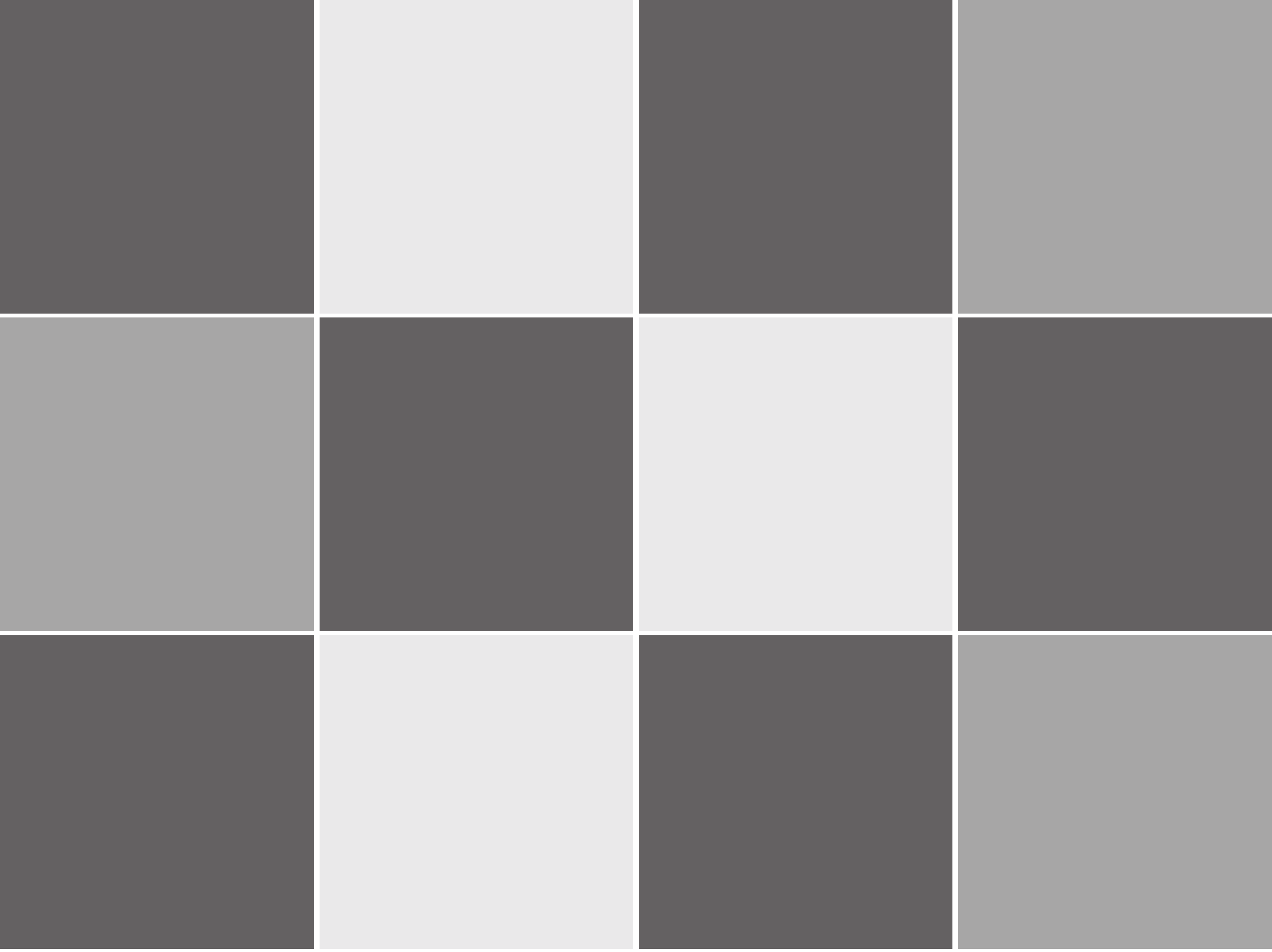


STEPS To Care Facilitator’s Guide

Third Edition
Initial Publication Date (PACT): 2009
Last revised (STEPS to Care): April 2017

Partners In Health

STEPS TO CARE

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 and distributed by the New York City Department of Health and Mental Hygiene through their Care Coordination Program.

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.

We acknowledge the support provided by the Centers for Disease Control and Prevention (CDC) through Cooperative Agreement # U62PS004242 for the revisions of this product under the STEPS to Care (StC) project. The StC Project supported the development and pilot implementation of the StC online toolkit that is designed to support diverse agencies in the uptake and implementation of three evidence-informed strategies to improve retention in HIV care and reduce viral loads: Patient Navigation, Care Team Coordination and HIV Self-Management.

Special thanks go to the PACT project and New York City Department of Health and Mental Hygiene for sharing this information and allowing it to be reproduced with modifications.

Table of Contents

Overview

How should I use the STEPS to Care Client Workbook Facilitator's Guide?

The **STEPS to Care Client Workbook Facilitator's Guide** is a guide for the Patient Navigator (PN) to use during HIV Self-Management sessions with clients. Each Patient Navigator (PN) receives only one STEPS Facilitator's Guide.

What is the STEPS to Care Client Workbook?

Each client receives a **STEPS to Care Client Workbook** full of information, tools and resources that correspond to the conversations in the STEPS Facilitator's Guide. The Workbook and separate pages and tools can also be accessed on mystctools.org. The Patient Navigator (PN) works with the client to study the tools in the Workbook during home visits. When the client is no longer in need of intensive navigation services, the client keeps the completed Workbook as a resource.

How is this Guide and the Client Workbook part of the larger STEPS to Care program? How does this fit in?

This Facilitator's Guide contains lesson plans, discussion prompts, and instructions for Patient Navigators delivering the HIV-Self Management topics. Patient Navigation and HIV Self-Management are two of the key strategies supported by STEPS to Care. Topics in the Facilitator's Guide correspond with the HIV Self-Management tools in the Workbook and on the mystctools.org site. You can find the full list at HIV Self-Management Tools on the STEPS to Care website. As you read through and use the Facilitator's Guide, you may find it helpful to have a complete copy of the Workbook nearby for reference.

How much time do I need to cover the STEPS to Care Client Workbook Facilitator's Guide topics with my client?

The Patient Navigator (PN) will discuss each topic in the STEPS to Care

Client Workbook Facilitator's Guide during the first 10 months of the client's participation in STEPS to Care. 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 HIV Self-Management session takes about 20-40 minutes.

How is the STEPS to Care Client Workbook Facilitator's Guide organized?

There are 16 topics in the Facilitator's Guide. It is important that you assess whether the topic is useful for the client and if your client is *ready* to discuss the topics. You may also find it helpful to speak with your supervisor about which topics to address using the goals set in your client's Care Plan.

Each topic begins with its objectives, describes the necessary preparation for Patient Navigators, and includes conversations on that topic that coordinate with the STEPS to Care Client 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 client. 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. They can also be found on mystctools.org. Because the tools on mystctools.org are organized into topic pages, use this document, HIV Self-Management Tools, to easily find which topic pages house specific tools. The conversation guides include prompts, instructions and notes to the Patient Navigator on issues such as: how to assess whether a client 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 client's particular concerns and tailor the conversation specifically to that client's needs.

Each topic concludes with a Wrap Up exercise to discuss what the client 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 topic, with the remaining 25 minutes focused on building your relationship and connecting your client to social and economic services. Although some clients may need more time or less time to complete each session, generally 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 until the patient is no longer in need of intensive Patient Navigation services. This schedule allows us to give all clients the most consistent intervention. When a client misses or cancels a session, the Patient Navigator should prioritize catching up with the missed topic to try to keep on track. If your client misses sessions, talk to your supervisor about how best to catch up.

How do I document my sessions with clients?

Patient Navigators track conversation progress with each client. At the end of each conversation, record the date of completion in a progress note in the client database, print it out and put in the client'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 client during meetings with your supervisor. Your supervisor can help identify which conversations should be completed for a particular client and when.

Topic 1: Introduction to the STEPS to Care Sessions

Learning objectives

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

- Anticipate the content of sessions with the PN.
- Understand the STEPS to Care program's goals.
- Identify client's personal goals, and the barriers and facilitators of those goals.
- Complete or update the Comprehensive Care Plan.
- Identify a place to store the STEPS to Care Client Workbook or the website address (mystctools.org)

Preparation

☐ Label the STEPS to Care Client Workbook.

☐ Bring the STEPS to Care Client Workbook and the client's Comprehensive Care Plan.

☐ If possible, bring a laptop or tablet to show the client how to access the workbook on mystctools.org.

☐ Review your client's medication list, and know what each medication is for and when each should be taken.

☐ Ask the client's provider if the medications on the list are active or if any have been discontinued.

☐ Review any special instructions for medications your client is taking.

☐ Review conversations and PN instructions for this topic.

Topic Overview

Conversation	**Materials and Tools** Tools are accessible on mystctools.org
A: Initial Adherence Discussion	
B: Introduce the STEPS to Care Sessions	STEPS Facilitator's Guide Table of Contents
C: STEPS to Care HIV Self-Management Goals	
D: SMART Goals-Setting for the Care Plan	Comprehensive Care Plan Form
E: STEPS to Care Client Workbook Storage or Online Access	STEPS to Care Client Workbook and website address (mystctools.org)
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 client's adherence to HIV medications, prophylaxis medications, and other medications. The objective of this conversation is NOT to teach your client about what is right or wrong. You just want to learn about how your client takes their medications and get a measure of the client's general understanding about them. After you complete the conversation, however, you can tell the client if they are taking their medications correctly and explain any special instructions.

Before you start: Make sure you have reviewed what pills your client 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 client's medications. You can use the StC Adherence Assessment: Daily and Adherence Assessment: Non-Daily Forms that are available for download in the StC toolkit to record client answers.

Note to PN: Frame this assessment as a way for you to learn about your client. 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 client does not want you to write down any answers, or if you notice that your client 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 client's answers, summarize them in your progress notes.

STEPS to Care Adherence Assessment

For clients who are currently on ART, you can use the StC Adherence Assessment: Daily and Adherence Assessment: Non-Daily Forms that are available for download in the StC toolkit to record client answers. Use the Non-Daily form if the patient has an ART regimen in which the number of doses per day varies.

These questions can help guide you through the two forms. Some of the questions below are not on the forms but can help you gather additional useful information.

1. Can you tell me about your pills? Which ones do you take for your HIV? Which ones do you take daily? Which ones do you not take daily?

   ____

   ____

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 daily/non-daily HIV pills yesterday?

   ____

   ____

5. How about the day before?

   ____

6. And the day before that? How about 4 days ago?

7. Did you miss any of your prophylaxis pills yesterday? *(**Note to PN:** Make sure client 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. When was the last time you missed any of your HIV medications?

14. **If the client reports missed doses/pills, say:** People may miss taking their medications for various reasons. Here is a list of possible reasons why you may miss taking your medications. Have you missed taking your HIV medications because you… (read from forms and complete)?

15. **If the client 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 client 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. 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 STEPS to Care Sessions

Objective: The objective of this conversation is to discuss what the client 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 STEPS Facilitator's Guide Table of Contents.

Say: These are 16 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 STEPS to Care 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 STEPS to Care HIV Self-Management Goals

Objective: The objective of this conversation is for the client to understand The STEPS to Care program's HIV self-management goals.

Say: Let me tell you a little about the STEPS to Care program's HIV self-management 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: SMART Goals-Setting for the Care Plan

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

Note to PN: The best goals are small, reachable steps that your client has the ability to control (often called SMART goals or objectives). We suggest you review the Care Plan topic page and take the training "Developing SMART Goals for a Client-Centered Comprehensive Care Plan" on the STEPS to Care website prior to this conversation. Afterwards, the PN should use this information to update the Comprehensive Care Plan, which should be signed by the client at the next home visit. Help your client 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 client 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 HIV visits?

