: 718-285-8388
	Brooklyn Public Library, Education and Job Information Center	718-623-7000 brooklynpublib.org
	Church Avenue Merchants Block Association (CAMBA), Economic Development Program	718-287-2600/800-662-1220 (TDD) camba.org
	Catholic Charities Brooklyn and Queens, Neighborhood Services World of Work Program	Brooklyn: 718-758-9491 Queens: 718-779-1831 ccbq.org
	Goodwill Employment Support and Training	Bronx: 718-401-2555 Brooklyn: 718-372-0450 Queens: 718-777-6345
	Chinese-American Planning Council, Inc., Employment and Training Division	212-941-0041 cpc-nyc.org
	Federation Employment Guidance Services, Employment Services	212-524-1790 fegs.org
	New York City Housing Authority, Resident Employment Services	718-289-8100 nyc.gov/html/nycha
	New York State Education Department, Adult Career and Continuing Education Services-Vocational Rehabilitation	Bronx: 718-931-3500 Brooklyn: 718-722-6700, 718-722-6736 (TDD) Manhattan: 212-630-2300 or 2302 Queens: 347-510-3100, 718-760-8835 (TDD) Staten Island: 718-816-4800 vesid.nysed.gov
	New York State Department of Labor, Division of Employment and Workforce Solutions	Bronx: 718-960-7901 Brooklyn: 718-780-9200 Manhattan: 917-493-7200/212-775-3771 labor.state.ny.us

Resources

	StreetWise Partners, Inc.	646-705-0029 streetwisepartners.org
	Dress for Success Worldwide (low-income women)	212-532-1922 dressforsuccess.org
	New York City Department of Youth and Community Development (under 21)	800-246-4646 nyc.gov/html/dycd
	US Department of Labor, Occupation Information Network	online.onetcenter.org/find
	State University of New York Educational Opportunity Center	Bronx: 718-530-7000 brx.eoc.suny.edu Brooklyn: 718-488-9843 bkl.eoc.suny.edu Manhattan: 212-961-4320 man.eoc.suny.edu North Bronx: 718-547-1001 nbx.eoc.suny.edu Queens: 718-725-3300 qns.eoc.suny.edu
Legal Services	African Services Committee, Inc.	212-222-3882 africanservices.org
	AIDS Center of Queens County, Inc.	718-896-2500 acqc.org
	Bronx AIDS Services, Inc.	718-295-5605 basnyc.org
	The Family Center, Inc.	212-766-4522 x113 thefamilycenter.org
	Gay Men's Health Crisis, Inc.	212-367-1040 gmhc.org
	HIV Law Project, Inc.	212-577-3001 hivlawproject.org

Resources

Legal Services	Legal Aid Society, HIV/AIDS Representation Project	212-426-3000 legal-aid.org
	Manhattan Legal Services	212-348-7449 legalservicesnyc.org
	New York Council on Adoptable Children, Inc.	212-475-0222 coac.org
	Project Hospitality, Inc.	718-720-8172 projecthospitality.org
	South Brooklyn Legal Services, Inc.	718-237-5500 sbls.org
Mental Health Services	AIDS Center of Queens County (Rego Park)	212-896-2500 acqc.org
	Community Counseling and Mediation (Prospect Heights)	718-935-9201
	Gay Men's Health Crisis, Inc.	212-367-1165 gmhc.org
	Haitian Centers Council	718-221-9640 hccinc.org
	Harlem United Community AIDS Center	212-803-2850 x2383 harlemunited.org
	Henry Street Settlement (Lower East Side)	212-233-5032 henrystreet.org
	HHC Harlem Hospital	212-939-1000
	Community Healthcare Network	866-CHN-8259 chnnyc.org
	HHC Woodhull Medical and Mental Health Center (Bushwick/Bedford)	718-963-8033
Mental Health Providers	Housing Works, Inc.	212-966-0466, x1141 housingworks.org

Resources

Mental Health Providers	Institute for Community Living, FOCUS Program (Bedford Stuyvesant)	212-385-3030 iclinc.net
	New York Presbyterian Hospital, Pediatric Special Needs Clinic (Washington Heights)	212-305-9099
	Project Hospitality, Inc. (Staten Island)	718-876-7716, x234 projecthospitality.org
	Salvation Army (Belmont)	718-329-5410
	Sunset Park Family Health Center Network of Lutheran Medical Center (Achieve Clinic)	718-437-5280
Post-Incarceration Services	Exponents	212-463-8180 exponents.org
	The Fortune Society	212-691-7554 fortunesociety.org
	Women's Prison Association	212-292-7741 wpaonline.org
STD Clinics	Bushwick	335 Central Avenue (between Linden and Grove Streets)
	Central Harlem	2238 Fifth Avenue (137th Street)
	Chelsea	303 Ninth Avenue (28th Street)
	Corona	34-33 Junction Blvd. (Roosevelt/Northern)
	East Harlem	158 East 115th Street (off Lexington Avenue)
	Fort Greene	295 Flatbush Avenue Extension
	Jamaica	90-37 Parsons Boulevard, 1st Flr. (off Jamaica Avenue)
	Morrisania	1309 Fulton Ave (E. 169th Street off 3rd)
	Riverside	160 West 100th Street (between Columbus and Amsterdam)
	Staten Island	51 Stuyvesant Place (St. George)

Resources

STD Clinics	Test Results Line	347-396-7959 (in NYC) 877-364-8191 (outside NYC)
	Substance Use (General)	
	Alcoholics Anonymous	212-647-1680 nyintergroup.org
	Narcotics Anonymous	212-929-6262 na.org
	National Clearinghouse for Alcohol and Drug Information	800-729-6686 samhsa.gov
	National Council on Alcoholism and Drug Dependence	800-NCA-CALL (800-622-2255) ncadd.org
	New York City Al-Anon	212-941-0094 nycalanon.org
	New York City Crisis Intervention and Referral Services	800-LIFENET (800-543-3638) 877-AYUDESE (877-298-3373)
	NYC Smoking Cessation Programs	311 nyc.gov/health
Substance Use (Harm Reduction)	AIDS Center of Queens County	718-739-2525, x6564 acqc.org
	AIDS Service Center of Lower Manhattan	212-645-0875, x342 ascnyc.org
	Beth Israel Medical Center (Women's Project)	212-420-2326
	The Bridge, Inc.	212-663-3000 thebridgeny.org
	Bridging Access to Care (Formerly Brooklyn AIDS Task Force)	718-596-3635 bac-ny.org

