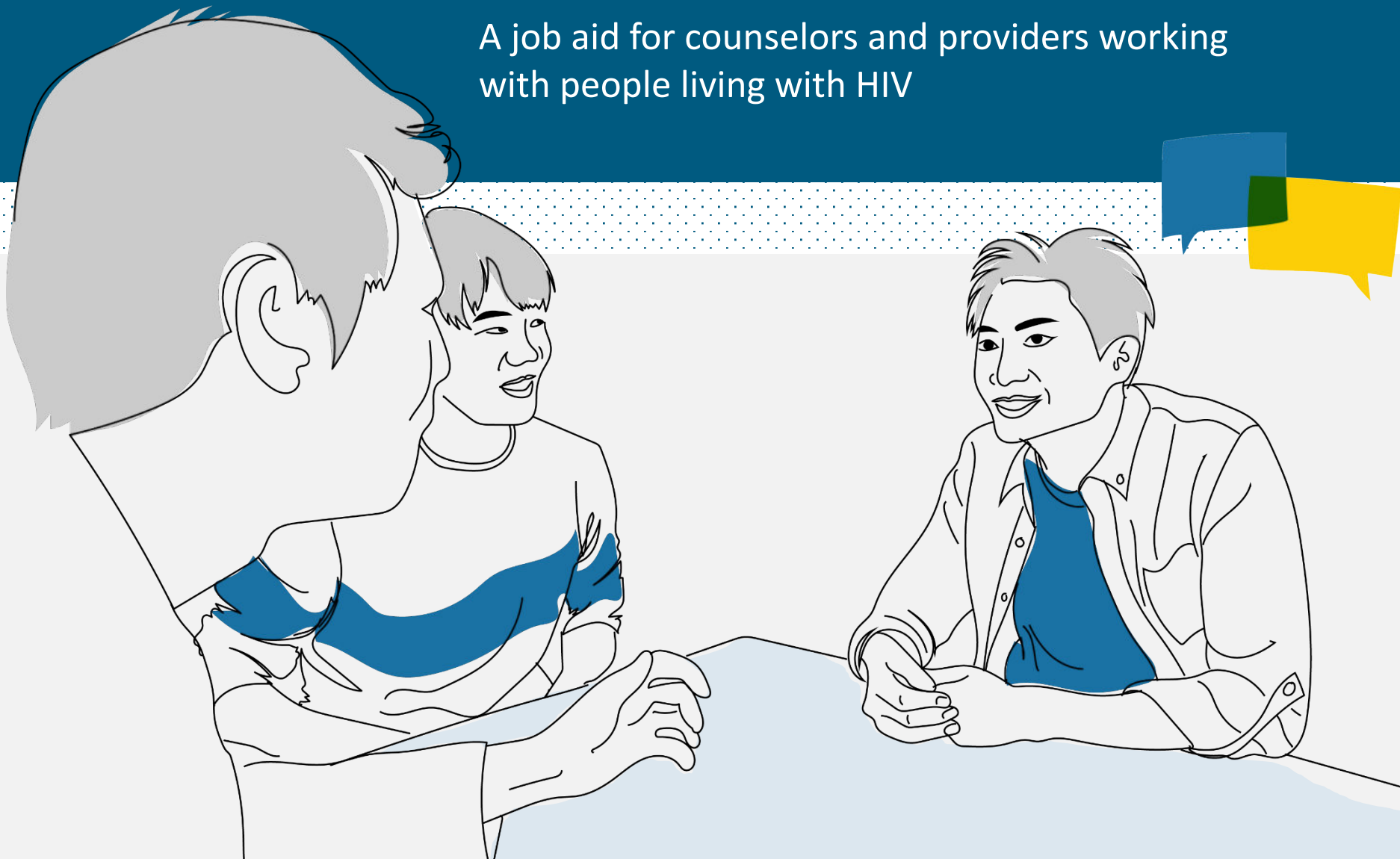


July 2020

HIV Treatment Adherence Counseling and Retention Guide

A job aid for counselors and providers working
with people living with HIV



This tool was adapted from the Life Steps for ART Adherence tool developed by Lena Anderson, John Joskin, and Steve Safren, and the Viral Load Monitoring Tool developed by ICAP at Columbia University.

It was developed with funding from the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) through the United States Agency for International Development (USAID) under the terms of the Meeting Targets and Maintaining Epidemic Control (EpiC), led by FHI 360, cooperative agreement # 7200AA19CA00002. Its contents are the sole responsibility of the authors and do not necessarily represent the views of the U.S. Government.

The tool is intended for use by counselors and providers in order to inform and support people living with HIV to plan for and remain on lifelong treatment.



How To Use This Tool

The purpose of this tool is to guide people living with HIV (PLHIV) to plan and achieve their treatment adherence goals. It can be used in the first or second counseling session to introduce a client to treatment and develop plans for adherence or in subsequent sessions when challenges arise that affect viral suppression (i.e., *enhanced adherence counseling*). When used in conjunction with the **Adherence Barriers and Interventions Log**, it can help counselors determine if a client may be at risk for missed appointments or loss to follow-up, identify supportive interventions, and track progress.

Structure

The tool has three different sections. Each section focuses on a specific topic or potential challenges clients might face in maintaining adherence.

Section 1. Introduction to HIV treatment. Slides 13-23 introduce clients to HIV treatment, resistance, and viral load; helps clients determine their own reasons/motivation for starting and/or staying on treatment; and helps clients identify challenges they have faced or may face in remaining adherent to their treatment.

Section 2. Addressing barriers to adherence. Slides 24-46 help guide clients to discuss potential barriers they have experienced or may potentially experience, and formulate a plan and backup plan for each barrier. Not all slides may be relevant for a given client.