If your client 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 STEPS to Care 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 client has trouble identifying facilitators, suggest some of the following examples:

- A readiness or desire to change
- The information necessary to make the change

- The client has a relative or friend for support while changing

- The access to the resources to make the change

Summarize what your client 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 client 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 visit for you to sign.

Conversation E: STEPS to Care Client Workbook Storage or Online Access

Objective: The objective of this conversation is to identify a place to keep the Workbook or understand how to access it online at home at **mystctools.org**.

Present the client with a copy of the STEPS to Care Client Workbook and the address of mystctools.org where the client can also download and print all the pages separately.

Note to PN: Taking the Workbook home or using mystctools.org at home empowers the client to integrate the tools completed during the PN sessions into everyday life. If the client agrees to take the Workbook home, discuss ways to prevent it from getting lost. You may also want to discuss ways to help the client 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 clients paint their Workbooks or glue on photos or pictures from magazines to personalize it.

Ask: How do you feel about keeping this Workbook?

If client doesn't want keep the Workbook, Say: Another reason we like clients to keep the Workbook is because it is your book and you own it; you are in to 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?
- 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 client has concerns about disclosure or misplacing the Workbook, or if the client just does not want to keep it in the home, don't insist. You can then introduce the client to mystctools.org and discuss how you can print separate pages as you work on them together.

Say: If you don't feel comfortable keeping the full Workbook with you, that is okay. I can also print specific pages from the Workbook through a website at **mystctools.org**. In fact, this a website that you can also access on your own any time as well. Once we've worked on some of these pages in the Workbook together, you can then download and print any of the pages you need on your own. There are also videos that you can watch on your own time.

Note to PN: If you have online access at that time, you can go on to the website together and watch the introductory video, or let your client know you will show your client the website the next time they are in a place with online access.

Try to identify a safe place to keep the Workbook or separate pages.

Ask: Where would be a good place for you to keep the Workbook or the different pages 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 client will be able to:

- Identify the impact that HIV has on everydaylife
- 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 STEPS to Care Client Workbook.

☐ Review your notes on this client 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 and Tools** Tools are accessible on mystctools.org
Review from last session	
A: Me and HIV	Me & HIV Discussion Guide (FG page 30)
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 client during your last session together. Ask your client 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 client thinks and feels about HIV and HIV treatment, and how your client is coping with their illness. This is an opportunity for you to listen deeply to your client's intellectual, social, emotional and spiritual thoughts and feelings about HIV and treatment. This conversation is designed to help you get to know your client in a general way and to create a safe environment to discuss feelings and challenges faced by the client. This is a **listening** rather than a **teaching** conversation. Try to avoid telling your client 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 client so that you understand what areas to work on and can meet your client where they are to help them overcome their adherence barriers.

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

A note on record-keeping: You do not need to write down your client'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 client's readiness to talk. If you do proceed, it is important to offer the client 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 client to discuss these topics, or if you feel that your client 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 client told you about their goals during the Me and HIV conversation to check for understanding.

Instructions for PN: Explain to the client 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.

<u>What were your goals before you knew you had HIV?</u>

1. ______________________________
2. ______________________________
3. ______________________________
4. ______________________________
5. ______________________________

<u>What are your goals now that you have HIV?</u>

1. ______________________________
2. ______________________________
3. ______________________________
4. ______________________________
5. ______________________________

<u>What can you do now to accomplish those goals?</u>

1. ______________________________
2. ______________________________
3. ______________________________
4. ______________________________
5. ______________________________

Conversation C: Me, My HIV, and Other People

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

Instructions for PN: Explain to the client 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 client 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 STEPS to Care Client Workbook or specific pages.
☐ 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 client has medications at home to practice with (or bring medications with you).
☐ Have 2-4 empty pillboxes available.
☐ Review your notes on this client 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 and Tools** Tools also available on mystctools.org
Review from last session	
A: How to Read a Pill Bottle	Material: Client's medication bottles Tool: How to Read a Pill Bottle (Workbook Page 15)
B: Medication List	Tool: Medication List (Workbook page 14)
C: Benefits of Pillboxes	
D: Medication Organizing	
E: Filling a Pillbox	Tool: Filling a Pillbox (Workbook Page 16) Tool: Medication List (Workbook 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 client during your last session together. Ask your client 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 client 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 STEPS to Care Client 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 client and answer any questions. If possible, go over the labels on your client's actual medication bottles in addition to the image in the STEPS to Care Client Workbook. This exercise may help your client 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 client needs to take the medication. Make sure that your client understands the instructions for each medication and check to make sure the doctor's instructions match what is on the label. Ask your client to explain the instructions for each medication to you to demonstrate their understanding. Encourage your client 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 client:

- 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 client reads and understands these stickers on each of their medications and includes this information in the Medication List tool.
- If your client 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 client 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, **clients 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 client's different medications. By the end of this conversation, the client 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 STEPS to Care Client 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 STEPS to Care Client Workbook. Continue with each medication (both ARTs and other meds). Your client 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 client experienced for each medication.
- In the **Things to Watch For** column, list any possible adverse effects that are associated with your client's medications, and discuss what steps the client should take if they were to notice any of these effects.
- Ask the client 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 client may have many different types of medications. Be sure that your client understands what each medication is for. Explain the following types of medications to your client, explaining which of their pills falls into each category:

What is ARV Therapy?

Anti**r**etro**v**iral drugs are referred to as **ARVs**. **AR**V **T**herapy 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 Mycobacterium Avium Complex (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.

Conversation C: Benefits of Pillboxes

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

Assessment: All STEPS to Care clients should be using a pillbox. If your client is already using a pillbox effectively, skip this section. If they are not yet using a pillbox, <u>or not using a pillbox effectively</u>, take the time for this conversation.

Instructions to PN: Explain to your client 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 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 clients **organize** their medications.
- A pillbox gives people a **visual cue** when refills are needed.
- Using a pillbox can **eliminate unnecessary anxiety and frustration** because clients 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 client to use a pillbox since, among other benefits, pillbox checks are the easiest and most reliable way for you to assess adherence.

If your client 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 client can use pre-filled pillboxes, blister packs, daily key chain pillboxes, beepers or pill counters. Work with your client to find an option that works best for them. Ask your client what support you can provide to help ensure the best option. If your client 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 client's pharmacy to get information regarding their refills.

If your client still refuses to use a pillbox, make a statement that allows for discussion when the client 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 client'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 client's medications, compare against the correct medication list, discard the expired pills and with the consent of the client, organize the correct pills into a pillbox. Remember that the client 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 client present) to determine if the client 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. For pills that are unrecognizable to the client and PN, attempt to identify them with the resource tool or call your Care Coordinator for help.

Conversation E: Filling a Pillbox

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

Turn to Page 16 of the STEPS to Care Client Workbook or download and print from mystctools.org: 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 client to demonstrate how to fill it and **assist them as necessary until they feel comfortable filling it on their own.** Some clients 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

Objective: The objective of this conversation is to help the client 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 client will be able to:

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

Preparation

☐ Bring STEPS to Care Client 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 client's completed Medication List (Workbook, page 14) to use as a reference.
☐ Review your notes on this client 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 and Tools** Tools also available on mystctools.org
Review from last session	
A: Pharmacy Information	Pharmacy Information checklist (Workbook Page 17)
B: Refilling Your Medication	Refilling Medication checklist (Workbook Page 18)
C: Barriers and Solutions	Barriers and Solutions table (Workbook 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 client during your last session together. Ask your client 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 client locate important information for filling and refilling prescriptions at a pharmacy.

Turn to Page 17 of the STEPS to Care Client Workbook or download and print from mystctools.org: 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 client 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 STEPS to Care Intake and Assessment forms 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 client. Encourage the client 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 client 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.

Conversation B: Refilling Your Medication

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

Turn to Page 18 of the STEPS to Care Client Workbook or download and print from mystctools.org: Refilling Medication.

Instructions to PN:

- Walk through each step for refilling medications with your client using this checklist.

- Some steps may not be relevant for all clients, in which case cross them out.

- To encourage better communication, it can be helpful to some clients if you **take them to the pharmacy and introduce your client and yourself to the pharmacist and pharmacy staff**. If your client 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 client 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. Depending on the pharmacy, if you have your refill number on your pill bottle, you can usually order the refill using the automated phone system or online.

☐ 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 client 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 client may face when trying to refill a prescription and discuss potential solutions for each barrier.

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

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 STEPS to Care Client Workbook: Barriers and Solutions or download and print from mystctools.org: 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 client and discuss how to address each one.
Use the barriers and solutions table for help.

Conversation D: Practice Calling the Pharmacy

Objective: The objective of this conversation is to give the client 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 client to practice calling in to make a refill request. Then, switch roles. Once your client 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 client's phone is not in service.

Conversation E: When to Call the Pharmacy

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

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

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

- How will the client call the pharmacy for a refill?
- How will the client get the pillboxes from the pharmacy?
- How will the client check the pillboxes to make sure that they are filled correctly?
- How will the client correct any problems there might be with the pillboxes?
- If the client 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 client only has one pillbox per week and changes pillboxes on the same day each week.

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

- How will the client call the pharmacy to let them know they need a refill?
- How will the client get the medication from the pharmacy?
- How will the client check the bottles to make sure they are the correct medications?
- How will the client correct any problems there might be with the medications?
- On what day of the week will the client 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 clients keep from switching between pillboxes and pill bottles, because switching makes it hard to remember if the pills were taken or not.

If your client will be receiving blister packs, ask:

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

For all clients, ask about storing medications:

- Where does the client keep medication?
- Why did the client choose this location?
- Does any medication need special storage (i.e., refrigeration)?
- Does the client have small children so medication should be kept out of reach?
- Are there disclosure concerns?
- Does the location of medications fit into your client'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 client 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 STEPS to Care Client Workbook or the specific pages.
- ☐ Review client's chart for documented problems in adherence.
- ☐ Review your notes on this client 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 and Tools** Tools also available on mystctools.org
Review from last session	
A: Your Client's Perception of Treatment	
B: What is Adherence?	Elements of Adherence Resource (FG page 65)
C: Why is Adherence to ART Important?	
D: Taking Medications on Time	Tool: Pill Chart (Workbook page 22) A Day in the Life of a Pill (Workbook page 23) Surrounding HIV (FG page 71)
E: Resistance	Conversation E1 guide (FG page 75) Conversation E2 guide (FG page 78) Conversation E3 guide (FG page 80) Conversation E4 guide (FG page 82) Conversation E5 guide (FG page 83)
F: Daily Routine Chart	Daily Routine Chart (Workbook page 21)
Wrap Up	

Review

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

Review areas that were particularly challenging for your client during your last session together. Ask your client 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 Client's Perception of Treatment

Objective: The objective of this conversation is to deepen your understanding of your client's perspective of HIV treatment. This will help you to learn about the barriers to adherence in your client'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: Clients are non-adherent to their treatment for a variety of reasons and these reasons vary depending on the client's beliefs, mental health, socioeconomic situation, and many other factors. It is important not to assume that your client has the same understanding of their treatment as you or their doctor. Show respect for your client'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 client 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 client 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 client 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, clients 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. Talk to your doctor if you plan on using **alcohol**, as this may cause dangerous interactions when mixed with certain medications.

Conversation C: Why is Adherence to ART Important?

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

Instructions for PN: Ask your client the following questions and answer your client'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 client 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 client 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.

Conversation D: Taking Medications on Time

Objective: The objective of this conversation is to help your client 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 STEPS to Care Client Workbook: Pill Chart.

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

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

Instructions to PN: Graph one of the HIV medications your client listed on the Pill Chart to show the client 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 client's medication-taking practice.

Turn to the Surrounding HIV reference on page 71 of the STEPS Facilitator's Guide.