Resources

Substance Use (Harm Reduction)	Callen-Lorde Community Health Center	212-271-7200 callen-lorde.org
	CitiWide Harm Reduction Program	718-292-7718, x225 citiwidehr.org
	Bronxworks The Living Room	718-893-3606 bronxworks.org
	Center for Community Alternatives	Crossroads for Men: 718-858-9658, x206 Crossroads for Women: 212-691-1911 communityalternatives.org
	Exponents	212-463-8180 exponents.org
	FROST'D	212-924-3733 frostd.org
	Gay Men's Health Crisis, Women in Action Harm Reduction Program	212-367-1357 gmhc.org
	Gay Men's Health Crisis, Positive Prevention (women)	212-367-1325 gmhc.org
	Gay Men's Health Crisis, Team 119 Mental Health and Group Services	212-367-1165 email: team119@gmhc.org
	Harlem United Community AIDS Center	212-531-1300 harlemunited.org
	Heritage Health and Housing	212-690-0195 heritagenyc.org
	HHC Bellevue Hospital Center (Virology Clinic)	212-562-4038
	HHC Harlem Hospital Center	212-939-3701
	HHC Metropolitan Hospital Center	212-423-6262
HHC North Central Bronx Hospital Center	718-519-3305	

Resources

Substance Use (Harm Reduction)	HHC Queens Hospital Center	718-883-4975
	Iris House	646-548-0100, x243 irishouse.org
	Lower East Side Harm Reduction Center	212-226-6333, x139 leshrc.org
	Planned Parenthood of New York City (Project Street Beat)	212-965-4823 ppnyc.org
	Project Hospitality	718-876-7716, x315 projecthospitality.org
	Safe Horizon (Youth Streetwork Project)	212-695-2220, x1 safehorizon.org
	Tolentine Zeiser Community Life Center	718-364-7650 tzclc.org
	United Bronx Parents, Inc.	718-617-6060 ubpinc.org
	William F. Ryan Community Health Center	Upper West Side: 212-749-1820 Lower East Side: 212-477-8500 Midtown West: 212-265-4500 ryancenter.org
Counseling and Family Services	African Services Committee	212-222-3882 africanservices.org
	Church Avenue Merchants Block Association (CAMBA)	718-287-2600 camba.org
	New York Coalition on Adoptable Children	212-475-0222 coac.org
	Project Hospitality	718-876-7716 projecthospitality.org
	Research Foundation of State University of New York (Star Center)	718-270-3745
	The Family Center	212-766-4522 thefamilycenter.org

Topic 15: Healthy Living – Diet and Exercise

Learning objectives

After completing this topic, patients should be able to:

- Understand basic principles of good nutrition and food safety
- Explain why diet and exercise are important for patients living with HIV
- Discuss at least four changes they can make to improve their diet and increase exercise

Preparation

- Bring Care Coordination Workbook.
- Review your notes on this patient from the last topic you completed together, and identify any areas of confusion that need review.
- Review conversations and PN instructions for this topic.

Topic Overview

Conversation	Materials & Tools
Review last conversation completed	
A: Healthy eating knowledge and behavior assessment	Dietary Tool (Wkbk. page 58)
B: Why does eating healthy matter for people living with HIV?	Discussion Guide: Managing HIV symptoms and ART side effects (FG page 269)
C: Principles of Good Nutrition and Exercise	<ul style="list-style-type: none"> • Dietary Tool (Wkbk. page 58) • (Wkbk. page 65)
D: Barriers to Healthy Eating and Potential Solutions	<ul style="list-style-type: none"> • Discussion Guide: A Healthy Diet Doesn't Have to be Expensive (FG page 281) • Local Food Resources (Wkbk. page 61)
E: Food Safety	Discussion Guide: Six Techniques to Avoid Food Poisoning (FG page 289)
F: Setting Healthy Eating Goals	<ul style="list-style-type: none"> • Scratch paper • Dietary Tool (Wkbk. page 58)
Wrap Up	

Review

“Let’s go over what we talked about last time.”

Review any areas that were particularly challenging for your patient during your last session together.

Ask your patient to:

1. Demonstrate a skill that was learned from last session’s discussion;
2. Explain one of the key points from that session.

Information for PN: The focus of this topic is the importance of healthy eating and exercise for individuals living with HIV. First, the patient and the PN will discuss what the patient knows about nutrition and the patient’s current diet. Next, the PN will share principles of good nutrition with the patient. Then, the PN will incorporate those basic principles into a conversation about how diet and exercise can help the patient feel better, be healthier, and better manage symptoms associated with HIV. The patient and PN will then review food safety practices. At the end of this topic, the patient will make a plan to implement a few small diet and exercise changes.

Note to PN: Although there are basic ideas about nutrition and food safety that you should introduce, the interests of the patients should guide the conversations. Your patients will be much more likely to remember information about what they are interested in. This topic requires multiple sessions as there is a lot of information to discuss and quite a bit of work to do.

Conversation A: Healthy Eating Knowledge and Behavior Assessment

Objective: The objective of this conversation is to obtain information about your patient's eating habits and understanding of healthy eating.

Say: Today we will talk about healthy eating, something that we all struggle with. Healthy eating is good, whether you have HIV or not. This is something we know but that is often hard to do. We all struggle to follow a healthy diet, and I am here to help you meet goals that are important to you.

Knowledge Assessment

Say: What comes to mind when you hear “healthy eating”? or What does it mean to you to eat healthy?

If no answer, ask: Tell me about three food items that are healthy or that everyone should eat to be healthy.

Rephrase to check for understanding: So, to you, healthy eating means... [repeat or rephrase patient's answer].

Feedback: Many health specialists say healthy eating means eating a mix of foods that help us live well and feel good. This usually means eating more fruits and vegetables, better kinds of fats, less sugar, and more whole grains.

Say: You just told me that healthy eating is... [fill in what patient said earlier]. Thinking about that, where does the way you usually eat rank on a scale of one to five, with one being very unhealthy and five being very healthy?

After the patient responds, ask why the number is not lower or higher. For example,

Ask: What would it take for it to be 5 instead of 4? Why is it a 4 and not a 3?

Behavior Assessment

Turn to Page 58 of Care Coordination Workbook: Your Daily Diet.

Ask: Think back to yesterday morning; what was the first thing you had to eat? How about for the rest of the day? Describe all of the foods and beverages (including snacks) you ate yesterday.

If patient has difficulty remembering,

Ask: What foods do you like to eat or what do you generally eat during the day?

Note to PN: Be sure to find out as much information as you can about the food your patient mentions. For example, if your patient says he ate pizza, then ask, "What was on the pizza?" The nutritious value of a vegetable pizza with a whole-wheat crust is much different than a pepperoni pizza on white crust.

Record patient's responses in the Daily Diet.

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		

Feedback: It looks like you eat [a lot/ a little] of foods that are [healthy/ not healthy]. Eating a healthy diet doesn't mean you can never have something that is a little unhealthy. Most health specialists say that as long as you eat healthy foods most of the time, it's okay if you eat something less healthy once in a while. So, a midnight ice cream or a take-out burger once or twice a month is probably fine if you're eating healthy foods the rest of the time. It's nice to know we don't have to completely give up the foods we love, even if they are unhealthy.