Section 3. Returning to care and special situations. Tabs 47-67 are designed to guide clients through specific situations, such as unsuppressed or high viral load, or what to expect when returning to treatment after having stopped.

Directions

The flipchart should be positioned on a desk or table so that the client can see the pictures while you see the side with notes.

Each card contains one or more of the following elements:

- Talking points to prompt and guide discussions – each point is optional (clients will tire quickly if all points are read to them)

- Key messages** to convey to the client (printed in **bold**)

- Provider instructions* with specific guidance on how to optimize messaging and/or counseling

- A *Let's Review* box with questions to assess the client's understanding of what was discussed, and provide opportunities for motivational interviewing techniques to address misconceptions

- A *Document* box with instructions on the use of additional tools

The **Adherence Barriers and Interventions Log** tool can be used in initial and follow-up counseling sessions to document findings from the discussions. It should be included in the client's file, and updated with each session.

Card Topic (also shown on client card)

KEY MESSAGES

Also shown to the client



Let's Review

Points to guide review with the client

TALKING POINTS

- Notes to prompt and guide discussion
- Suggested steps for follow-up
- **Key points in bold**



Document

Tells providers which forms to use to document discussions with the client



Provider Instructions

Gives providers specific instructions about their interaction and conversation with the client

Setting the stage for a productive session

Steps you can take to ensure your client is comfortable sharing, planning, and problem solving with you.

- Choose a quiet, private space.
- Sit face-to-face, make eye contact.
- Speak clearly, respectfully, and in a non-threatening voice.
- Use terms the client can understand.
- Explain the limits of confidentiality. You will not tell the client's information to others unless you are concerned for their health and safety or the health and safety of others.
- Don't assume your clients lack knowledge. Before you present information, check what they already know.
- When presenting new information, stop frequently and seek the client's understanding of the material.

Maintain focus on the client's needs and motivations.



Motivational interviewing (MI) and communication skills

Communication skills are critical for supporting clients to initiate and remain on treatment. Use the following MI techniques where appropriate (example language provided below):

A. REFLECTIVE LISTENING (use “you” statements; interpret non-verbal signs to gather information, guide the conversation, and reinforce the client’s motivations for change)

- *You’re wondering if it matters if you take your meds.*
- *You are so overwhelmed that your health is the least of your problems right now.*
- *Let me see if I understand. You want to start treatment, but you are worried your partner will find out. You want to tell him or her, but this does not feel like the right time. Is that right?*

B. AFFIRMATION (accentuate the positive, recognize client’s worth, support, and encourage)

- *I appreciate you for being honest about the challenges you are facing taking your meds.*
- *You are clearly a resourceful person to manage so many challenges.*
- *You’ve worked really hard to take your medications despite these challenges.*

C. QUESTIONING (use open-ended questions that seek information and the client’s perspective)

- *What makes it difficult to take your meds everyday?*
- *What have you already done to try to take your meds every day?*
- *What do you think is likely to happen if you keep taking your meds as you are now?*

Motivational interviewing and communication skills

D. ASK-TELL-ASK (ask what the client knows; ask permission to offer new information; ask what the client thinks of the new information)

- *I get that question a lot. First, let me ask you, what have you heard about this?*
- *I understand you're feeling concerned about how your partner might react.*
- *Many people have felt the same way when they first encountered this problem.*
- *We've found that there are effective ways to talk to your partner about this.*
- *Would you like to hear more about that?*

E. RECOGNIZE WHEN CLIENTS TALK ABOUT CHANGE

- *When clients express desire, ability, rationale, need, plan, or commitment to change*

F. STRENGTHEN WHAT CLIENTS SAY ABOUT CHANGE (reflect, affirm, ask for examples, summarize)

- *Use the confidence/importance ruler; ask questions about desires, abilities, needs, or reasons for change*

Avoid communication “traps”

Avoid these:

- Assuming you know the client better than they know themselves
- Telling the client why they should change or pushing the client to agree to change when they aren't ready
- Arguing with the client
- Ordering or commanding the client to do something
- Blaming, shaming, or judging the client



Try these instead:

- Use open-ended questions to understand the client's knowledge, experiences, and challenges
- Learn about the client's own reasons for making a change
- Explore reasons why the client is resistant; shift the focus to something else if necessary
- Use simple and double-sided reflection when the client is not sure about a decision
- Involve the client in problem solving
- Emphasize the client is free to make decisions for themselves



Counseling Cue Cards Flipchart

- A. Introduction to counseling
- B. Starting ARV treatment
- C. Viral load basics
- D. Adherence planning
- E. Follow-up adherence counseling visit
- F. Returning to care after having stopped treatment
- G. Tips to improve taking meds
- H. Your viral load is low
- I. Your viral load is high
- J. ARVs are not working

COUNSELING CUE CARD TOPICS

Introduction to counseling

1. Starting ARV treatment

2. Resistance

3. Viral load: Undetectable = Untransmittable (U=U)

4. Why start and stay on treatment?

5. Planning to stay on treatment

6. Transportation to the clinic

7. Keeping appointment dates and obtaining medication refills

8. Making a daily medication schedule

9. Storing medications

10. Traveling away from home

11. Identifying social supports

12. Coping with side effects

13. Communicating with the treatment team

14. Substance use

15. Handling missed doses

16. Review and summary of adherence planning

17. Follow-up adherence counseling visit

18-20. Returning to care after having stopped treatment

21-23. Tips to improve taking meds

24. Your viral load is low

25. Your viral load is high

26. ARVs are not working well

Introduction to counseling



Introduction to counseling



KEY MESSAGES

- Treatment is a process and we are here to provide support.
- It can feel like a lot at first; feel free to ask questions at any time.
- If I don't have the answer, I will try to find it for you by our next session.