Instructions to PN: Use the Surrounding HIV reference as a guide as you draw out the images in it for your client on a piece of scratch paper. The goal is to give your client 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.

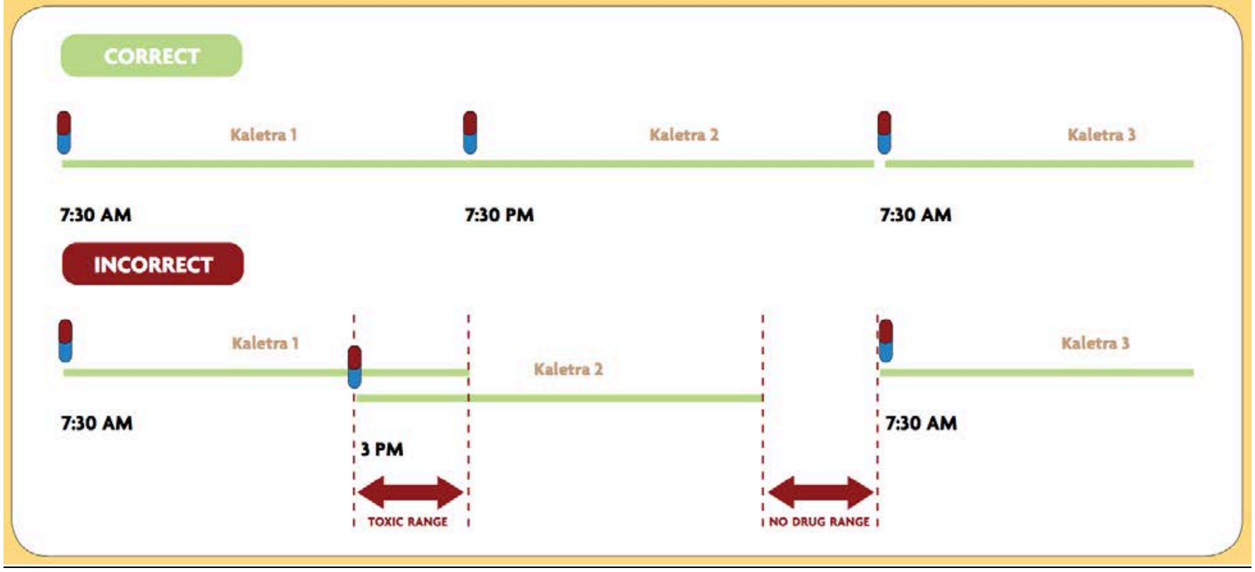
Ask: Why is it important not to take medications late?

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, which means the HIV virus has assumed a new form, so your medication can no longer keep the virus under control.

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.

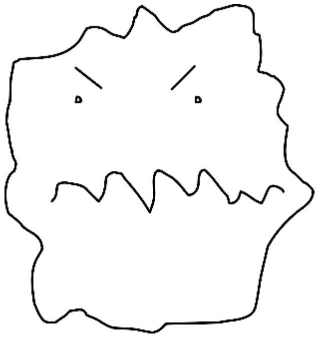
In addition, you would have no medications in your body between 3 am and 7:30 am because the 3 pm dose will have run its course by 3 am. This leaves five hours for the HIV virus to build up its numbers in the body and develop resistance to the Kaletra. This is best demonstrated in the following picture:



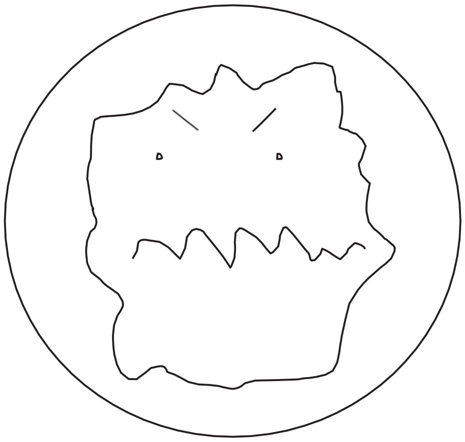
Teaching point: It is easier to draw this picture by hand for your client than show them the diagram above. Pause and stop as you draw. Take your time with this section.

Conversation D Resource: Surrounding HIV

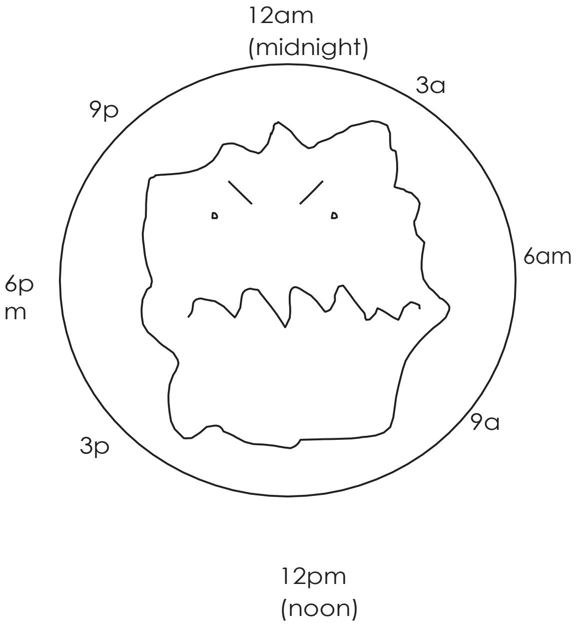
Instructions to PN: Talk about the following points with your client. It is usually helpful to draw the pictures for your client while you discuss.



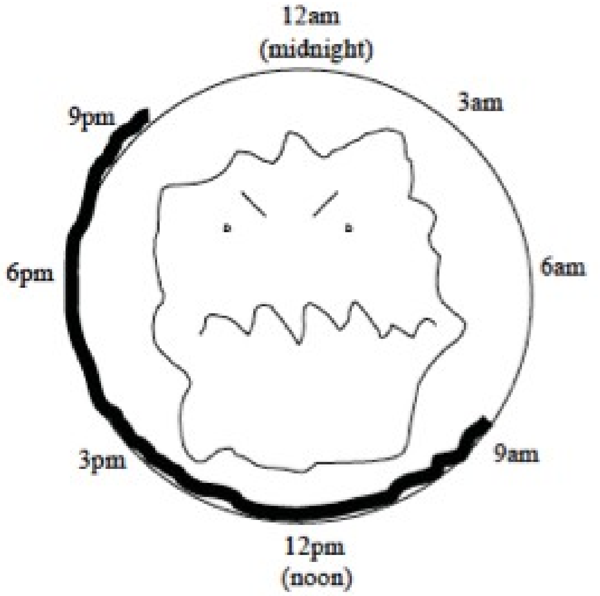
Here's HIV.



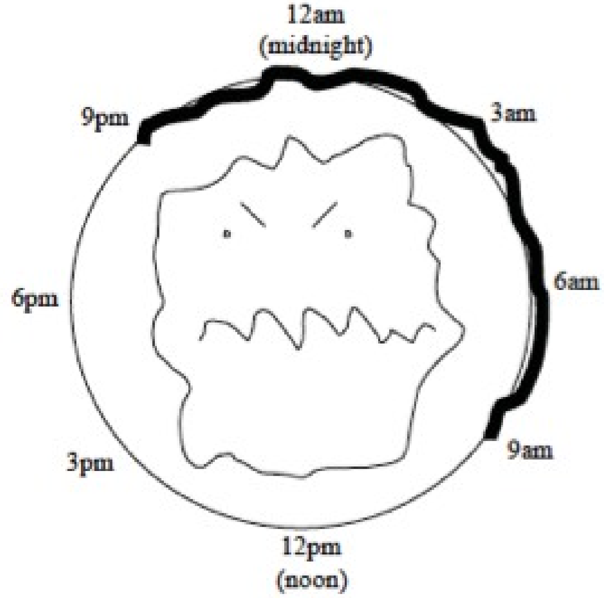
When you take HIV medications, they enclose the HIV like this and protect your body from being hurt by the HIV. The medications keep bad things out of your body.



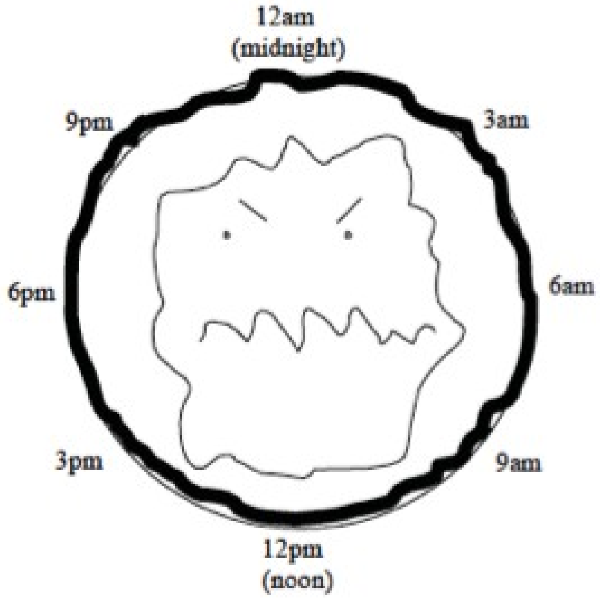
There's a **24-hour clock** on the HIV medications like this.



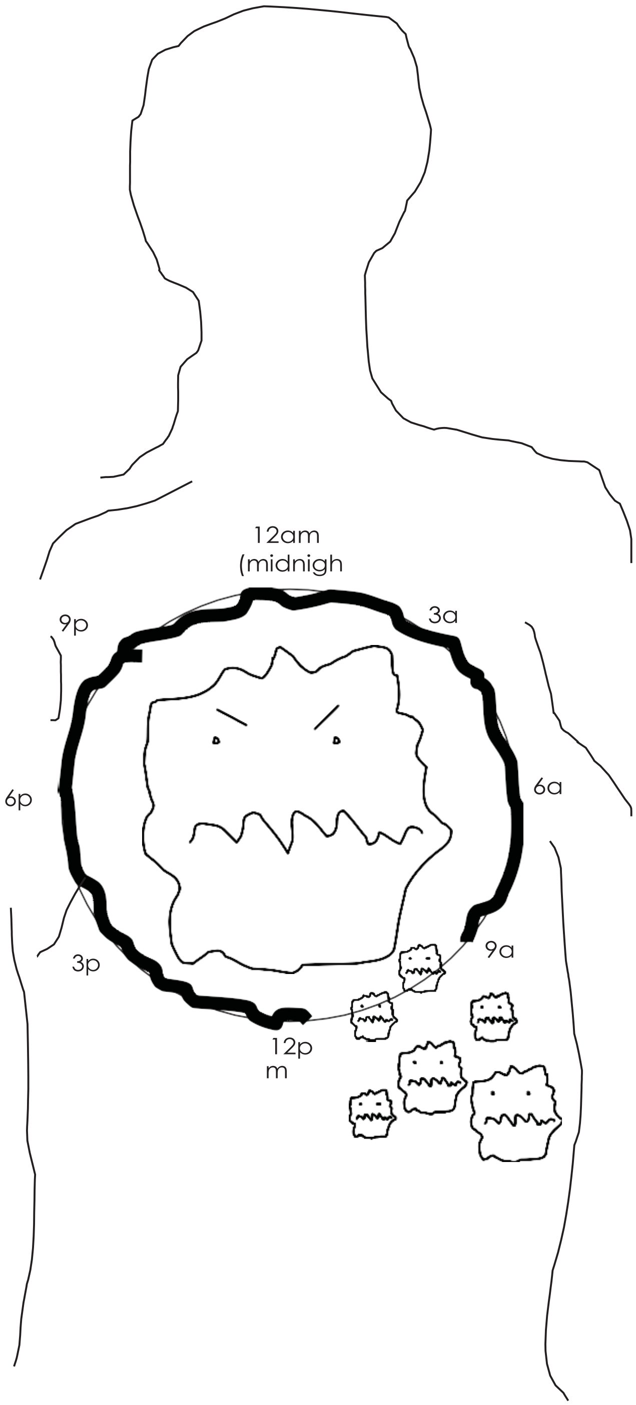
If you are supposed to take your pills at 9am and 9pm, then the morning pill keeps the HIV covered all day from 9am until 9pm.