Say: Let's talk more about what healthy eating means (either now or next time).

Conversation B: Why Does Eating Healthy Matter for People Living with HIV?

Objective: The objective of this conversation is to help your patient understand that healthy eating can help them feel better and be better able to fight HIV, while unhealthy eating can make it harder for their body to fight HIV.

Say: Let's talk about how a person's diet can affect their health.

Ask: What do you think is the point of eating? Why do we have to eat to stay alive?

Complete what your patient said by emphasizing: Eating food **nourishes** our body. It allows us to build muscle, skin, and bone. It gives us the **energy** to allow our heart to beat, our brain to think, our lungs to breath, our immune system to work. Food is the **fuel** that allows all of the different parts of us to work.

Say: Many people's diets are based on things that the body doesn't use as nourishment or energy; instead, these are toxins that have to be eliminated.

Ask: What are some of the things that people eat that don't actually nourish the body?

Check for understanding: So you think that [fill in what patient said] might not be helpful to the body; is that right?

Fill in gaps in understanding: Many foods have unhealthy sugars and fats in them that do not provide nourishment to the body. For example, [point out some examples of overly sweet, or fattening

foods based on what the patient mentioned in the 24-Hour Dietary Recall].

Explain: Some fats and some sugars are okay to eat, like sugars in fruits or fats in vegetable oils. But if you eat **too much** sugar or fat, or types of fats and sugars that are not healthy, then the body does not recognize it as nourishment.

Explain: If the immune system is busy dealing with substances like sugars and unhealthy fats, then the body has to use valuable energy that could be used elsewhere in its fight against HIV.

Ask: How might eating healthily help people build a stronger immune system?

Explain: **Healthy eating** and **exercise** make the body stronger and can give a person more energy. These things also give the **immune system** more energy.

Say: Being healthy doesn't just involve medications. Good nutrition is essential to make the medications work.

Explain: If you don't get enough nourishing food, your body doesn't have enough energy to build a strong immune system. The reason is because when the body is not getting enough nutritious food, it uses the healthy food it does get to fuel important functions like making your heart beat and your lungs breathe. This means that if you don't eat enough nutritious food, there is less fuel for your immune system to fight the HIV.

Say: A sick body needs even more nutrition than a healthy body in order to recover. Think about how hungry you usually are just after you've been sick and lost weight.

Say: For people living with HIV, healthy eating along with exercise is one of the main ways to avoid future health problems.

Say: Good nutrition gives your body energy and keeps your immune system stronger with more energy to fight the HIV. Good nutrition also helps the body process the medications for HIV and deal with their side effects, such as diarrhea, nausea, and fatigue. What a person eats can also help them cope with symptoms of HIV, such as weight loss and fatigue. Do you experience any of these symptoms?

Go over the relevant sections of the Managing HIV symptoms and ART side effects discussion guide on the next page.

Discussion Guide: Managing HIV symptoms and ART side effects

Considering your patient's needs and interests, review the following tips:

If your patient does not feel like eating:

- Emphasize that it is important to eat to maintain weight.
- Eat small meals or snacks every 1-2 hours.
- Eat with friends or family to make eating more fun.
- Use home delivery meal services if available.
- Talk to your doctor or nutritionist about medications or foods that might help increase your appetite.

Diarrhea

- Keep eating and eat even more calories than normal! Your body needs food in order to have enough energy to fight the diarrhea.
- Keep drinking fluids, especially sports drinks like Gatorade, juice, broth or a mix of sugar, salt and water. (Take an empty 1 liter container, fill with water to the brim, add 8 level teaspoons of sugar and ½ level teaspoon salt, mix and drink).
- Eating white bread, oatmeal, white rice (including the water the rice is cooked in also helps), bananas and applesauce can slow diarrhea by absorbing the water not being absorbed by the body.
- Avoid raw fruits and vegetables, fruit and vegetable skin, whole wheat bread, brown rice and dairy products. (**Note:** Normally, it is much better to eat whole wheat bread and brown rice and to avoid white bread and white rice. Try to eat fruit and vegetable skins because this is often where the most vitamins and nutrients are located. But, if you have diarrhea, it is a special exception!)
- Avoid greasy or spicy foods such as fried foods, fast food, salad dressings, desserts.
- Increase foods high in salt.
- Increase foods high in potassium such as baked potatoes, cooked spinach, bananas, raisins and other dried fruits.
- Eat small meals and snacks. Larger meals and snacks might make the diarrhea worse.
- Decrease caffeine (coffee, caffeinated tea, soda).

- If diarrhea is a side effect of taking antibiotics, it might help to try taking “probiotics.” These are the good bacteria normally found in the gut that antibiotics tend to kill. You can get them by eating yogurt or miso soup. You can also buy a probiotics supplement at pharmacies and some grocery stores.
- In some cases, a nutritional supplement like L-glutamine or calcium carbonate may help reduce diarrhea. Talk to your doctor about medications that might help reduce diarrhea.

Fatigue

- Eating more vegetables and whole grains and less fat and sugar can give you more energy.
- Limit caffeine. When caffeine wears off, it often makes you feel more tired than normal.
- Keep food around all day so you make sure that you eat.
- Try to exercise regularly. Forcing your body to move can often give you more energy.
- Check with your doctor if you are feeling fatigued for a long time.

Nausea

- Eat something small every 1-2 hours.
- Eat bland, low-fat foods such as bananas, rice, oatmeal, ginger ale or plain pasta. Also salty or starchy foods such as canned tuna/chicken or baked potatoes.
- Avoid fatty, greasy or fried foods, very sweet or spicy foods and foods with strong smells.
- Avoid lying down flat after eating.

Note to PN: Your patients might also mention body image issues, particularly around how HIV has changed and impacted their body. Make sure that if body image is an issue that your patients discuss it with their doctor.

Conversation C: Principles of Good Nutrition and Exercise

Objective: The objective of this conversation is to help your patient understand basic principles of good nutrition and exercise.

Turn to Page 65 of Care Coordination Workbook: Food Plate.

Say: Let's talk about some of the ways you can improve your diet and take better care of your body.

Refer to the Food Plate to point out the foods that are healthy to eat a lot of and those that should be eaten sparingly.

Point out: **Exercise** is a key to good health.

Ask your patient: Why is **exercise** the foundation of a healthy diet?

Explain: **A healthy diet is built on a base of regular exercise, which keeps calories in balance and weight in check.** Exercise also stimulates the immune system so that the immune system has more energy to fight HIV. Exercise can help stabilize or prevent declines in CD4 count. It also controls stress, improves most people's moods, and can help improve your energy level so you feel less tired. Any activity is better than none, and more is usually better.