TALKING POINTS

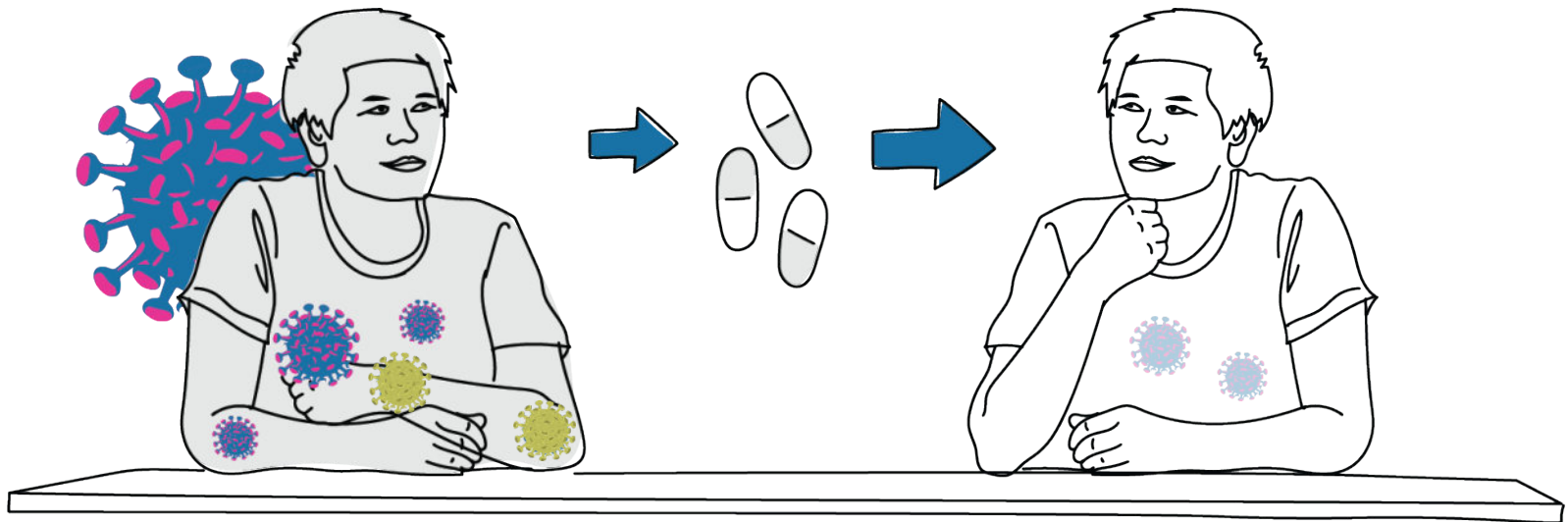
- Thank you for coming. It shows you are serious about taking care of yourself.
- My name is _____, and I am a [Title] working here at [Name of site].
- Today I would like to help orient you to your HIV treatment.
- My role is to support you to take your medication as you were advised and to help you live free from illness and the worry of passing HIV on to someone else.
- We are going to meet a few times over the next ___ months to ensure your treatment is working and to address any challenges along the way.
- You can contact me anytime you have a question or would like support.
- How does that sound to you?
- To begin with, what would you like to get from our discussion today?

SECTION

1

Introduction to HIV
treatment

1. Starting treatment

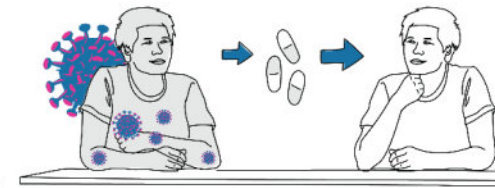


HIV treatment **stops HIV from making more copies of itself**, allowing you to stay healthy.

While treatment **will not cure HIV**, when you stay on it, **the amount of the virus in your body becomes very low and remains hidden.**

It is important to **take your meds every day** as prescribed.

1. Starting treatment



KEY MESSAGES:

- HIV treatment stops HIV from making more copies of itself, allowing you to stay healthy
- While treatment will not cure HIV, the amount of the virus in your body becomes very low and remains hidden
- It is important to take your meds every day as prescribed.



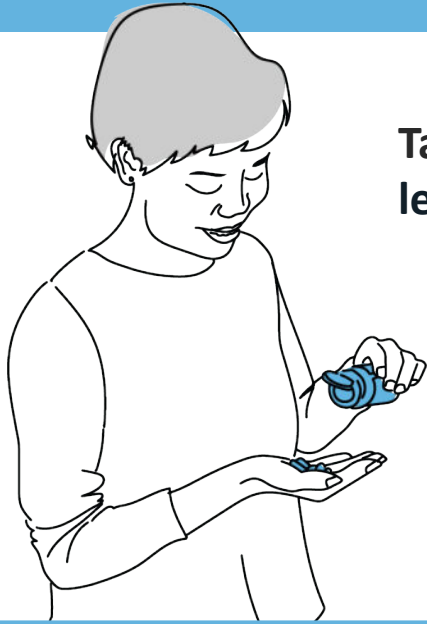
Let's Review

- In your own words, what does treatment do?
- What medicines do you take and when?
- What do you think may be hard about taking your meds every day?