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 sicker you will be. You can prevent HIV from making copies by taking your HIV pills every day at the right time.

Conversation E: Resistance

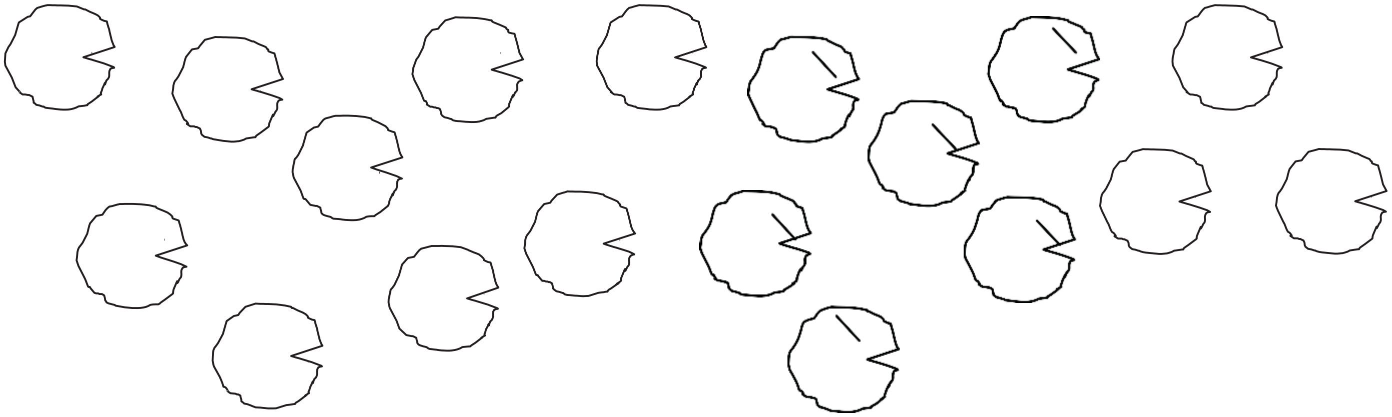
Objective: The objective of this conversation is to explain how resistance takes place in a way that your client can understand and relate to. You want your client to understand that taking 18 or 19 out of 20 pills is necessary to prevent resistance.

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

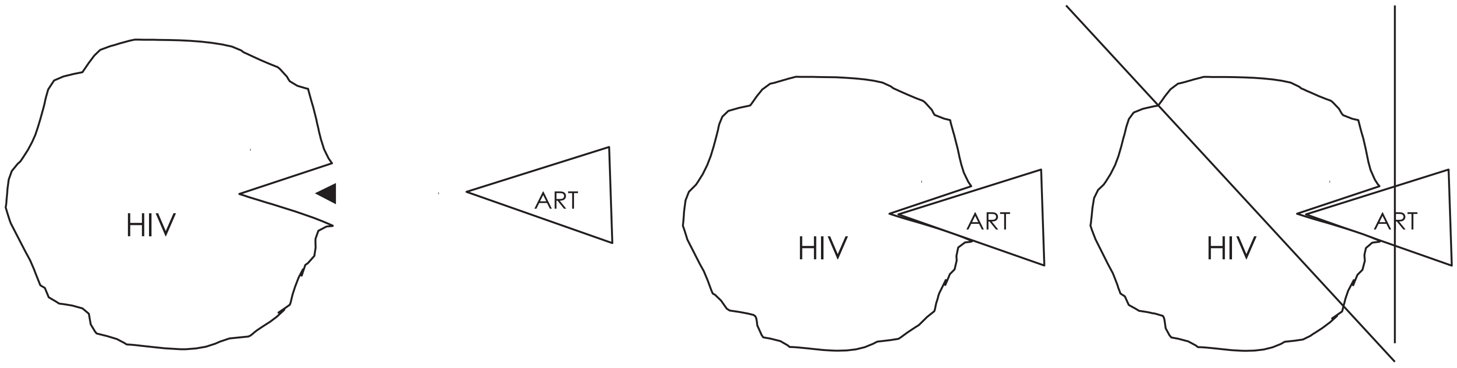
Conversation E1 Guide: Resistance

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

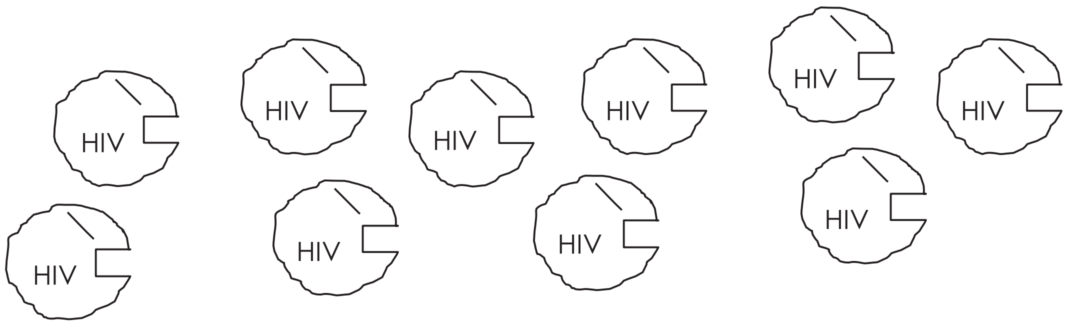
Say: When you have a lot of HIV in your blood, you are weak and sick.



Say: When you take your ART pills, they stop the HIV A virus from making any more copies and slows down its growth.



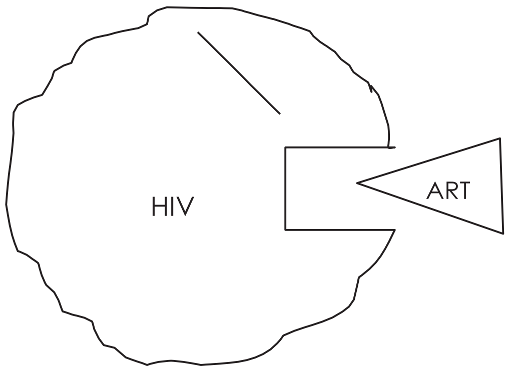
Say: If you miss more than 2 out of every 20 ART pills, the HIV can change shape. This new shape of HIV is called **resistant** because it **resists** the ART. Sometimes it can also be called a **mutant** type of HIV.



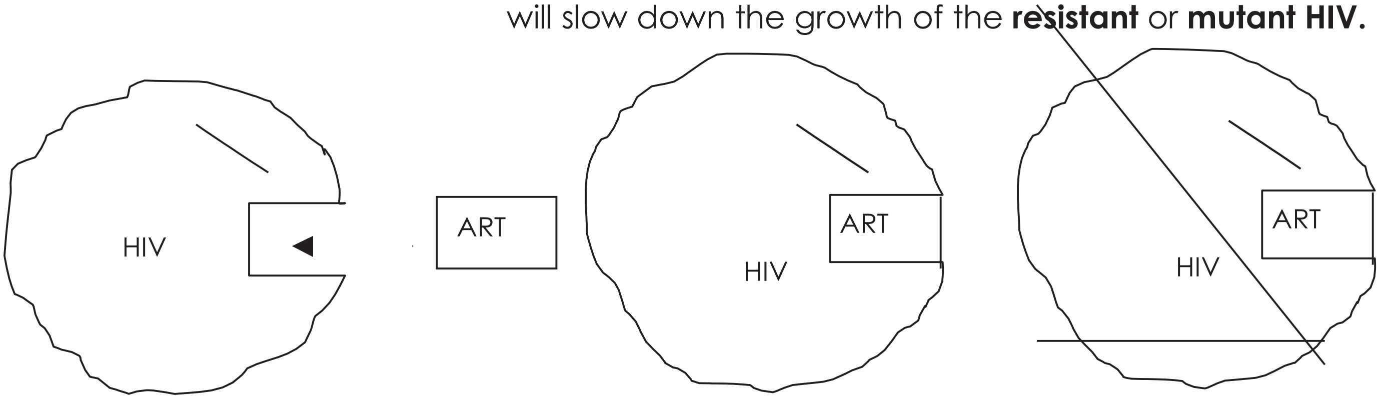
Say: The new shape of HIV doesn't fit into ART anymore.

Ask: Is there a problem with this?

Say: Yes! ART can't work to prevent the virus from making copies if it doesn't fit.



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

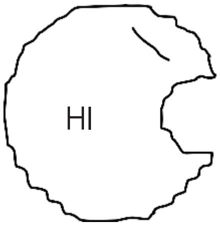


Ask: So if you can get a new type of ART that will still work, what's the problem?

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 can work against, 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 prevent your HIV from copying 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 client.

AAAAAAAAAAAAAAAAAAAAAA
AAAAAAAAAAAAAAAAAAAAAA
AAAAAAAAAAAAAAAAAAAAAA
AAAAAAAAAAAAAAAAAAAAAA
AAAAAAAAAAAAAAAAAAAAAA
AAAAAAAAAAAAAAAAAAAAAA
AAAAAAAAAAbAAAAAAAAAAA
AAAAAAAAAAAAAAAAAAAAAA
AAAAAAAAAAAAAAAAAAAAAA

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 shut down the A virus 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 prevented them from making more copies.

- 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 work.
- This means that the A virus will be making enough copies to make mistakes and accidentally make b viruses. Since HIV medications work against the A viruses but not the b viruses, a lot of the A viruses will be affected, but the b viruses will survive.
- Once the b viruses don't have to compete with the A virus, which is weakened 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 work with 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 won't work with 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 client, then do a teach back 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 client's understanding.

Conversation E4 Guide: Cocktails and Resistance

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

Ask your client 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 client 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 client figure out how to remember to take their ART. It will also help you assess your client's situation. This conversation helps many clients to visualize adherence and how it fits into their day.

Note to PN: If it is not useful to your client 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 STEPS to Care Client Workbook: Daily Routine Chart.

Instructions to PN: Ask your client 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 client does every day that could help them remember to take ART.
- Discuss your client'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

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 client 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 STEPS to Care Client Workbook or download specific pages from mystctools.org.
- ☐ Review Medication List and bring it.
- ☐ Review client's chart for concerns about side effects.
- ☐ Review your notes on this client 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** Tools also available on mystctools.org
Review from last session	
A: Understanding Side Effects	
B: Identifying Side Effects and Managing Symptoms	Symptom Management Chart (Workbook page 25) Medication List (Workbook page 14)
C: Severe Side Effects	
D: Managing Side Effects	Symptom Management Action Plan (Workbook page 27)
Wrap Up	

Review

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

Review any areas that were particularly challenging for your client during your last session together. **Ask your client 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 clients and explain the benefits of discussing side effects. Some clients 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 client 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 client'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 client 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 client'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 client 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.

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

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 client 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: Side effects can differ for each person and each type of ART medicine. Some side effects can occur once you start a medicine and may only last a few days or weeks. Other side effects can start later and last longer.

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 and Managing Symptoms

Turn to Page 25 of the STEPS to Care Client Workbook: Symptom Management Chart.

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

If your client is not experiencing any side effects, the objective is to help your client understand that side effects can be minimized in the event that they occur. The point is not that your client 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 STEPS to Care Client 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 STEPS to Care Client Workbook: Symptom Management Chart.

For clients currently experiencing side effects, say:

Are you experiencing any of the following?

- Diarrhea
- Dry Mouth
- Fatigue
- Headaches
- Nausea
- Pain and Nerve Problems
- Dry Skin
- Rash
- Weight Loss

Ask: Are you experiencing any other symptoms?