Turn to Page 58 of Care Coordination Workbook: Your Daily Diet.

Instructions to PN: Look at the foods your patient listed in the Daily Diet as you talk about the concrete ways that following healthy eating could fit into your patient's diet.

1. Eat more fruits and vegetables (ideally at least 9 servings each day!).

Explain: Eat a rainbow of fruits and vegetables (red, orange, yellow, dark green, blue, and purple) to get all the benefits that fruits and vegetables offer. Each color has different nutrients in it, and we need all of those nutrients to stay healthy. Potatoes don't count. Tomatoes have more vitamins when they are cooked.

Ask: Can you think of fruits and vegetables from each color?

Ask: Where could you add more colorful fruits and vegetables into meals?

Ask: Do fresh, frozen, canned or dried fruits and vegetables have the highest nutrient quantity? Or are they all the same?

Fill in gaps in understanding: Generally, frozen fruits and vegetables are as nutritious as fresh fruits and vegetables because they are frozen soon after they are harvested, and freezing locks in many vitamins and minerals. Fresh vegetables are also high in vitamins and minerals, and the fresher the more nutritious they are. Canned vegetables and fruits lose a lot of their nutritious value during the canning process. They also often have salt or sugar added. If you have to eat canned fruits and vegetables, look for ones with no salt or sugar added.

2. Try to eat whole grains whenever possible.

Explain: Brown rice, whole-grain/multi-grain bread and whole-wheat pasta are healthier choices than white rice, white bread and regular pasta. They have more nutrients and fewer sugars than white products.

Ask: Do you ever eat “the browns” instead of “the whites”? How do you eat them? Are there ways you can build more of the browns into your diet?

Ask: Where could you add more browns into meals?

Remind the patient: White rice that is yellow or orange from spices is not healthier! It has to say “brown rice” to get those vitamins. You can then add spices to brown rice if you choose.

3. Choose healthy fats, limit saturated fat, and avoid trans fat.

Say: Eating a **little** fat is actually good for you, but there are several different kinds of fats. Some fats are healthy **in small amounts**. Other fats can be very harmful. If we eat too much of any fats then we overwhelm the body and it takes extra energy to digest them. This is energy that could otherwise fight HIV!

Ask: What kinds of oils and fats do you normally eat? [Look at the Daily Diet together and help your patient identify the fats.]

Explain: Plant oils, fish, and uncooked nuts and seeds are the healthiest sources of fat. Any oils that are solid at room temperature, like butter, lard, Crisco or shortening, cheese and other types of animal fat, are not healthy sources of fat.

Say: You don't have to cut fats out of your diet altogether. Just switching the fats you use can make a huge difference. For example, instead of butter, cook with vegetable oil. Plant fats are usually best. The only plant-based fats you have to watch out for are tropical oils like coconut oil/coconut butter or coconut milk and Palm oil because they are solid or semi-solid at room temperature and have a lot of saturated fat. **But all fats, even those that are liquid at room temperature, should be eaten in small amounts.**

Ask: Why do you think we should reduce fats that are solid or semi-solid at room temperature?

Fill in gaps in understanding: If fats are solid or semi-solid at room temperature, they are more likely to build up in our arteries and make us sick.

Ask: Do you know what the worst kind of fat is?

Fill in gaps in Understanding: **Trans fat** is an artificial fat that is dangerous to eat. It is illegal for restaurants to serve it in New York City. The FDA requires food manufacturers to list trans fats on Nutrition Facts and some Supplemental Facts panels, so you can look on food labels at the grocery store to see if there is any trans fat in the food before you buy it. Also avoid food that contains ingredients that say "**partially hydrogenated**," since this means the same thing as trans fat.

Ask: Can I look in your pantry and use some examples of different foods you have to show you how to compare the different kinds of fats?

Instructions to PN: If possible, select a food item that is high in saturated fat, one that is low in saturated fat but has some unsaturated fat, and an item containing trans fat. Show the patient how to recognize different types of fat on the food labels and answer any questions they have.

4. Get enough calcium in your diet.

Ask: What are some good sources of calcium?

Fill in gaps in understanding: Milk isn't the best source of calcium. Good sources of calcium include collard greens, broccoli, bok choy, fortified soy milk, baked beans and supplements. If you eat or drink dairy products, low or nonfat is best since the fat in dairy products is solid at room temperature.

5. Choose lean proteins such as fish, skinless poultry, nuts and beans.

Ask: Do you eat meat? Or what kinds of meat do you normally eat?

Explain: If you eat red meat, you might consider eating less of it or choosing extra-lean pork and beef. A lot of the same nutrients you get in meat are available in beans, and beans are usually healthier and less expensive than meat. Fish and poultry are also better options.

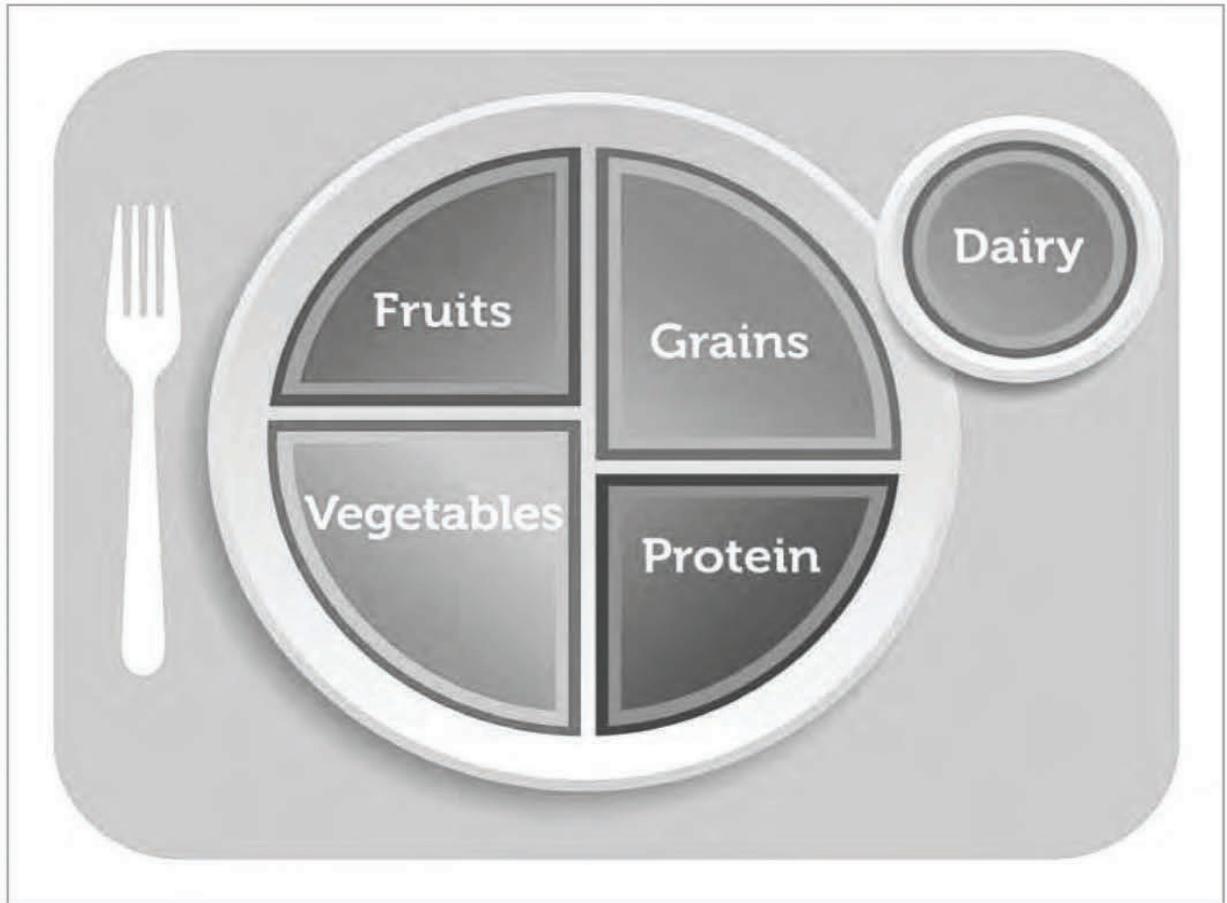
Ask: Looking at the 24-Hour Dietary Recall, where could you replace pork and beef with extra-lean pork and beef or with fish, poultry or beans?