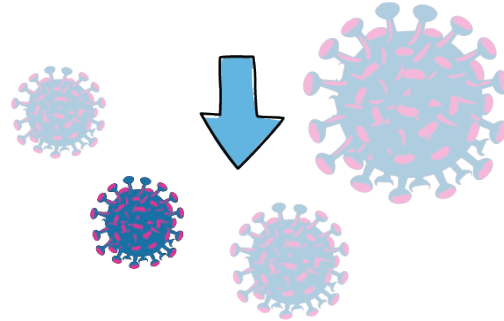
TALKING POINTS:

- What do you know about HIV treatment?
- When **HIV** is in your body without treatment, it makes **more of itself** which can make you **sick** and more likely to **spread HIV to sexual and injecting partners**, and from mother to baby during pregnancy, during delivery, and breastfeeding.
- **Treatment stops HIV** from making more virus and prevents you from getting sick.
- When there is enough medicine in your blood, HIV almost disappears from your body, remaining hidden.
- If you forget to take your meds or run out of medication, the virus makes more of itself and can lead to illness.
- **Treatment does not cure HIV**, which is why you must continue taking your meds even if you are feeling well.

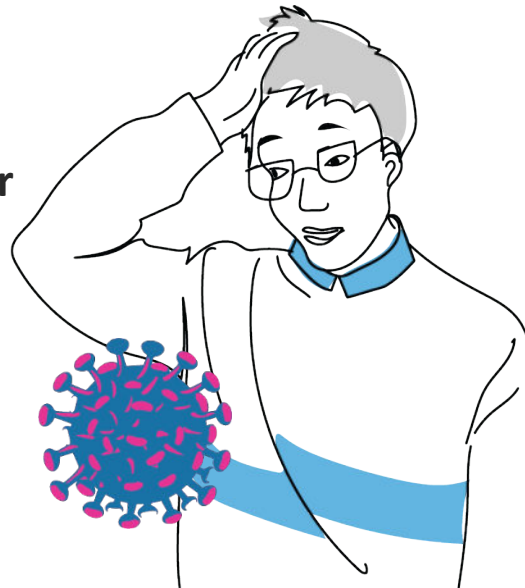
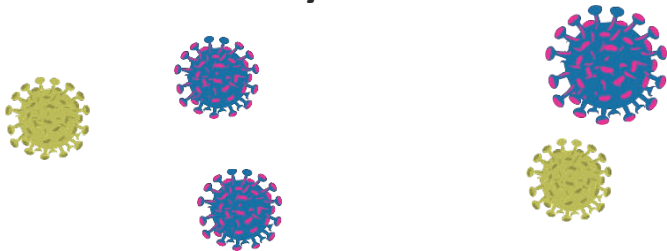
2. Resistance



Takes meds everyday = very low levels of the virus in the body



Misses doses = virus produces more of itself and your meds may no longer work as efficiently



If you miss too many doses of your medication, it will be harder to stay healthy and protect your loved ones.

2. Resistance



KEY MESSAGES

- If you miss too many doses of your medication, the virus can change and your treatment may no longer work.
- This can make it harder for you to stay healthy and protect your loved ones.



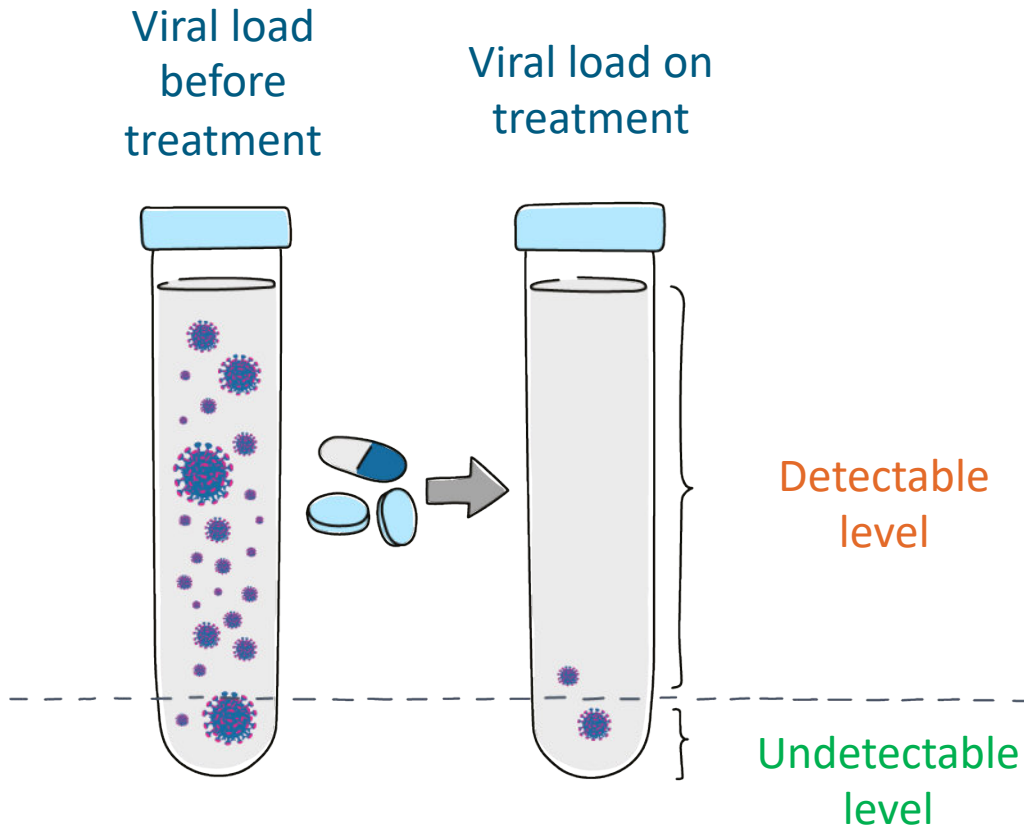
Let's Review

- In your own words, what can happen if you miss too many doses of your medication?
- What does it mean if you develop resistant copies of HIV?