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

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

1. Refer to the Symptom Management Chart and the list of side effects your client identified.
2. Go through your client's medication list and refer to medications listed in the Veteran Administration (VA) site's Drug Dosing Toolkit to try to determine which medications might be causing the symptoms identified.
3. Talk about the strategies your client is currently using to manage these symptoms.
4. Go over other strategies in the chart that can minimize discomfort.
5. Fill out the Symptom Management Action Plan with your client. If your client is experiencing any side effects, make sure that the client's doctor is aware of them**.** As you go over the chart together, identify any side effects that have not been discussed with your client's provider, and make sure that the provider becomes informed.

6. Also discuss when your client should talk to their physician and what they should say.

7. Provide Clients with a copy of the Resource: Managing Symptoms

Instructions to PN: Make sure your client has their doctor office’s number and other necessary emergency contact information.

Symptom Management Chart

Source: U.S. Department of Veterans Affairs
https://www.hiv.va.gov/patient/side-effects-guide/index.asp
For list of medications and potential side effects, go to: Drug Dosing Toolkit

Side Effect	Symptom Management	Important Notes
Diarrhea	• Try the BRAT diet (bananas, rice, applesauce, and toast). • Eat foods high in soluble fiber. This kind of fiber can slow the diarrhea by soaking up liquid. Soluble fiber is found in oatmeal, grits, and soft bread (but not in whole grain). • Try psyllium husk fiber bars (another source of soluble fiber). You can find these at health food stores and many groceries. Eating two of these bars and drinking a big glass of water before bedtime may help your diarrhea. • Your provider may recommend treatments such as calcium, loperamide (Imodium), methylcellulose (Citrucel), or psyllium (Metamucil). • Drink plenty of clear liquids. • Stay away from foods high in insoluble fiber, such as whole grains, brown rice, bran, or the skins of vegetables and fruits. These kinds of foods can make diarrhea worse. • Avoid milk products. • Don't eat too many greasy, high-fiber, or very sweet foods. • Don't take in too much caffeine. • Avoid raw or undercooked fish, chicken, and meat.	Contact your doctor if the diarrhea is bloody or continues for more than a day, if you have abdominal pain, or you start to become dehydrated.
Dry Mouth	• Rinse your mouth throughout the day with warm, salted water. • Carry sugarless candies, lozenges, or crushed ice with you to cool the mouth and give it moisture. • Try slippery elm or licorice tea (available in health food stores). They can moisten the mouth, and they taste great!	Ask your doctor about mouth rinse and other products to treat your dry mouth.

Side Effect	Symptom Management	Important Notes
Fatigue	• Get plenty of rest. • Go to sleep and wake up at the same time every day. Changing your sleeping habits too much can actually make you feel tired. • Drink 8 to 12 glasses of water per day; if you want a caffeinated beverage, drink it in the morning. • Try to get some exercise every day. • Take a short nap during the day. • Decrease your work schedule if possible. • Keep prepackaged or easy-to-make food in the kitchen for times when you're too tired to cook. • Follow a healthy, balanced diet. Your VA health care provider may be able to help you create a meal plan.	Talk to your doctor about the possibility that you have anemia or other medical problems. Anemia means that you have a low red blood cell count, and it can make you feel tired.
Headaches	For on-the-spot headache relief, try some of these suggestions: • Lie down and rest in a quiet, dark room. • Take a hot, relaxing bath. • Give yourself a "scalp massage"--massage the base of your skull with your thumbs and massage both temples gently. • Check with your doctor about taking an over-the-counter pain reliever, such as acetaminophen (Tylenol) or ibuprofen (Motrin, Advil). To prevent headaches from happening again, try the following: • Avoid things that can cause headaches, like chocolate, red wine, onions, hard cheese, and caffeine. • Reduce your stress level. • Drink 8 to 12 glasses of water per day.	Your doctor may be able to recommend some over-the-counter or prescription medications. If your pain is severe or lasts more than a day contact your doctor right away.

Side Effect	Symptom Management	Important Notes
Nausea	• Eat smaller meals and snack more often. • The BRAT Diet (bananas, rice, applesauce, and toast) can help with nausea and diarrhea. • Keep dry crackers by your bed. Before getting out of bed in the morning, eat a few and stay in bed for a few minutes. This can help reduce nausea. • Try some herbal tea--such as peppermint or ginger tea. • Sip cold, carbonated drinks such as ginger ale. • Try eating ginger, such as in ginger tea, ginger ale, or ginger snaps. • Talk with your VA health care provider about whether you should take medicine for your nausea. • If you do vomit, be sure to "refuel" your body with fluids such as broth, carbonated beverages, juice, or popsicles. • Avoid things that can upset the stomach, such as alcohol, aspirin, caffeine, and smoking. • Avoid foods or smells that trigger nausea. • Avoid hot or spicy foods. • Avoid greasy or fried foods. • Don't lie down immediately after eating.	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.
Pain and Nerve Problems	• Massage your feet. This can help make the pain go away for a while. • Soak your feet in ice water to help with the pain. • Wear loose-fitting shoes and slippers. • When you're in bed, don't cover your feet with blankets or sheets. The bedding can press down on your feet and toes and make the pain worse. • Ask your doctor about taking an over-the-counter pain reliever to reduce the pain and swelling.	

Side Effect	**Symptom Management**	**Important Notes**
Dry Skin	• Drink 8 to 12 glasses of water per day. • Avoid long, hot showers or baths. • Avoid soaps and skin products that contain alcohols or harsh chemicals. • Use moisturizing lotion after showers (such as Aquaphor, Absorbase, or Lac-Hydrin). • Use mild, unscented laundry detergents and avoid fabric softeners. • Use petroleum jelly on dry, itchy areas; your provider may recommend other agents to help. • Use sunscreen.	
Rash	• Avoid very hot showers or baths. Water that is too hot can irritate the skin. • Avoid being in the sun. Sun exposure can make your rash worse. • Try using unscented, non-soapy cleansers for bathing or showering. • Try rubbing or pressing on the itchy areas rather than scratching. • A rash that blisters, or involves your mouth, the palms of your hands, or the soles of your feet, or one that is accompanied by shortness of breath, can be dangerous: contact your care provider right away, or go to an emergency room for evaluation.	You should call your doctor to help find out what is causing the rash; you may need to go into clinic, as it is often difficult to treat a rash over the phone.

Side Effect	Symptom Management	Important Notes
Weight Loss	• Be sure to keep track of your weight, by weighing yourself on scales and writing down how much you weigh. Tell your doctor if there are any changes. • Create your own high-protein drink by blending together yogurt, fruit (for sweetness), and powdered milk, whey protein, or soy protein. • Add dried milk powder, whey protein, soy protein, or egg white powder to foods (for example, scrambled eggs, casseroles, and milkshakes). • Between meals, try store-bought nutritional beverages or bars (such as Carnation Instant Breakfast, Benefit, Ensure, Scandishake, Boost High Protein, NuBasics). Look for ones that are high in proteins, not sugars or fats. • Spread peanut butter on toast, crackers, fruit, or vegetables. • Add cottage cheese to fruit and tomatoes. • Add canned tuna to casseroles and salads. • Add shredded cheese to sauces, soups, omelets, baked potatoes, and steamed vegetables. • Eat yogurt on your cereal or fruit. • Eat hard-boiled (hard-cooked) eggs. Use them in egg-salad sandwiches or slice and dice them for tossed salads. • Add diced or chopped meats to soups, salads, and sauces.	Your doctor can help monitor your weight over time and suggest resources and a safe program for maintaining your weight.

Conversation C: Severe Side Effects

Objective: The objective of this conversation is to acquaint your client 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 clients who experience more severe side effects or allergic reactions should **contact their doctorimmediately**.

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

Feedback: If your client has not talked to their doctor about their symptoms, ask if your client 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 STEPS to Care Client Workbook: Managing Side Effects.

Say: This **Symptom Management Chart** lists possible symptoms caused by side effects 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 client. If your client is experiencing any side effects, make sure that the client's doctor is aware of them**.** As you go over the chart together, identify any side effects that have not been discussed with your client's provider, and make sure that the provider becomes informed.

To determine whether or not one of these other symptom is linked to a client's medication, go through your client's medication list and refer to medications listed in the Veteran Administration (VA) site's Drug Dosing Toolkit to try to determine which medications might be causing the symptoms identified.

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

Instructions to PN: Make sure your client has their doctor office's number and other necessary emergency 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

Instructions to PN: If your client 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 client. **Be careful not to scare your client.** These are not common side effects, but in case they occur, it is important that your client know what is happening.

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

Delayed hypersensitivity – itchy rash, blistering oral sores, bruise-like lesions on skin, lesions on skin that look like bullseye targets.

Anaphylaxis – can also include swelling of the mouth, face, lips and tongue, respiratory (chest tightness, cough, wheezing), gastrointestinal (vomiting, diarrhea, abdominal pain/cramping), cardiovascular (fast or irregular heartbeat) and hallucinations, seizures, dizziness, lightheadedness, headache, tremor, vision changes.

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, difficulty urinating or inability to urinate 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 (yellowing of the skin and eyes), 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 CLIENT'S DOCTOR IMMEDIATELY. If your client 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 client is willing to adopt in managing their side effects.

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

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

If your client 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 client'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 Chart** on page 94 of the STEPS 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 client fill out the Symptom Management Action Plan with the management strategies they would like to try. As part of this exercise, your client 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 client knows possible causes and symptom management ideas, they can feel more comfortable discussing it with their doctor.

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?

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

Learning objectives

After completing this topic, the client 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 STEPS to Care Client Workbook.

☐ Bring client's CD4 and viral load count records; review before meeting.

☐ Review your notes on this client 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 and Tools** Tools also available on mystctools.org
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?	My CD4 and Viral Load Journal (Workbook page 33)
F: What is an Opportunistic Infection?	Sites of Possible Infection (Workbook page 30)
G: How is HIV Transmitted?	How is HIV transmitted? (Workbook page 28)
Wrap Up	

Review

Let’s go over what we talked about last time. Review any areas that were particularly challenging for your client during your last session together. Ask your client 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 client understand how HIV affects the body and how medications help fight HIV. You and your client 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. Clients 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 client and go from there. **This topic contains a lot of information. Take time to make sure your client understands each conversation before moving on.**

Note to PN: If your client 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. You can also refer your client to the CDC HIV Risk Reduction Tool when covering any relevant topics: https://wwwn.cdc.gov/hivrisk/

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 client understands their HIV and how it has affected them.

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

Instructions for PN: Use information your client 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 client 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.

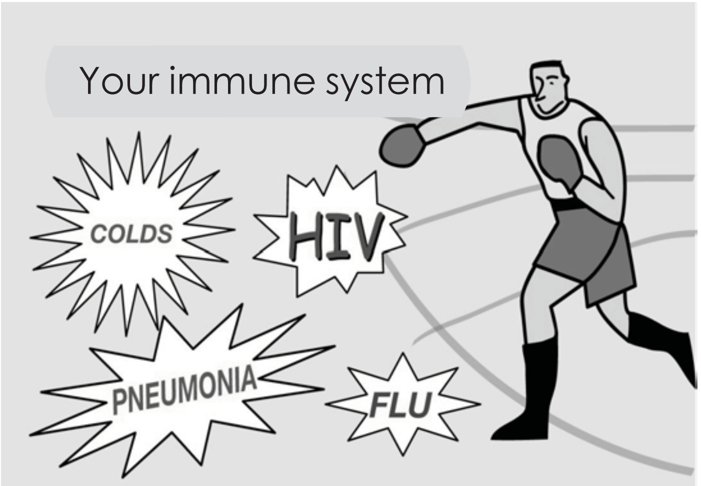
Conversation B: The Immune System

Objective: The objective of this conversation is to help your client 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 client'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 client'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 500-1600 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 teach back exercise of what was previously covered.