6. Limit sugar, sweets, soft drinks, sugary drinks and juices, and junk food.

Say: These “empty calories” foods fill you up but do not give you any nutrients.

Explain: This does not mean that you can never have treats or junk food. It should be a “sometimes” food and never an entire meal or snack.

Food Plate



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

Conversation D: Barriers to Healthy Eating and Potential Solutions

Objective: The objectives of this conversation are to assess patient's barriers to healthy eating and to develop solutions to facilitate healthy eating.

Note to PN: Access to healthy food is a **human right**. Nobody should have to eat unhealthy food just because they don't have enough money to buy healthier options. There are state, federal, and community programs that exist to help people buy healthy food. You can connect your patient to these programs. Even so, it can still be very hard to eat healthy food, especially in the inner city where there are lots of fast food restaurants and few grocery stores that sell affordable fruits and vegetables. This conversation introduces some strategies for eating healthy without spending a lot of money.

Say: For the most part, we know what we need to do in order to eat healthy, but there are lots of things that make it difficult to do. Eating healthy is hard and eating healthy on a budget can be even harder.

Ask: Do you find that eating healthy is hard for you? What are some of the difficulties you experience as you try to eat healthy?

Ask: Which problems/difficulties are the ones you need the most help with?

Suggestions for overcoming barriers to healthy eating:
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PN Note: Below is a list of common difficulties and potential solutions. Go over the ones that address the obstacles mentioned by your patient.

If your patient doesn't mention any obstacles:

Say: Some patients experience difficulties in eating healthy food because...[list some of the things below].

Lack of time, limited cooking skills or not interested in preparing healthy meals

Advice

- A good way to address this problem is planning meals and cooking in advance.
- Find friends or relatives who like to cook and ask them to help you on the weekend to prepare meals for the week – use this time as social time, too.
- Make cooking a family activity.

Fear of judgment or rejection by peers

Advice

- Find a buddy with the same goals who can support you as you make changes together.
- Tell judgmental peers that you are concerned about your health.
- Role play situations listed above.

Veggies/Fruits spoil before I eat them

Advice

- Teach patients about freezing.
- Make soup or a cooked dish for the week that uses the produce at risk for spoiling.
- Make sure patient has working refrigerator and adequate electricity. Refer to utility assistance if necessary.

Family likes to eat other things

Advice

- Remember that healthy food is good for everyone, so everyone benefits from eating healthy.
- Replace family favorites with acceptable alternatives (like chicken nuggets with baked chicken, regular soda with diet soda, etc.).

- Prepare “unhealthy” favorite foods only on special occasions, like birthdays or other celebrations.
 - Make cooking a family activity.
 - Do NOT make shopping a family activity (so as to avoid struggles in the cereal/candy aisle).
- **Stores in the neighborhood do not carry healthy foods.**
- **Advice**
 - Find stores in nearby neighborhoods that carry healthy foods and are affordable.
 - Figure out how to get there.
 - Consider finding or purchasing a basket on a wheels that can be filled with grocery store food and transported easily on public transportation.
 - Think beyond the supermarket. Consider farmers’ markets, ethnic food stores, co-ops or food stands.
 - Consider shopping at more than one store. For example, the cheapest rice might be available at a local ethnic food store but the cheapest vegetables might be available at a farmers’ market.
- **High cost of healthy food**
- **Advice**
 - Offer suggestions of less expensive and better quality food; use the **“A Healthy Diet Doesn’t Have to be Expensive” discussion guide** on the next page to facilitate a conversation about this.
 - Assess if patient is eligible for food stamps. Refer if necessary, using the **Food Resource guide on page 61 of the Care Coordination Workbook.**
 - Assess if patient is using local food pantries and other community food resources. Refer if necessary, using **the Food Resource guide on page 61 of the Care Coordination Workbook.**
 - Accompany the patient to the market if patient needs extra help or does not read.

Discussion Guide: A Healthy Diet Doesn't Have to be Expensive

Discuss the following tips and strategies for healthy eating on a budget:

Shopping

- **Shop the outside aisles of the store first** where you'll find the basics for a healthful diet (produce, meats and dairy) instead of stacking your cart with junk food.
- **Look beyond the supermarket** – You may find cheaper healthy foods at farmers' markets, ethnic food stores, co-ops, food stands and other specialty places.
- **Look at what you pay for how much you get** – Figure out how much the food costs per ounce. Compare costs between brands and different sized packages. Choose the cheaper variety!
- **Choose generic or store brand** whenever possible, for example store brand ketchup instead of Heinz ketchup... Generic often has the exact same ingredients but is less expensive. Check higher or lower shelves for cheaper items because more expensive items are at eye-level.
- **When buying canned foods**, choose fruits packed in juice and vegetables, beans, soups and other products labeled "low sodium" or "sodium free." Try to buy less canned food. Canned foods are less nutritious and often more expensive than fresh, frozen or dried foods.
- **Look for older food** – Fruits and vegetables closer to expiration may be marked down and offer a good value for money.