TALKING POINTS

- The picture on the top is of someone who took their meds everyday. The meds stop the virus from making more of itself, and the person has very little virus in their body.
- The bottom picture is of someone who missed doses.
- When you miss doses, the virus can make more of itself. It can also change. See how they look different?
- If the virus changes, the medicine may no longer work. You might pass the new virus to someone else, and the medicine would not work for them either.
- This is why it is important not to miss doses.

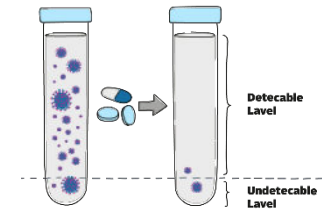
3. Viral load: Undetectable = Untransmittable (U=U)



- For those newly starting treatment, you will conduct a test in 6 months to see how much virus is in your body.
- **If treatment is working, the laboratory may not find virus in your blood. This is called **undetectable**.** HIV is still there, but at a very low level.
- If the virus cannot be detected, then you can no longer give HIV to others through sex.
- It is important to know your viral load results.

Source: <https://aidsinfo.nih.gov/understanding-hiv-aids/glossary/876/undetectable-viral-load>

3. Viral load: Undetectable = Untransmittable (U=U)



KEY MESSAGES

- You will conduct a test in 6 months to see how much HIV is in your body.
- If treatment is working, the laboratory may not find HIV in your blood. This is called **undetectable**. HIV is still there, but at a very low level.
- If it is undetectable, then you will no longer transmit HIV to others through sex.
- It is important to know your viral load results.



Let's Review

- In your own words, what is a viral load?
- What are the benefits of achieving a low viral load?
- For those newly initiated in ART, when will you return for your viral load test?*

TALKING POINTS

- The **viral load** test measures **how much virus** is in your body.
- If treatment is working, the laboratory may not find HIV in your blood. We call this being **undetectable**. It is still there, but at a very low level.
- If you stop your meds, HIV will make more of itself. You may not look sick, but over time, you will get sick and increase the risk of giving HIV to someone else.
- If your meds are working, and you take them every day, your viral load number will usually be less than 1,000 after six months. The goal is a low viral load number.
- **What might be some of the benefits of having a suppressed viral load?**
 - Prevent illness and live longer
 - Fewer hospital visits
 - If undetectable (VL <200ml), PLHIV cannot transmit HIV to sexual partners. However, condoms are important to protect against other sexually transmitted infections.
- Please come back in _____ to check your viral load.
- A late dose is better than a missed dose!

*Refer to national guidelines for appropriate timing and algorithms

4. Why start and stay on treatment?



Benefits of staying on treatment

1.

2.

3.

4. Why start and stay on treatment?



KEY MESSAGES

A simple sticker/notecard system in your home may help you remember why you need to stay on your meds.



Provider instructions

Ask what support the client might need from you, a friend, partner, or loved one to maintain motivation to stay healthy?



Document

Document the specific barriers you identify with the patient on the **Adherence Barriers and Interventions Log**.

TALKING POINTS

- **What could be some benefits or reasons for starting and staying on treatment?**
 - Please write them on a notecard.
- Some people use a system to help them remember their reasons for staying on treatment.
- You can place a reminder (like a sticker, string, or colored piece of paper) somewhere in your home to help you remember:
 - To take your medicine daily and on time
 - The reasons you just identified for taking your medication and coming to your appointments
- **If a sticker/card system might not work for you, what other plan might work for you?**

5. Planning to stay on treatment



Taking meds on time can be challenging.

Making a plan to address possible challenges will make it easier when they arise.

We will:

- A. Identify possible challenges
- B. Develop a plan and back-up plan to address each potential challenge

5. Planning to stay on treatment



KEY MESSAGES

- Taking meds on time can be challenging.
- Making a plan to address possible challenges will make it easier when they arise.



Provider Instructions

- Use MI techniques such as the importance/confidence ruler to gauge the client's readiness and confidence in initiating treatment
- Based on the challenges identified by the client, proceed to the relevant cue cards in this section

TALKING POINTS

- **On a scale of 1-10 how important is it for you to start and stay on treatment? (1 = not important; 10 = very important)**
 - What makes you a [CLIENT'S NUMBER], as opposed to a [INSERT LOWER NUMBER]?
- **How confident are you that you could do so, on a scale of 1-10?**
 - What might make you more confident?
- **What do you see as some potential challenges?**
- Based on the challenges you identified; we can discuss some methods to help you achieve your treatment goals.
 - With each one we will create a **plan** and **back-up** plan
 - This will help you stay healthy, and live the lifestyle you want to live.
- **How does this sound to you?**
- **Any questions before we talk about those challenges?**

SECTION

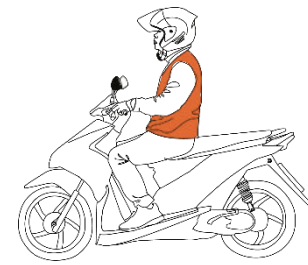
2

Addressing barriers
to adherence

6. Transportation to the clinic



6. Transportation to the clinic



KEY MESSAGES

Transportation challenges are common, but can be overcome by planning ahead.



Provider Instructions

- Use open-ended questions (for example:
What support might you need to make it to your next appointment?)
- Identify possible solutions based on potential risks for missed appointments



Document

Document the specific barriers you identify with the patient on the **Adherence Barriers and Interventions Log**.