Objective: The objective of this conversation is to help your client 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, and rabies.

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

> ***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.

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

Instructions to PN: Help your client 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 teach back exercise of what was previously covered.

Objective: The objective of this conversation is to help the client 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,* <u>or</u> 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 clients that the AIDS diagnosis is technically reversible. However, you should discuss this together with your client 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 teach back exercise of what was covered.

Objective: The objective of this conversation is to define the term *viral load* and to help your client 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. The amount is called your **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 client 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:

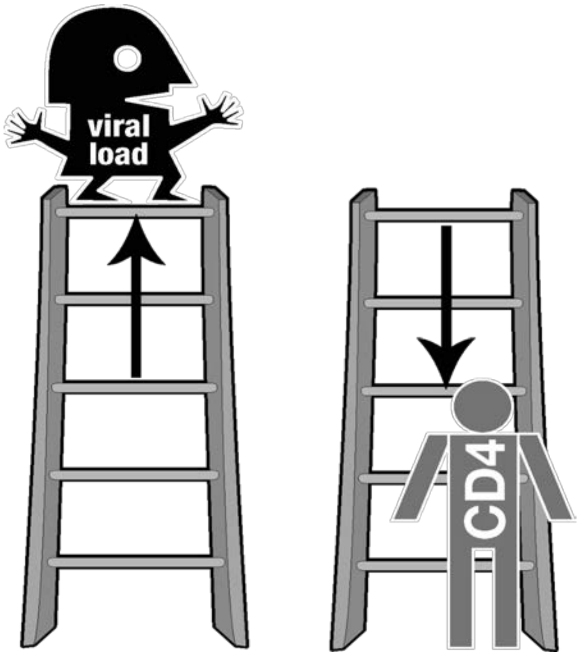
- Successful treatment with HIV medication can reduce the viral load to below 50/75/400 copies (depending on the test used), to an undetectable level.
- As the viral load goes up the number of CD4 cells goes down. As the viral load goes down the CD4 goes up.

- 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 than100) or if you have had a low CD4 count for a long time.

Checkpoint:

Make sure that your client 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 STEPS to Care Client 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 client.

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 client 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 client'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 client 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 STEPS to Care Client Workbook: CD4 and VL Journal.

Directions for Tool: CD4 and Viral Load Journal:

Many clients 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.

Conversation F: What is an Opportunistic Infection?

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

Objective: The objective of this conversation is to teach your client 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 STEPS to Care Client Workbook: Sites of Possible Infection.

Directions for Tool: Sites of Opportunistic Illness
Use the body map in the STEPS to Care Client 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 client'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 possible infections listed below. It may not be necessary to go in depth with each OI; tailor the discussion to your client.

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 clients 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 uterus 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 client 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 teach back exercise of what was covered.

Objective: The objective of this conversation is to help your client 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 STEPS to Care Client Workbook: How is HIV Transmitted?

Ask: How is HIV transmitted?

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

- A person can get HIV from anyone who has HIV; however, someone with an undetectable viral load has effectively no risk of transmitting HIV during sex.
- 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, rectal fluid* and *semen and pre cum.*

A person can get HIV through:

- Vaginal or anal sex with someone who has HIV without a condom or medicines to prevent or treat HIV (e.g., PrEP or ART).

Note to PN: Make sure that your client 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 riskiest in terms of getting or giving HIV.

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

- 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.

- Your HIV-negative partner may want to consider using pre-exposure prophylaxis (PrEP), a daily medicine that is taken every day to prevent HIV infection.
- You may want to talk to a partner about post-exposure prophylaxis (PEP) if you think they may have been exposed to HIV (for example, if they had anal or vaginal sex without a condom or if the condom broke during sex). Your partners should talk to a health care provider right away (within 72 hours) after a possible exposure. Starting PEP immediately and taking it daily for 28 days will reduce their chance of getting HIV.

Note to PN: Follow the links above for more information on PrEP and PEP from CDC's website.

Assessment of client'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 client can negotiate these options with a partner. Ask your client 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 client'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 client.

Refer to visuals on Page 28 of the STEPS to Care Client Workbook: How is HIV Transmitted?

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 client 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 client 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 client 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 STEPS to Care Client 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 five fluids are involved).

Refer to visuals on Page 29 of the STEPS to Care Client Workbook or on mystctools.org in How is HIV Transmitted? (How does HIV affect my body?).

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 or downloaded and printed from mystctools.org.

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 client will be able to:

- Identify some of the messages they are receiving from their community and how they affect them
- Map their non-STEPS to Care 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 STEPS to Care Client Workbook or pages from mystctools.org.
☐ Bring pens and highlighters of different colors.
☐ Review your notes on this client 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** Tools also available on mystctools.org
Review previous topic	
A: Understanding Social Support	
B: Community Influences	Tool: Talking to Others (Workbook page
C: Disclosure and Networks of Community Support	Tool: My Support Network (Workbook page 35)
D: Contact Information	Tool: Contacts (Workbook 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 client during your last session together. Ask your client 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 client to assess their social supports and think about ways to strengthen their social support network. You will help your client identify people who provide support, and emphasize people who are not STEPS to Care program staff. You and your client 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 client 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 client'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 client feels about themselves and their HIV. Your client 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 STEPS to Care Client Workbook: Talking to Others.

Instructions for PN: To help your client 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 client to fill in the section

   "How I talk about my illness."

   - Tell your client 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 client 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 client has actually heard, or things your client thinks people would say.

3. Unfold the paper and compare the two sides.

4. Ask your client 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 client to think positively during this part of the exercise.
   - Review the differences between the way your client's community talks about HIV and the way the client would talk about the illness with someone they care about. Tell your client that by talking to people about their illness and speaking about it in words that they choose, the client can help others to talk about and understand HIV in the same way they do.

Conversation C: Disclosure and Networks of Community Support

Objective: The objective of this conversation is to help your client 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 client begin thinking about new supports he/she could reach out to.

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

***Turn to Page 35 of the STEPS to Care Client Workbook*: *My Support Network*.**

Instructions to PN:

1. Place your client's name in the center of the *My Support Network* tool. Explain to your client how the tree is set up with the client in the center and their supports located around them.
2. Have your client name people who are supports in their life. Make sure he/she names specific people (not just agencies).
    - If your client names you or the STEPS to Care program 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 client 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 client struggles to name supports, some areas to consider are: family, friends, medical providers, social service and community services.
    - Ask your client 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 STEPS to Care Client 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 client 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 client. Using what your client 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 client 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 client to have realistic expectations of what might happen after a disclosure conversation. Make sure your client does not feel pressured to disclose to someone if they are not ready to—*disclosure is always the client's choice*.

Instructions to PN: Now have your client go back to the My Support Network tool on page 34 of the STEPS to Care Client 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 client 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 client wants to increase or decrease their contact with these people.
- Discuss ways in which your client 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 client 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 client 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 client. You can either play the part of the client, or the person your client wants to disclose to. Ask your client 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.

Conversation D: Contact Information

Turn to Page 39 of the STEPS to Care Client 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 clients may not be comfortable filling out the form provided. You can encourage your client 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 client 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 client 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 client 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 client 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 client 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?

Topic 9: Adherence Strengths and Difficulties

Learning objectives

After completing this topic, the client 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 STEPS to Care Client Workbook or pages from mystctools.org.
- ☐ Review chart progress notes for course of events.
- ☐ Review chart for information about days ART missed.
- ☐ Review your notes on this client 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** Tools also available on mystctools.org
Review previous topic	
A: Your ART Experience	Discussion guide: Your ART Experience (FG page 149)
B: Adherence Strengths and Difficulties	Tool: Adherence strengths and difficulties (Workbook page 44)
C: Difficult Days	Tool: Adherence Issues (Workbook page 43) Resource: Action Plans for handling common difficulties (FG page 156)
Wrap Up	

Review

Let's go over what we talked about last time. Review areas that were particularly challenging for your client during your last session together. Ask your client 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 clients understand their strengths and difficulties around adherence. This topic also addresses specific times when it is difficult to take HIV medications. You and your client 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 clients to reflect on the positive changes they have already made around adherence and to identify the barriers still preventing there 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 STEPS to Care Client Workbook: Adherence Strengths and Difficulties.

Instructions to PN: Use the "**Your ART Experience Discussion Guide**" on the next page to talk about how your clients feel about taking ART, and how they feel about their time in STEPS to Care. Help your client 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 client. Be sure to recognize and appreciate **all strengths**, including those not directly related to adherence or health management. Then, talk about **challenges** that your client still needs to work on and overcome.

As **strengths or skills** acquired or developed during HIV Self-Management are mentioned in this discussion, write them down on **page 44 of the STEPS to Care Client Workbook**. Also write down **challenges** that your client is still struggling with. If you start a list of things that are **strengths** for your client 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 client, 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 working on STEPS to Care?
- How did you feel, physically, emotionally and mentally?
- What were your thoughts about your heath?
- How were you taking your HIV medicines?
- What was your housing, food and social services situation like?
- What were your thoughts about the STEPS to Care 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 STEPS to Care program done for you?
- How has health promotion contributed to change?
- What role did your relationships with people at STEPS to Care 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 client identify adherence strengths and difficulties, and it will also help you to understand how your clients perceive their strengths and difficulties. You can use information about each client's strengths and skills to anchor your conversations about adherence.

Turn to Page 44 in STEPS to Care Client 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 client said].
Ask:	Am I correctly understanding the strengths you identified?

Instructions to PN: Note any corrections your client 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 proudest 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 client identifies on the **Strengths** side of the tool.

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

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 client 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 client said].

Ask: Am I correctly understanding the difficulties you identified?

Instructions to PN: Listen and watch your client 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 client identifies on the **Difficulties** side of the tool.

Say: Let me see if I understand the **difficulties** you identified. [List all the **difficulties** your client 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 client 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 clients 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 client is not addressing. If this happens, remember that this discussion is your opportunity to understand how your clients understand their life experiences. Guard against trying to educate your clients about how you understand their barriers.

Conversation C: Difficult Days

Objective: The objective of this conversation is to identify some of the things that happen on days when the client 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 clients may not relate to these questions immediately. Clients 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 STEPS to Care Client Workbook: Adherence Issues.

Instructions to PN: On the "Issue" side of the tool, write down any of the barriers to adherence that your client 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 client 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 client to try the plan for a set period of time.
7. **Refer** back to this tool regularly with your client 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 client 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 clients throughout the day (e.g., after brushing teeth or while watching television).

Client misplaces/loses pills

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

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

- Explore the feeling with the client.
- Refer back to the "Your Client'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 client's experience is.

Side effects

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

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 client 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 client 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 client's preferences.
- ☐ Bring STEPS to Care Client Workbook.
- ☐ Bring a copy of **Contact Information Form.**
- ☐ Bring a calendar.
- ☐ Review your notes on this client 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 Tools also available on mystctools.org
Review previous topic	
A: Appointment Logistics	Tool: Preparing for Your Appointment (Workbook page 47)
B: Communicating with Providers	Tool: Pre-Visit Form (Workbook page 47) Discussion Guide: Communicating with Providers (FG page 162)
C: Keeping Track of Medical Information	Tool: Post-Visit Form (Workbook 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 client during your last session together. Ask your client 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 client how to make and keep appointments as well as how to communicate effectively with providers. Clients have a wide range of skills in this area. Evaluate how your client 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 client'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 STEPS to Care Client Workbook.

Instructions to PN: Fill out logistical information for your client'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 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 client 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 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?

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 client wants to discuss with their provider. This conversation will also help the client learn how to improve communication with the provider. This conversation helps your client ask hard questions and build confidence in interacting with their provider.

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

Turn to the Preparing for Your Visit form on Page 47 of the STEPS to Care Client Workbook.

Discuss the reasons for filling out the form with your client:	For many people, filling out the Pre-Visit form improves confidence, helps makes 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?