Buying Produce

- Always shop for produce that's in season for the best flavor and prices. Tomatoes, for example, can be very expensive in the winter but affordable in the summer, while collard greens and oranges are usually cheaper in the winter and more expensive in the summer. In season items are front and center at the grocery store. Ask somebody who works at the store what is in season if you are unsure.
- Compare frozen and fresh produce; buy the cheaper variety; they are equally nutritious.
- One of the cheapest ways to eat healthy is to grow your own food, especially vegetables and herbs.
- Buy apples, oranges, grapefruit, potatoes, onions, etc. by the bag, not by the piece — it's often cheaper and will cover more meals.
- Buy produce in bulk and wash and freeze it right away so you can use it for months. You could also cook with it and then freeze it. You can freeze most fruits and vegetables. If you want to freeze oranges, consider peeling them and separating the sections first.
- Look for produce on sale; usually a different fruit is on sale each week at most supermarkets.
- Leave skins on potatoes, sweet potatoes, apples, beets and most other produce. The skin is often the most nutritious part of the fruit or vegetable. Eat the greens on beets, yams, sweet potatoes, and other roots. They are sometimes more nutritious than the root!
- Avoid buying bagged/washed/chopped lettuce, cabbage and carrots; it costs more but you get less.

Buying Meat and Protein

- Base more meals on beans, rather than meats. Meats are expensive, and only healthy in small amounts. Beans are cheap, tasty, and very good for you.
- Buy cereals, grains and beans in bulk to store in airtight containers. Ask somebody who works at the store if they sell grains in bulk if you are unsure.
- Ready-to-cook meats are more expensive (e.g., marinated boneless, skinless chicken). Buy plain and skin/season yourself.
- Buy 90% lean ground beef instead of 95% lean since it's cheaper; just make sure to drain the extra fat after cooking.
- Use canned fish and chicken for sandwiches, enchiladas, casseroles and salads.
- Ask for the end cuts of meat, which are usually less expensive but just as good especially for soups and sauces.

Buying Grains

- Oatmeal is nutritious, economical and can be dressed up with fresh fruit like bananas.
- Check out day old breads (a great value and still fresh).
- Whether you use a warehouse club like Costco, your regular supermarket, an ethnic food store, or a co-op, you may be able to buy cheaper (and healthier) in bulk. Buying bulk is especially good for grains, legumes, beans and other healthy foods.
- Eat more grains, legumes, fruits And vegetables—they're more filling and less expensive than meats and dairy. If you want to have meat or dairy, decrease the portion and add more of the above. Make $\frac{1}{2}$ your plate veggies, $\frac{1}{4}$ grains, and $\frac{1}{4}$ meat/protein.

Buying Dairy

- Soy milk, rice milk, or almond milk can be cheaper than cow's milk.
- Used dried milk powder for recipes (it's cheaper), use fluid for drinking.
- Choose skim or 1% dairy products.
- Buy block cheese and shred it yourself for recipes (versus pre-shredded which is more expensive).

Cooking and meal planning tips

- Eat out less often. Eating out, especially for fast food, is often unhealthy and it can be expensive. (Spending \$5 a day on a "value meal" for lunch adds up to more than \$1,200 per year!)
- Cook extra portions of soups, stews, chili, sauce, etc., to stretch your food dollars further and save some for later... make a big meal and freeze into smaller portions! This also makes it easy to eat a healthy meal later.
- As a general rule, making things from scratch is less expensive and healthier than eating processed foods.
- Avoid Shortcut Foods – Sure, it may just be easier to buy microwave popcorn or bottled iced tea, but you'll save a lot more money if you make your own from scratch.
- Keep a bag or a few bags of frozen vegetables to add to rice or any meal.
- Turn food waste it into something the next day instead of throwing it away. For example, try making vegetable scraps into a broth that can be frozen and used in recipes later.
- Drink less soda, juice and sugary beverages; drink more water — tap water is just as good as bottled water, and it's free. Keep a pitcher of tap water in your refrigerator so you can have a glass of cold water whenever you'd like. Use reusable plastic or stainless steel bottles to bring water with you to work or when you are out.

See: <http://www.thedietchannel.com/Meal-Planning-Healthy-Eating-on-a-Budget.htm>

Local Food Resources Guide

- To apply for food stamps (Supplemental Nutrition Assistance Program/SNAP) in New York City:
<http://www.nyc.gov/html/hra/html/services/snap.shtml>
- **To apply for SNAP/EBT in person or get assistance on a SNAP application: Centers are all open Monday – Friday 8:30 a.m. – 5 p.m. The ones marked with an asterisk stay open until 6 p.m. daily and are also open on Saturday from 9 a.m. – 5 p.m.**

<p><u>Brooklyn</u></p> <p>Coney Island 2865 West 8th Street 1st Floor Brooklyn, New York 11224 718-265-5621 718-265-5612</p> <p>East New York 404 Pine Street 1st Floor Brooklyn, New York 11208 718-827-3961 718-827-3444</p> <p>Ft. Greene 275 Bergen Street 1st Floor Brooklyn, NY 11217 718-473-8510 718-694-8196 Mon. - Fri. 8:30 - 6 pm Saturdays 9:00 am - 5 pm</p> <p>North Brooklyn 500 Dekalb Avenue 5th Floor Brooklyn, NY 11205 718-398-5057 718-636-7046</p>	<p>Williamsburg 30 Thornton Street 4th Floor Brooklyn, NY 11206 718-963-5115 718-963-5140</p> <p><u>Bronx</u></p> <p>Concourse* 1375 Jerome Avenue 2nd Floor Bronx, NY 10452 Mon. - Fri. 8:30 am to 6:00 pm Sat 9:00 am to 5:00 pm 718-637-2401 718-590-7235</p> <p>Crotona 1910 Monterey Avenue 5th Floor Bronx, NY 10457 718-901-0287 718-901-5459</p> <p>Melrose 260 East 161 Street 4th Floor Bronx, NY 10451 718-664-1607 718-664-2175</p>
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Manhattan

East End

2322 Third Avenue
3rd Floor
New York, NY 10035
(212) 860-5159
(212) 860-5147

Washington Heights

4055 10th Avenue
Lower Level
New York, NY 10034
(212) 569-9829
(212) 569-9835

St. Nicholas

132 W. 125th Street
3rd Floor
New York, NY 10027
(212) 666-1434
(212) 666-8788

Waverly*

12 West 14th Street
4th Floor
New York, NY 10011
Mon., Wed., Thur.,
Fri. 8:30 a.m. to 6:00 p.m.
Tues. 8:30 a.m. to 6:00 p.m.
Saturdays 9:00 a.m. to 5 :00 p.m.
(212) 352-2519
(212) 352-2524