TALKING POINTS

- How do you usually get to your medical appointments (walk, drive, moto, bus, taxi, friend?)
- What is your goal for getting to your appointments for HIV treatment on time?
- Identify potential barriers
 - What problems might you experience with transportation?
 - Examples: Not enough money, rainy season, transport not available at time of appointment, distance is too far, etc.
- What is your plan and back-up plan to address them?
 - Client will get to appointments by _____ (walk, bus, taxi, etc.)
 - In case of a problem (e.g., no bus fare, rain, etc.) client will get to appointment by _____

7. Keeping appointment dates and obtaining medication refills



7. Keeping appointment dates and obtaining medication



KEY MESSAGES

We can help you remember your appointments with an SMS or phone call.



Provider Instructions

Use open-ended questions:

- What support might you need to ensure you remember your appointments?
- How can I support you to help you disclose your status to a family member or loved one?
- Remind client of days/hours of operation of clinic.



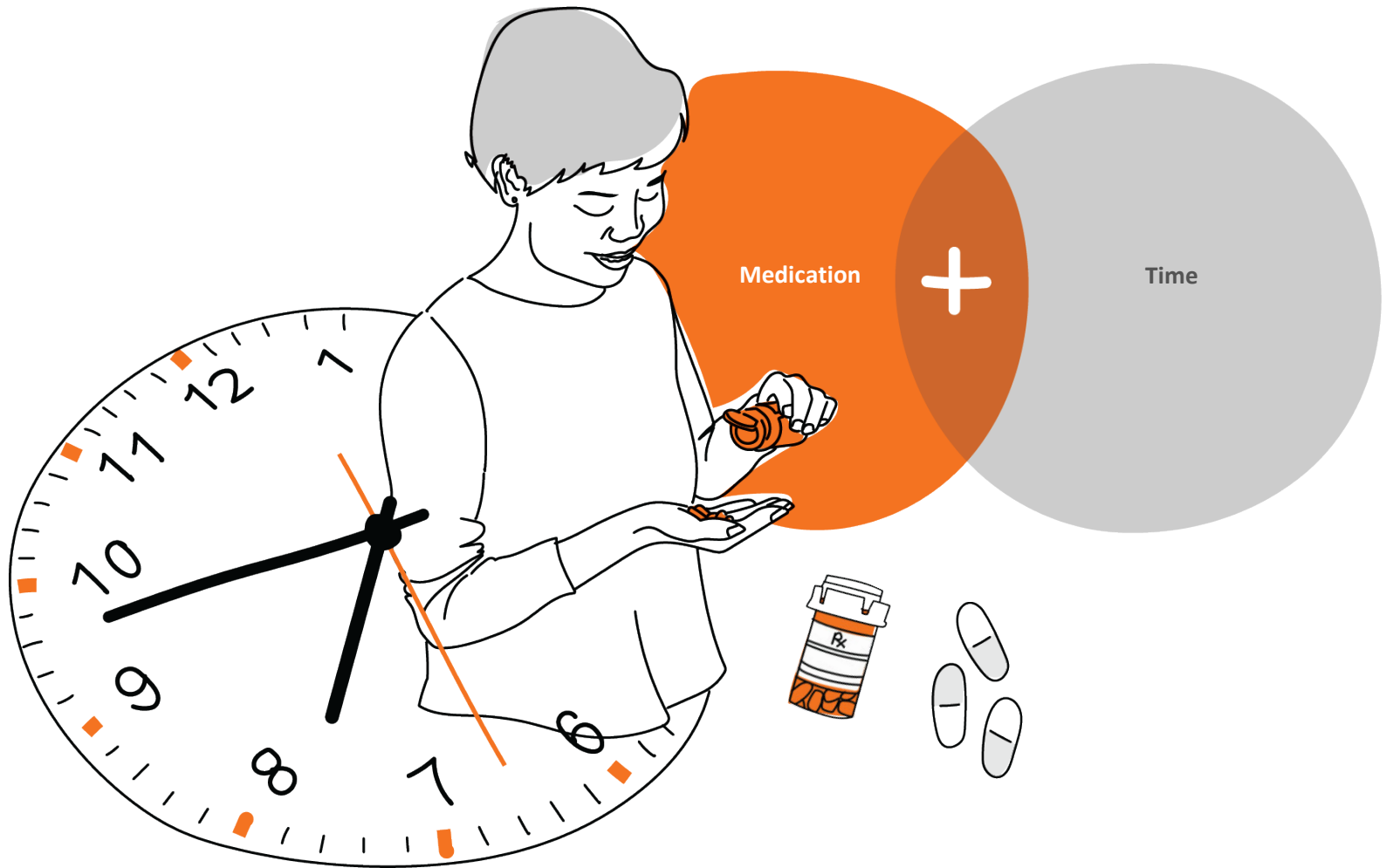
Document

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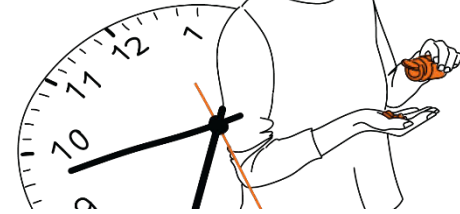
TALKING POINTS

- **What is your goal to keep appointments and obtain drug refills?**
- **What might cause you to miss your appointments?**
 - Illness, child illness, can't get time off work, etc.
 - Plan to change treatment site/moving soon
- **What might happen if people were to learn about your HIV status?**
 - Concerned about violence if HIV status were revealed?
- **Would you like support in disclosing your status to a family member or loved one?**
- **What can you or I do to make sure that you keep your appointment dates and obtain your refills?**
 - SMS/phone call appointment reminders from clinic
 - Have a friend pick up refills
 - Create a physical calendar
 - Set up automatic reminders using a phone or request support from counselor to send SMS reminders/calls

8. Making a daily medication schedule



8. Making a daily medication schedule



KEY MESSAGES

A simple cue in your home can help you remember to take your meds.