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 client. 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 client during this conversation include:

- The client and the provider are both parts of the same team.
- The provider doesn’t see the client every day and doesn’t know all that’s going on, so it’s important for the client to tell the provider things that may be relevant to their health and to raise any questions or concerns.
- If the client 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 clients to question their providers on anything they don’t understand or agree with. If there is any disagreement with the provider, or the provider seems offended, they may want to consider changing to a provider who is willing to listen to their concerns.
- Decisions are ultimately made by the client, not the provider.

Conversation C: Keeping Track of Medical Information

Objective: The objective of this conversation is to help your client 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 STEPS to Care Client Workbook: After Your Visit.

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

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 client 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 STEPS to Care Client Workbook.
☐ Review your notes on this client 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** Tools also available on mystctools.org
Review previous topic	
A: Intro to Health Maintenance	
B: Building Client-Doctor Relationships	
C: Routine Questions and Tests at the Doctor's Office	
D: Appointment Tracking	Health Maintenance Appointment Tracker tool (Workbook page 45)
E: Roles of Different Service Providers	Tool: Contact Information (Workbook page 39)
Wrap Up	

Review

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

Ask your client 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 client will discuss how your client 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 client 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 checkup, 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 checkup. 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 Client-Doctor Relationships

Objective: The objective of this conversation is to help your clients 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 client shares 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 client 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. These tests are typically performed by your primary care provider (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 client is probably familiar with many of these questions and tests that occur during regular follow-up appointments. Ask your client 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 client is already familiar with.**

Taking a general history

Your doctor will ask how you 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 client 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
- 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 of your 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.
- It is a good idea to talk to your doctor about the **Gardasil** vaccination which is recommended for women AND men 26 years of age or younger.

Vaccinations

If you have HIV infection and your CD4 count is 200 or greater [1], talk with your doctor about:

- Influenza vaccine each year to protect against seasonal flu
- Tdap vaccine to protect against whooping cough and tetanus
- Pneumococcal vaccine to protect against pneumonia and other pneumococcal diseases
- Meningococcal conjugate vaccine series which protects against meningococcal disease
- Hepatitis B vaccine series to protect against hepatitis B
- HPV vaccine series to protect against human papillomavirus if you are a man or woman up to age 26 years
- MMR vaccine to protect against measles, mumps, and rubella if you were born in 1957 or after and have not gotten this vaccine or do not have immunity to these diseases
- Varicella vaccine to protect against chickenpox if you were born in 1980 or after and have not gotten two doses of this vaccine or do not have immunity to this disease

If you have HIV infection and your CD4 count is less than 200[2], talk with your doctor about:

- Influenza vaccine each year to protect against seasonal flu
- Tdap vaccine to protect against whooping cough and tetanus
- Pneumococcal vaccine to protect against pneumonia and other pneumococcal diseases
- Meningococcal conjugate vaccine series which protects against meningococcal disease
- Hepatitis B vaccine series to protect against hepatitis B

- HPV vaccine series to protect against human papillomavirus if you are a man or woman up to age 26 years

Source: https://www.cdc.gov/vaccines/adults/rec-vac/health-conditions/hiv.html

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.
- If a hard bump of a particular size forms, then the person may have been exposed to TB." Further testing and examination is recommended.
- People living with HIV and who have TB need to be treated with antibiotics to eliminate the bacteria from their system. Your doctor will develop a treatment plan for you.

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 client 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 client has either virus.

Screening for opportunistic infections

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

- Clients 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 client 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 STEPS to Care Client 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 checkups 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 client of the different service providers that may be available to your client in the hospital, community health center or medical practice that your client visits, and to explain the roles of each provider.

Instructions to PN: Go over the following list of types of providers with your client 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 or Patient Navigators

- 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 STEPS to Care Client Workbook: Contact Information.

Instructions for PN:

1. Work with your clients 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 clients.

2. Make sure the contact information for each provider connected to your client 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 clients to reach out for help from their providers when they have questions or concerns.

3. Review a few scenarios with your clients 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 clients 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.

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 client 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

Preparation

☐ Bring STEPS to Care Client 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 client's file
☐ Review your notes on this client 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** Tools also available on mystctools.org
Review last topic completed	
A: What is Harm Reduction?	
B: Risky Sex and Possible Harms	Tool: Harm Reduction Body (Workbook page 51)
C: Safer Sex	
D: Why Safer Sex is Important for People with HIV	Tool: "But why?" (Workbook page 52)
E: My Sexual Behaviors	Tools: Risk continuum (Workbook page
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 client during your last session together. Ask your client 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 client and the PN will discuss why safer sex is particularly important for people with HIV and their partners. Next, the PN will ask the client 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 client'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 client's bedroom, etc.);
2. Acknowledge when your client looks uncomfortable;
3. Lighten up the conversation when necessary;
4. Tailor the discussion and the completion of the tools around your client's comfort level;
5. Demonstrate a high level of ease in talking about sex and related topics;
6. If you notice that your client 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 clients if they would like one, and start the conversation from there.

Explain to your client 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 clients 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 client 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 STEPS to Care Client Workbook: Harm Reduction Body.

Objective: The objective of this conversation is to have your client 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 clients 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 client.

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 STEPS to Care Client Workbook: Harm Reduction Body Map.

Instructions for PN:

1. Ask your clients to list some sexual acts and behaviors that they are familiar with or engage in. You can add behaviors that your clients 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 clients just identified. These ideas should come from the clients, 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 clients 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. <u>Safer Sex</u> 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 client 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 client 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 STEPS to Care Client Workbook: But Why?

Objective: The objective of this conversation is to have your clients 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 client provides about **why** safer sex is important around the center circle on page 52 of the STEPS to Care Client 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 client 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 couples in which one or both are HIV+, and who want to have a child, should consult their doctors
- Other issues that may be beneficial to include, if the client did not think of them, are:
    - **HIV re-infection or super-infection**, which means the client 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.

- HIV-negative people becoming infected with HIV;
- Staying adherent to medication reduces the risk of transmitting the virus to uninfected partners
- Sexually Transmitted Infections (STIs) are particularly dangerous for people with compromised immune systems;
- Staying adherent to medication when pregnant reduces the risk of mother-to-child transmission;
- The importance of speaking to a physician about concerns about sexual health.

Note to PN: Emphasize re-infection and make sure that your client 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.

Conversation E: My Sexual Behaviors

Objective: The objective of this conversation is to help your client 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 and prevent HIV transmission.

Note to PN: If the clients 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 STEPS to Care Client Workbook: Risk Continuum

Instructions for PN:

1. Explain to the client that "sexual behaviors" should be defined broadly in this activity. Rather than only considering penetrative sex, have the client think about anything that is sexually exciting or arousing.
2. Write the client's sexual behaviors along the continuum, wherever the behavior fits, from "High Risk" to "Low Risk," on Page 53 of the STEPS to Care Client 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 client's previous or current sexual behaviors, switch to a different color pen or marker. Ask your clients 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 clients 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 client 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
    - Get tested and treated for other sexually transmitted infections (STIs) and encourage your partners to do the same
    - Staying adherent to HIV medication so that your viral load is suppressed or undetectable.
    - Talking to your doctor and partner about using pre-exposure prophylaxis (PrEP), a daily medication that can reduce an HIV-negative person’s chance of getting HIV if they take it every day.
    - Talking to your doctor and partner about post-exposure prophylaxis (PEP) if you think a partner may have been exposed to HIV during sex (within 3 days)

6. Put a circle around reduced risk behaviors that the clients 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 clients 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 are some things you can start to change right now? (address both sexual behaviors, adherence and options like PrEP or PEP)
Ask:	What things might get in the way of your being able to change your behavior?

Feedback: Address the concerns your client has expressed. If your client 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, staying adherent, getting tested and using PrEP or PEP.

Instructions for PN: After you have discussed these points, ask your clients if they want to practice a negotiation conversation with you. You can play the role of the client and the client 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 client is more comfortable, switch roles.

Conversation F: Condom Demonstration

Objective: The objective of this conversation is to discuss any ways in which your client 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 client is done, the PN should do the demonstration, emphasizing anything that the client 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 client 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 clients if they would like to demonstrate how to put on the condom again. The clients should explain each step in their own words, being sure to include any new information shared by the PN.

Offer your clients 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 clients 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 client 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 STEPS to Care Client Workbook.

☐ Review notes about substance use in client's file.

☐ Discuss the client'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 client's file.

☐ Review your notes on this client 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** Tools also available on mystctools.org
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 (Workbook page 54)
E: Relationships and Substance Use	
F: Substance Use and HIV Transmission	
G: Create a Harm Reduction Plan	Risk Continuum (Workbook page 53)
Wrap Up	

Review

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

Review any areas that were particularly challenging for your client during your last session together. **Ask your client 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 client is ready to discuss substance use harm reduction with you.

Try hard to discuss this topic with:

- Clients who you know are actively using and are open with you or others at your STEPS to Care program about it
- Clients you suspect are using but are not open about it

Try to discuss this topic with:

- Clients 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:

- Clients who are open about being in long-term recovery (more than two years)
- Clients who you do not suspect use currently or within the past two years

Instructions to PN: Discuss the following points with your client. If client 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 clients who are using or who you suspect are using

Say: (if appropriate):	In your annual Assessment or Reassessment, you expressed a history of substance use, so today we're going to work on that.
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 are 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 clients 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 clients 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 client says yes, do not discuss this topic with them now.
If client 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 clients 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 clients the impression that substance use isn't harmful as long as it is "safe."

For all clients

Say: I like talking about this with all of my clients. 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 client, some of the conversations may not be relevant to all clients.

You do not need to take notes during these conversations, unless you want to and your client is comfortable with it. However, be sure to document in your progress note what you learn about your client as well as what you think your client learns during these conversations.

Conversation B: Introduction to Harm Reduction

Objective: The objective of this conversation is to help your client 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 client 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 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 client 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 client 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 client 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 clients' 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

Objective: The objective of this conversation is to discuss 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 client are on the same page.

Note to PN: Before you have this conversation, it will be important for your client 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: You will use the chart that is currently available in the Client Workbook: Substance Chart.

If your client is not actively using, go over this chart if client expresses an interest in it; otherwise, client can just keep it as a reference. Check in with clients 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 chart with your client, focusing on the drugs that are currently used by your client. Consider also discussing drugs formerly used by the client, drugs used by the client's partner or other people the client knows, or any other substances the client expresses an interest in learning about. You do not need to go over the whole chart if it is not all relevant to your client.

Turn to Pages 54 of the STEPS to Care Client Workbook: Substance Chart

Ask:	Could you please look at this chart and read the different names used for the drugs (e.g., coke, blow for cocaine)?
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 client says with information from the chart.

Ask: How does this substance impact a person's behavior and health?

Complete what the client says with information from the chart.

Ask: Do you know if this substance interacts with ART?

Complete what the client 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.

Say: Although you may feel uncomfortable at first, you should talk with your doctor what recreational drugs you are using. That way, your doctor will know how the substances you are using affect your HIV drugs and your overall health. Most likely, your doctor will then be able to explain some things going on in your body.[1] As part of your care team, I can help you with these kinds of discussions.

---

[1] Source and for additional information: https://www.hiv.va.gov/patient/daily/alcohol-drugs/interactions-with-meds.asp

Conversation E: Relationships and Substance Use

Objective: The objective of this conversation is for clients 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 clients.

Note to PN: This conversation is an opportunity for you to practice **motivational interviewing**, to help your clients 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

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; **<u>it is not recommended for those in recovery.</u>**

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 client said].

Fill in gaps in client'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 client uses with or has sex with are more at risk for contracting HIV. It is also possible that clients can put themselves at risk for **HIV re-infection or super-infection**, which means the client 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

Objective: The objective for this conversation is to discuss strategies your client 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 STEPS to Care Client Workbook: Risk Continuum.