Queens

Long Island City

32-20 Northern Blvd.
4th Floor
LIC, NY 11101
(718) 784-6123
(718) 784-6315

Jamaica*

165-08 88th St. Nicholas
132 W. 125th Street
3rd Floor
New York, NY 10027
(212) 666-1434
(212) 666-8788

Rockaway

219 Beach 59th St.
1st Floor
Rockaway, NY 11692
(718) 637-2754
(718) 637-2750

Staten Island

Richmond*

201 Bay Street
1st Floor
Staten Island, NY 10301
Mon. - Fri. 8:30 a.m. – 6:00 p.m.
Saturdays 9:00 a.m. – 5:00 p.m.
(718) 390-6827
(718) 390-6994

**To apply for WIC (Women, Infants
and Children):**

Call 1-800-522-5006

Food Programs for People Living with HIV/AIDS in New York City

God's Love We Deliver

www.glwd.org

166 Avenue of the Americas

New York, NY 10013

(212) 294-8102 or (800) 747-2023

- Home-delivered meals
- Nutritional counseling

The Momentum Project

themomentumproject.org/client/index.html

322 Eighth Avenue

New York, NY 10001

(212) 691-8100 extension #2121

- Congregate meals
- Pantry bags
- Nutrition counseling

Gay Men's Health Crisis

gmhc.org/get-support/get-connected/become-a-client

446 West 33 Street

New York, NY 10001-2601

(212) 376-1263

- Congregate meals
- Nutrition counseling and education
- Nutritional supplements
- Pantry bags (including short-term/emergency)

La Nueva Esperanza

213 Johnson Avenue

Brooklyn, NY 11206

(718) 497-7592

- Congregate meals
- Home-delivered meals
- Pantry bags (including take-home cooked meals)

*Congregate meals are meals that you eat with others in a group. Most of the time this happens at the food program location.

Conversation E: Food Safety

Objective: The objective of this conversation is to introduce the concept of food safety to your patient.

Note to PN: Emphasize that practicing food safety is important for all people, and that it is especially important for those with weak immune systems, like young children, older people, and those living with HIV.

Ask: What do you know about food safety?

Ask: Have you ever heard of “E. coli” or “salmonella”?

Explain: These are two bacteria that cause illness from food when food safety is not practiced.

Explain: Practicing food safety lowers the risk that food will make one sick (or “food poisoned”).

Ask: What are some things that people can do to protect themselves from getting food poisoning?

Rephrase to check for understanding: So you can [fill in what your patient said above]

Ask: Anything else?

Fill in gaps in understanding: Use the [Six Techniques to Avoid Food Poisoning Discussion Guide](#) on the next page to explain each of the food safety practices your patient didn't already mention.

Discussion Guide: Six Techniques to Avoid Food Poisoning

- 1. Cleaning:** Wash hands and clean surfaces often
 - Wash hands with warm water and soap for at least 20 seconds (enough time to sing “Twinkle Twinkle Little Star” to yourself).
 - Wash cutting boards, dishes, utensils and countertops with hot soapy water before and after you cook.
 - Rinse fresh fruits and vegetables under running tap water.
- 2. Raw foods:** Foods such as clams, oysters, sushi, very rare meats, undercooked eggs, even alfalfa and bean sprouts contain infectious bacteria and intestinal parasites. Infections that would not bother most people can be life-threatening for those with weaker immune systems. They really should be cooked before eating. Raw fruits and vegetables should be well washed before eating.
- 3. Separating:** Don't mix raw foods with ready-to-eat ones
 - Keep raw meat, chicken, fish and eggs away from your other foods.
 - Never place cooked food on a plate that had raw meat, chicken, fish or eggs on it (before the plate is washed).
 - Use a plastic cutting board for cutting up your raw meat; use a different cutting board for cutting up things like vegetables.
- 4. Cooking:** Cook to proper temperatures
 - Always cook meat, chicken, fish, egg dishes and other cooked foods to the suggested temperature.
 - Make sure all meat, chicken, fish and egg dishes are cooked through.
 - Once the food is cooked, don't leave it out on the stovetop all day. Cooked food should not stay out for more than two hours because after that, bacteria get in and can contaminate the food.
- 5. Chilling:** Refrigerate right away
 - Keep cold foods cold.
 - Defrost frozen foods in the refrigerator, NOT at room temperature.
 - Raw meat should not stay in the fridge uncooked for more than 2-3 days. Chicken and other meats can start to get infected with bacteria if they stay in the fridge too long. If you can't get to the meat right away, put it in the freezer.

6. Throwing away: When in Doubt, Throw It Out

- Check the expiration dates on all your foods, before you buy them and before you use them.
- If you are not sure whether your food is good or not, throw it away. It is ALWAYS better to be safe than sorry.

Conversation F: Setting Healthy Eating Goals

Conversation's objective: To help your patient set realistic and achievable goals related to healthy eating.

Say: We have talked about what you usually eat, and how healthy you think the foods you eat are. What would you like to change about the way you eat? If you don't want to change anything, why not? Do you need help in order to make changes?

Rephrase to check for understanding: You would like to... [fill in what patient said earlier] or
You do not want to make any changes, because...
You need help with making these changes: _____

Say: What do you think about turning what you just said into achievable goals (or baby steps) that could lead to better and healthier eating?

Refer back to the Diet tool (Workbook page 58) you completed together to emphasize the good nutrition habits your patient already has and to discuss areas where your patient could improve their eating habits.

Ask: What ways do you think you can try eliminating or reducing one or two of the less healthy foods?

Note to PN: Changes should be specific, personalized and do-able. "Eat healthy" is not a good goal. Make sure the goals you set with patients are appropriate for them. The following are examples of specific, possible goals:

- Decrease rice portion size at evening meal by half.
- Replace whole milk with 1%.
- Choose liquid oils instead of solid fats for cooking.

- Take a favorite recipe and change it to make it healthier — i.e., substitute regular meat, fish or chicken for lean meat, fish or chicken, add less sugar to a recipe, etc.

Ask: How do you think you can add more of the beneficial foods?

Note to PN: It is important to remember that what is do-able for one patient may not be for another. You may want to provide some examples —

- Eat baked fish 2-3 times per week.
- Choose whole grain bread for breakfast.
- Replace white potatoes with sweet potatoes.
- Keep several types of frozen vegetables in the freezer, and add one to each lunch and dinner.
- Eat 2-4 servings of fruit daily.
- Add fresh fruit to a dessert.

Ask: How do you think you can incorporate more exercise into your life?

Note to PN: You may want to provide some examples that are appropriate for your patient:

- Take the stairs instead of the elevator.
- Walk around the block before dinner each night for 30 minutes.
- Join the gym at the YMCA and exercise there for 30 minutes three times per week.

Ask: What changes do you want to make to increase food safety and decrease your risk of food poisoning?