Provider Instructions

- **Use open-ended questions for example:**

What support might you need to ensure you remember when to take your meds?

- **Identify possible solutions based on potential risks for missed appointments**



Document

Document the specific barriers you identify with the patient on the **Adherence Barriers and Interventions Log**.

TALKING POINTS

- **How do you plan to take your drugs on time?**
 - We can make a medication schedule together to ensure you take your drugs on time and keep your virus level low.
- **What happens in your typical day from when you wake up to when you go to sleep?**
 - What might prevent you from taking your medication? When might it be harder for you? (identify specific times and situations)
- **What activities can you do at the same time that you take your meds so that each time you do it you will remember to take your meds?**

Strategies:

- Put them somewhere easy to remember, near something you use everyday; take at dinner or during a nightly TV/radio show.
- Place reminders around the house (a piece of tape, a string tied around a door, in the bathroom, etc.)
- Set an alarm on your phone.
- Carry spare meds wherever you go.
- Use pillboxes and a calendar to keep track of when meds are taken.
- Ask for extra meds if you will not be able to return to the health facility in time for your next refill.
- Work with a treatment buddy; request SMS reminders from a counselor.

9. Storing medications



Storage place:

Back-up storage place:

Extra supply medication will be carried in:

Extra supply medication will be stored inside:

9. Storing medications



KEY MESSAGES

It may help to have extra meds in a place you can always access them.



Provider Instructions

Use open-ended questions (for example:

- What is a reliable place you can store your meds?
- What challenges might arise if you store your meds in _____?



Document

Document the specific barriers you identify with the patient on the **Adherence Barriers and Interventions Log.**

TALKING POINTS

- **How do you plan to store your meds safely?**
- **What might get in the way of storing your meds properly?**
 - What would happen if other people saw your meds?
 - Are there young children in the house who may open your medication containers?
 - If so, where are some private places in your home that you can store your meds away from children?
 - Where might you keep some extra medicine just in case?

Possible solutions:

- Store extra meds in a purse/handbag, backpack, jacket, special compartment, sealed container, etc.;
- some place where it is always with you.
- Use an unmarked pill bottle.
- Use pill boxes rather than bottles.

10. Traveling away from home



10. Traveling away from home



KEY MESSAGES

If you plan to travel, you must have a plan for ensuring you do not run out of medication.



Provider Instructions

Assess likelihood of travel:

- Have you worked abroad or in another province in the past?
- Do you have plans in the next 6-9 months to travel to another province or country for work?

Have the client program your/the clinic's number in their phone.

Obtain a back-up number of a friend or family member who will know about the client's status and can help reach them if needed.



Document

Document the specific barriers you identify with the patient on the **Adherence Barriers and Interventions Log**.

TALKING POINTS

• What might prevent you from taking your ARVs while you are away from home?

- Running out of meds, stolen, arrests, violence, alcohol, not wanting others to see you take your medication, feeling good and not wanting to think about your medication, etc.

• If you are going on a trip or planning to work away from home, how will you ensure you have enough meds while gone?

- Plan: _____
- Back-up plan: _____
- Would you be comfortable letting us know if you plan to travel for a long period, or change your number?

Possible solutions:

- A peer, friend, or family member may be able to help get you your medication. Who could do this?
- How could someone send you your medication (i.e., bus, friend, family member traveling to that area, etc.)?

11. Identifying social supports



My treatment supporter:

Plan for asking them for help/disclosing my status:

Back-up plan (second option for treatment supporter):

11. Identifying social supports



KEY MESSAGES

If you plan to travel, you must have a plan for ensuring you do not run out of medication.



Provider Instructions

- **Assess for potential violence that may result from disclosure:**

Would you like to role play disclosing your status to a partner or loved one?

- **Prepare disclosure aides if necessary/appropriate.**
- **Refer individuals for support if they are at risk of or experienced violence.**



Document

Document the specific barriers you identify with the patient on the **Adherence Barriers and Interventions Log**.

TALKING POINTS

- **Who can provide support to you?**
 - Who currently knows your HIV status or is supporting you?
 - If no one, what are the benefits of someone knowing your status?
- **What challenges have you or might you face in identifying someone?**
 - History of violence (verbal, physical, other?); concerns about potential violence.
 - If you currently have a supporter, are you happy with their support?
 - If you don't have a supporter, do you have a friend or family member who can support you?
 - What might make it difficult for this person to provide you support?
- **Who could you ask for support? (Plan)**
 - If you have not told this person about your status, how will you tell them?
- **If the person you ask for support says they are unable to help you with treatment, who else could you ask? (Back-up plan)**
 - You do not have to disclose to anyone, but it may help to have someone close to you to support your treatment plan.

12. Coping with side effects



12. Coping with side effects



KEY MESSAGES

Some people experience side effects, many of which will lessen over time. Keep taking your medication until you see your doctor.



Provider Instructions

If the client has not yet begun taking ARVs, you can discuss potential side effects and develop a plan for addressing them when they arise.

- Who can you contact if you experience discomfort or side effects?



Document

Document the specific barriers you identify with the patient on the **Adherence Barriers and Interventions Log**.