Instructions to PN: Together, write down the behaviors your client 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 use, 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 (Narrcan) 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 client 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 client 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 STEPS to Care Client Workbook.
- ☐ Bring two different color pens/markers.
- ☐ Review any notes about intimate partner violence in the client's file.
- ☐ Discuss the client's history of unsafe relationships and previous coping strategies with the Care Coordinator and/or other relevant STEPS to Care program staff.
- ☐ If relevant, call client 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 client 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** Tools also available on mystctools.org
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 68)
F: Additional Resources	Material: Resources (Workbook page 66)
Wrap Up	

Review

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

Review any areas that were particularly challenging for your client during your last session together. Ask your client 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 client may be in, talk to your supervisor.

Information for PN: In this topic, the concept of "Harm Reduction" will be introduced. The client and the PN will then apply a harm reduction perspective to the client's relationships. The client and PN will reflect on the client's relationships, discuss strategies for staying safe in relationships and then make a personal safety plan for the client. Adapt this topic to fit your client's circumstances and level of comfort. You can address a client's current or past unsafe relationships, or talk more generally about someone your client may know.

Note to PN: Make sure that you and your client will have **uninterrupted privacy** while completing this topic (i.e., the client'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 client 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 client's ideas begin the conversation. Add in any parts of the definition your client 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 client 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 and write down your client's answers in a chart like the one below:

Things I like	Things I don't like

Feedback: Respond to the information your clients 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 clients 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 clients identify abusive behaviors that they may be experiencing.

Note to PN: Many clients 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 clients 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 clients 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 STEPS to Care Client Workbook: Power and Control Wheel.

Instructions for PN:

1. Go through the Power and Control Wheel with your client. Discuss the different categories of power and control listed in the Wheel provided in the STEPS to Care Client Workbook and go over examples of each. Encourage your clients to come up with examples as well, from their own experiences or the experiences of others. Ask your client if they have ever experienced any of these things.
2. Write the client's personal examples on the Power and Control Wheel in the STEPS to Care Client Workbook.

<u>Definitions:</u>

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. **<u>Re-emphasize that your client is not at fault</u>**: 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 client about the resources available in dealing with these issues.

Conversation D: Identifying Safe and Unsafe Situations

Objective: The objective of this conversation is to think of practical ways in which your clients 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 clients who are currently in abusive relationships. It may not be applicable or useful for all clients; use your discretion in deciding whether this will be a beneficial conversation for your client.

Turn to Page 57 of the STEPS to Care Client Workbook: Safety Strategies Flow Chart.

Instructions for PN: Now that your client has begun identifying the harms of being in an unsafe relationship, transition to a reflection on unsafe occurrences that the client 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 clients list situations that made them (or others that they know about) feel unsafe in their current or previous relationship(s). The clients 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 clients 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 clients deserve to be safe and respected, and together you can think of ways that your clients can protect themselves. Ask your clients 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 clients 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 <u>the client's own ideas and strategies are empowering</u>.

Note to PN: It is possible that the client 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.

Conversation E: Personal Safety Plan

Objective: The objective of this conversation is to get your clients thinking about planning for potentially dangerous situations. The Personal Safety Plan will help your clients 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 STEPS to Care Client Workbook on page 68. 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 STEPS to Care Client Workbook and print it as a separate document from http://mystctools.org/tools/harm-reduction-safety-relationships .** You can then bring it back and forth to the client'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 clients 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?

Conversation F: Additional Resources

Objective: The objective of this conversation is to let your client 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.

Instructions to PN: Go over the resources that are available for people in unsafe relationships in your local area and the national resources in the Resources Chart. Your client 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 client during this session. Consider:

- Ability to talk about and share challenging issues
- Self-empowering strategies that the client 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 CLIENT FOR DISCUSSING THESE ISSUES! BE SURE TO TAKE THE COMPLETED TOOLS BACK TO THE OFFICE AND FILE THEM IN THE CLIENT'S CHART.*******

Resources

Health Care Provider		
STEPS to Care Program		
Care Coordinator		
Patient Navigator		
311	Connects to many government services	3-1-1
911	Connects to ambulances, fire services, and police	9-1-1
Addiction	SAMHSA's National Helpline / Treatment Referral Routing Service	1-800-662-4357
	National Council on Alcoholism and Drug Dependence	800-622-2255 https://www.ncadd.org/
AIDS	CDC-INFO / National AIDS Hotline	1-800-232-4636 https://www.cdc.gov/cdc-info/
	AIDSinfo	1-800-448-0440 https://aidsinfo.nih.gov/
Crisis	The National Domestic Violence Hotline	1−800−799−7233 http://www.thehotline.org/
	National Sexual Assault Hotline	800-656-4673 https://www.rainn.org/about-national-sexual-assault-telephone-hotline
	Youthline	877-968-8491 Text **teen2teen** to 839863 http://oregonyouthline.org/
Housing	Office of Fair Housing and Equal Opportunity (FHEO)	800-669-9777 https://portal.hud.gov/hudportal/HUD?src=/topics/housing_discrimination
	Section 811 Supportive Housing for Persons with Disabilities Program	https://portal.hud.gov/hudportal/HUD?src=/program_offices/housing/mfh/grants/section811ptl
Jobs and Careers	Job Accommodation Network (JAN)	800-526-7234 http://askjan.org/

	DOL Office of Disability Employment Policy: Employment and Living with HIV/AIDS: A Resource Guide	https://www.dol.gov/odep/topics/hivaids/EmploymentLivingwithHIVAIDS.pdf
Mental Health	National Suicide Prevention Lifeline	1-800-273-TALK (8255) https://suicidepreventionlifeline.org/
	MentalHealth.gov	https://www.mentalhealth.gov/
	SAMHSA Treatment Referral Helpline	1-877-726-4727
Nutrition	Department of Veterans Affairs: Diet and Nutrition for People with HIV	https://www.hiv.va.gov/patient/daily/diet/index.asp
	Smart Nutrition 101	https://www.nutrition.gov/smart-nutrition-101
	USDA: HIV/AIDS: Diet and Disease	https://www.nal.usda.gov/fnic/aidshiv
STDs	CDC National STD Hotline	1-800-232-4636 https://www.cdc.gov/std/

Topic 15: Healthy Living – Diet and Exercise

Learning objectives

After completing this topic, clients should be able to:

- Understand basic principles of good nutrition and food safety
- Explain why diet and exercise are important for clients living with HIV
- Discuss at least four changes they can make to improve their diet and increase exercise

Preparation

- Bring STEPS to Care Client Workbook.
- Review your notes on this client 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** Tools also available on mystctools.org
Review last conversation completed	
A: Healthy Eating Knowledge And Behavior Assessment	Your Daily Diet (Workbook page 58)
B: Why Does Eating Healthy Matter for People Living with HIV?	Discussion Guide: Managing HIV Symptoms and ART Side Effects (FG page 240)
C: Principles of Good Nutrition and Exercise	Your Daily Diet (Workbook page 58)
D: Barriers to Healthy Eating and Potential Solutions	Discussion Guide: A Healthy Diet Doesn't Have to be Expensive (FG page 251)
E: Food Safety	Discussion Guide: Six Techniques to Avoid Food Poisoning (FG page 256)
F: Setting Healthy Eating Goals	• Scratch paper • Your Daily Diet (Workbook page 58)
Wrap Up	

Review

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

Review any areas that were particularly challenging for your client during your last session together.

Ask your client 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 client and the PN will discuss what the client knows about nutrition and the client's current diet. Next, the PN will share principles of good nutrition with the client. Then, the PN will incorporate those basic principles into a conversation about how diet and exercise can help the client feel better, be healthier, and better manage symptoms associated with HIV. The client and PN will then review food safety practices. At the end of this topic, the client 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 clients should guide the conversations. Your clients 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 client'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 client'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 client 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 client 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 STEPS to Care Client 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 client 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 client mentions. For example, if your client 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 client's responses in the Daily Diet.

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 client 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 client 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 client 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 client 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 client's needs and interests, review the following tips: If your client 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 clients 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 clients discuss it with their doctor.

Conversation C: Principles of Good Nutrition and Exercise

Objective: The objective of this conversation is to help your client understand basic principles of good nutrition and exercise.

Turn to Page 59 of STEPS to Care Client 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 client: 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 STEPS to Care Client Workbook: Your Daily Diet.

Instructions to PN: Look at the foods your client listed in the Daily Diet as you talk about the concrete ways that following healthy eating could fit into your client'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 client: 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 client 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.

The FDA will require all US food manufacturers to eliminate trans fats from food products by 2018.

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 client 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.

Conversation D: Barriers to Healthy Eating and Potential Solutions

Objective: The objectives of this conversation are to assess client'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 client to these programs. Even so, it can still be very hard to eat healthy food, for example, in a place where there may be 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 a lot 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:

PN Note: Below is a list of common difficulties and potential solutions. Go over the ones that address the obstacles mentioned by your client.

If your client doesn't mention any obstacles:

Say: Some clients 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**
  - o **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**
  - o **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**
  - o **Advice**
    - Teach clients about freezing.
    - Make soup or a cooked dish for the week that uses the produce at risk for spoiling.
    - Make sure client has working refrigerator and adequate electricity. Refer to utility assistance if necessary.
- ☐ **Family likes to eat other things**
  - o **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.**
    - o **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**
    - o **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 client is eligible for food stamps.
        - Assess if client is using local food pantries and other community
        - Food resources.
        - Accompany the client to the market if client 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. 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 , 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 ½ your plate veggies, ¼ grains, and ¼ 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 is less expensive. 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: https://www.choosemyplate.gov/budget

Conversation E: Food Safety

Objective: The objective of this conversation is to introduce the concept of food safety to your client.

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 client 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 client didn't already mention.

Discussion Guide: Six Techniques to Avoid Food Poisoning

1. **Cleaning**: <u>Wash hands and clean surfaces often</u>
   - 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 <u>cooked before eating</u>. Raw fruits and vegetables should be well washed before eating.
3. **Separating:** <u>Don't mix raw foods with ready-to-eat ones</u>
   - 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**: <u>Cook to proper temperatures</u>
   - 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:** <u>Refrigerate right away</u>
   - 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 client 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 client 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 client already has and to discuss areas where your client 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 clients 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 client 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 client:

- 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 way around.
- Regularly check expiration dates.

Write down the ideas your client 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 client to select another option or to modify the goal. It is important to remember that what is do-able for one client 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 client should be able to:

- Review tools in the PN workbook
- Review the last conversations that were completed
- Review goals; review successes; see how far they have come
- Discuss the curriculum experience
- Discuss moving forward without these meetings and the future

Preparation

- Make sure that you've copied all of the completed STEPS to Care Client Workbook tools and filed them in the client's chart
- Review tools completed
- Bring STEPS to Care Client Workbook
- Review evaluation forms
- Review your notes on this client 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** Tools also available on mystctools.org
Review from last session	
A: Review Tools	All relevant tools in the Workbook
B: Review Goals	Care plans
Wrap Up	

Review

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

Review any areas that were particularly challenging for your client during your last session together. Ask your client 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 client has learned and emphasizing your client's confidence in these areas, particularly adherence to medications. Congratulate your client on making it through the curriculum!

Conversation A: Review the STEPS to Care Client 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 clients 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 STEPS to Care Client 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 client’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 client.

Instructions to PN:

- Review the client’s progress since the first conversation you completed together.
- Review each of the goals listed and discuss with your client whether the goal was met.
- Ask if there are any more goals the client wants to add.
- Emphasize successes with goals.
- If a goal was not met, find a partial success to discuss.

Say: The reason we no longer need to meet regularly is because you now have the tools and skills you need to take care of yourself, to be adherent to your medications and access 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 STEPS to Care program into your life?

Say: If you decide at any point in the future that you need to come back to the STEPS to Care 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: How do you want to commemorate the workwe 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 client, 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!