Note to PN: You may want to provide some examples:

- Wash hands before cooking.
- Cut vegetables first and raw meat second, instead of the other other way around.
- Regularly check expiration dates.

Write down the ideas your patient comes up with on a piece of scratch paper. Go over the list together.

Say: How long do you think it would take you to accomplish this goal?

Or: Is this something you can work on now?

Note to PN: Assess the challenges or obstacles to this goal. If the goal is unrealistic, encourage the patient to select another option or to modify the goal. It is important to remember that what is do-able for one patient may not be possible for another.

Ask: What kind of help do you think you need in order to do what you want to do?

For each goal, ask:

- What are the things that will help you achieve this goal?
- What are the obstacles you may encounter trying to achieve this goal?
- What are the steps you think you need to take to achieve this goal?
- Which step will you start with?

Wrap Up

- Say:** Today we talked a lot about the importance of setting small goals to create change in your diet.
- Ask:** In your own words, what did you learn today?
- Ask:** What was one thing you learned about nutrition today that you found especially interesting?
- Ask:** What are some of the small diet and exercise changes you are going to make in your life?
- Say:** Remember that goals are not always easy to achieve, but by drawing from your strengths you can overcome some of the barriers that make it hard.
- Ask:** What's most important for me to know about you and what we talked about today?
- Ask:** What questions came up for you that we can review for next time?
- Say:** The next time we meet I will check-in with you to see how you've been doing with this goal.

Further Resources on Diet, Exercise and Food Safety

Diet

- For ideas on building a high-quality diet:
 - General Reading
 - <http://www.hsph.harvard.edu/nutritionsource/>
 - <http://www.whfoods.com/>
 - <http://medicine.tufts.edu/Education/Academic-Departments/Clinical-Departments/Public-Health-and-Community-Medicine/Nutrition-and-Infection-Unit/Research/Nutrition-and-Health-Topics/Building-a-High-Quality-Diet>
 - <http://www.eatright.org/>
 - Whole Grains
 - <http://www.choosemyplate.gov/food-groups/grains.html>
 - Vegetables
 - <http://www.choosemyplate.gov/food-groups/vegetables.html>
 - <http://www.fruitsandveggiesmorematters.org/>
 - Fruits
 - <http://www.choosemyplate.gov>
 - <http://www.fruitsandveggiesmorematters.org/why-fruits-veggies>
 - Meat/Protein
 - <http://www.choosemyplate.gov/food-groups/protein-foods.html>
 - Dairy
 - <http://www.choosemyplate.gov/food-groups/dairy.html>
 - <http://www.nationaldairycouncil.org/>

Exercise

- For ideas for increasing physical activity:
 - <http://www.choosemyplate.gov/physical-activity.html>
 - http://www.fruitsandveggiesmorematters.org/?page_id=49
 - <http://www.cdc.gov/nccdphp/dnpa/physical/everyone.htm>
 - http://www.heart.org/HEARTORG/GettingHealthy/PhysicalActivity/Physical-Activity_UCM_001080_SubHomePage.jsp

Food Safety

- For ideas on practicing food safety:
 - <http://www.fightbac.org/>
 - <http://www.homefoodsafety.org/>
 - <http://www.foodsafety.gov/>
 - <http://www.cdc.gov/foodsafety/>

Topic 16: Wrap Up

Learning objectives

After completing this topic, the patient should be able to:

- Review tools in the PN workbook
- Review the last 3-4 CCPs that were completed
- Review goals; review successes; see how far they have come
- Discuss the curriculum experience
- Discuss graduation and the future

Preparation

- Make sure that you've copied all of the completed Care Coordination Workbook tools and filed them in the patient's chart
- Review tools completed
- Bring Care Coordination Workbook
- Review evaluation forms
- Review your notes on this patient from the last topic you completed together, and identify any areas of confusion that need review.
- Review conversations and PN instructions for this topic

Topic overview

Conversation	Materials & tools
Review from last session	
A: Review tools	All relevant tools in the Workbook
B: Review goals	1 st CCP and Pas 3-4 CCPs
Wrap Up	

Review

“Let’s go over what we talked about last time.”

Review any areas that were particularly challenging for your patient during your last session together. Ask your patient to:

- 1) Demonstrate a skill that was learned from last session's discussion;
- 2) Explain one of the key points from that session.

Introduction: This is the final session! In this session you are reviewing the skills your patient has learned and emphasizing your patient's confidence in these areas, particularly adherence to medications. Congratulate your patient on making it through the curriculum!

Conversation A: Review the Care Coordination Workbook Tools

Ask: Do you use the tools we have completed together during your day-to-day life, outside of sessions with me?

If yes, ask: What tools do you use?

If no, ask: Why not?

If your patients are already using tools, suggest others to supplement them. If they are not using the tools, suggest a few that might be useful for them to reference in the future. Review the tools that are especially important or useful.

Ask: When might each of these tools be used? When might you refer back to each of these tools? [go over especially important tools one at a time and ask these questions].

Say: The Care Coordination Workbook is a permanent resource for you. Some people continue to store health information, lab records or appointment information in it. Other people

decorate it with paints or beads. It's for you, and you can do whatever you want with it.

Ask:

What do you think about this? Do you have any questions for me?

Conversation B: Progress and Goals

Objective: The objective for this conversation is to review the patient's progress since the first Conversation you completed together.

Turn to the first Conversation completed as well as the past three to four Conversations completed with the patient.

Instructions to PN:

- Review the patient's progress since the first Conversation you completed together.
- Review each of the goals listed and discuss with your patient whether the goal was met.
- Ask if there are any more goals the patient wants to add.
- Emphasize successes with goals.
- If a goal was not met, find a partial success to discuss.

Say: The reason you're ready to graduate is because you've developed the tools you need to take care of yourself and to be adherent to your medications yourself and with the social supports that we've built together.

Ask: How can you take what we've done together and build it into your life?

Ask: What do you need to carry what you have learned and achieved in the Care Coordination program into your life?

Say: If you decide at any point in the future that you need to come back to the Care Coordination program that is fine. We won't think you have failed if you decide to come back. You can always come back. We'll still be here.

Ask: What do you want your graduation from Care Coordination to look like?

Ask: Do you want to talk about or reflect on the positive changes in your life at the graduation ceremony?

Ask: How do you want to commemorate the work we have done together and the goals you have achieved with the people who have supported you?

Wrap Up

Say: You have come a long way! Let's take a moment to appreciate this together! I appreciate our relationship and where it was at the beginning and where it is now.

Instructions to PN: Express your confidence in your patient, generally and specifically.

Say: We've talked about a lot today! In your own words, what did you learn today?

Ask: What's most important for me to know about you and what we talked about today?

Ask: Do you have any remaining questions for me?

Say: Congratulations! This was the last session!