TALKING POINTS

- **What side effects have you experienced before? If you haven't experienced any side effects, what have you heard about side effects related to HIV treatment?**
 - Common side effects: headache, nausea, muscle ache, dreams
 - Stay on treatment even if you are experiencing side effects.
- **What side effects have you experienced that made you stop your medication, or would make you stop if you had them?**
 - What have you done about any side effects you have experienced? Have you talked to your doctor about them?
- **What will you do if you experience any of the common side effects we have discussed?**

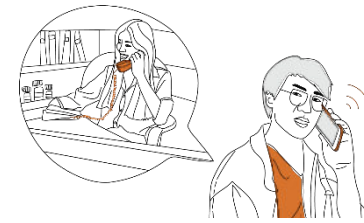
Possible solutions:

- Immediately contact your provider to discuss any side effects, and how you feel about your treatment. The provider will determine the need for treatment discontinuation or regimen change.
- Keep taking your medication until you have seen your doctor.
- Take with food (nausea/headache).
- Take at night (drowsiness/mood).

13. Communicating with the treatment team



13. Communicating with the treatment team



KEY MESSAGES

You should feel free to contact us anytime with questions, especially if you have complications or foresee complications in staying on treatment.



Provider Instructions

Assess ways in which the client feels comfortable making contact when they need support

- Support client to identify feasible options for contacting the health team if he/she has questions.



Document

Document the specific barriers you identify with the patient on the **Adherence Barriers and Interventions Log**.

TALKING POINTS

- **What will you do if you have questions or concerns related to your health?**
- What might prevent you from speaking to the doctor, nurse, or counselor at your clinic about any concerns that you have?
 - Do you sometimes forget questions or problems that you wanted to discuss with the staff at the clinic?
 - Are you planning to travel anytime soon for work? If yes, when?
- **What plan and back-up plans can we develop together in the event that you need to communicate with your treatment team?**
 - Who on your treatment team would you would feel most comfortable talking to?
 - How would you make sure to see this person during your visit?
 - If this person is not at the clinic on the day of your visit, who would you speak to about your concerns?
 - How would you feel about writing down questions for your provider on a piece of paper before your visit; how will you remember to bring this paper into your visit?
 - How do you feel about using your phone to call or send an SMS when you have a question? (provide number if desired)

14. Substance use



14. Substance use



KEY MESSAGES

If you use substances, it is important to ensure that your substance use does not prevent you from taking your meds everyday on time.



Provider Instructions

Refer the client to substance use treatment and counseling if desired and available.



Document

Document the specific barriers you identify with the patient on the **Adherence Barriers and Interventions Log**.

TALKING POINTS

- If you use substances regularly, we can plan together for how you will remember to take your medication while you are using. **What is your goal?**
- **Do you need help or support with stopping substance use?**
- **What aspects of your substance use might make it challenging for you to remember to take your meds?**
 - How often do you drink alcohol or use other drugs?
 - How might this interfere with taking your meds?
 - Do you forget to take medication when you are using?
- **What can you do to remember to take your medicine when you are using?**
 - Who are you usually with and where are you when you are drinking/using drugs?
 - Is there a friend/family member (e.g., support person) who could bring you medicine and encourage you to take it?
 - Would hearing an alarm/seeing stickers help you remember?
 - What if you were to change the time of your medication? Would that help you remember?

15. Handling missed doses



15. Handling missed doses



KEY MESSAGES

It's understandable to miss a dose from time to time. The important thing is that you get back on track as soon as you realize it. Define strategies to avoid missing future doses



Provider Instructions

Clients should never be made to feel foolish for missing one or more doses. Focus on strategies for the future to prevent missed doses.



Document

Document the specific barriers you identify with the patient on the **Adherence Barriers and Interventions Log.**

TALKING POINTS

- Some people forget to take their meds from time to time. Missing a dose is a learning experience.
- We will check in about this at the start of every session.
- What kinds of thoughts do you think may keep you from restarting your medication regimen if you miss a dose?
- **What would be the best way for you to respond when you miss a dose?**
 - What can you learn from missing a dose that will help you avoid it happening again in the future?
- Keep a positive attitude and try to return to your adherence goal as soon as possible.

16. Review and summary of adherence planning



16. Review and summary of adherence planning



KEY MESSAGES

You are taking charge of your own health by making these plans



Provider Instructions

Use MI techniques to reinforce what the client remembers from the discussion.

- Provide support for any items that the client may have forgotten.
- Always end on a positive note.
- Affirm that the efforts the client is making demonstrate how dedicated they are to protecting their health.



Document

Document the specific barriers you identify with the patient on the **Adherence Barriers and Interventions Log**.

TALKING POINTS

- Let's review what we have talked about today:
 - Motivation for starting (or) staying on treatment
 - Potential barriers to staying on treatment
 - Plans and back-up plans
- **Can you tell me the plans and back-up plans we agreed on today?**
 - PROBE ON, AND IF NEEDED, SUMMARIZE ANY PLANS AND BACK-UP PLANS THAT THE CLIENT DEVELOPED
- **Do you have any questions or thoughts about your plans, or anything else?**
- Thank you again for taking time today talk about why adherence to medication is important, and how to stay on treatment.
- I look forward to meeting with you again on _____.
- **Would you like a reminder for our next appointment?**

SECTION

3

Returning to care and
special situations

17. Follow-up adherence counseling visit

Welcome
back!



17. Follow-up adherence counseling visit



KEY MESSAGES

- Welcome back! Returning here shows you are committed to protecting your health.
- Together we will explore ways to help you stay healthy.



Provider Instructions

- **Explore barriers and challenges with the client.**
- **Use open-ended questions**
 - Affirm! Avoid having the client feel they have failed
 - Reframe: *You are really taking your health seriously despite facing a number of challenges.*
 - Note all challenges in the Log.
- **Go to the appropriate cue cards in the Adherence Planning section to review plans and adjust as needed**



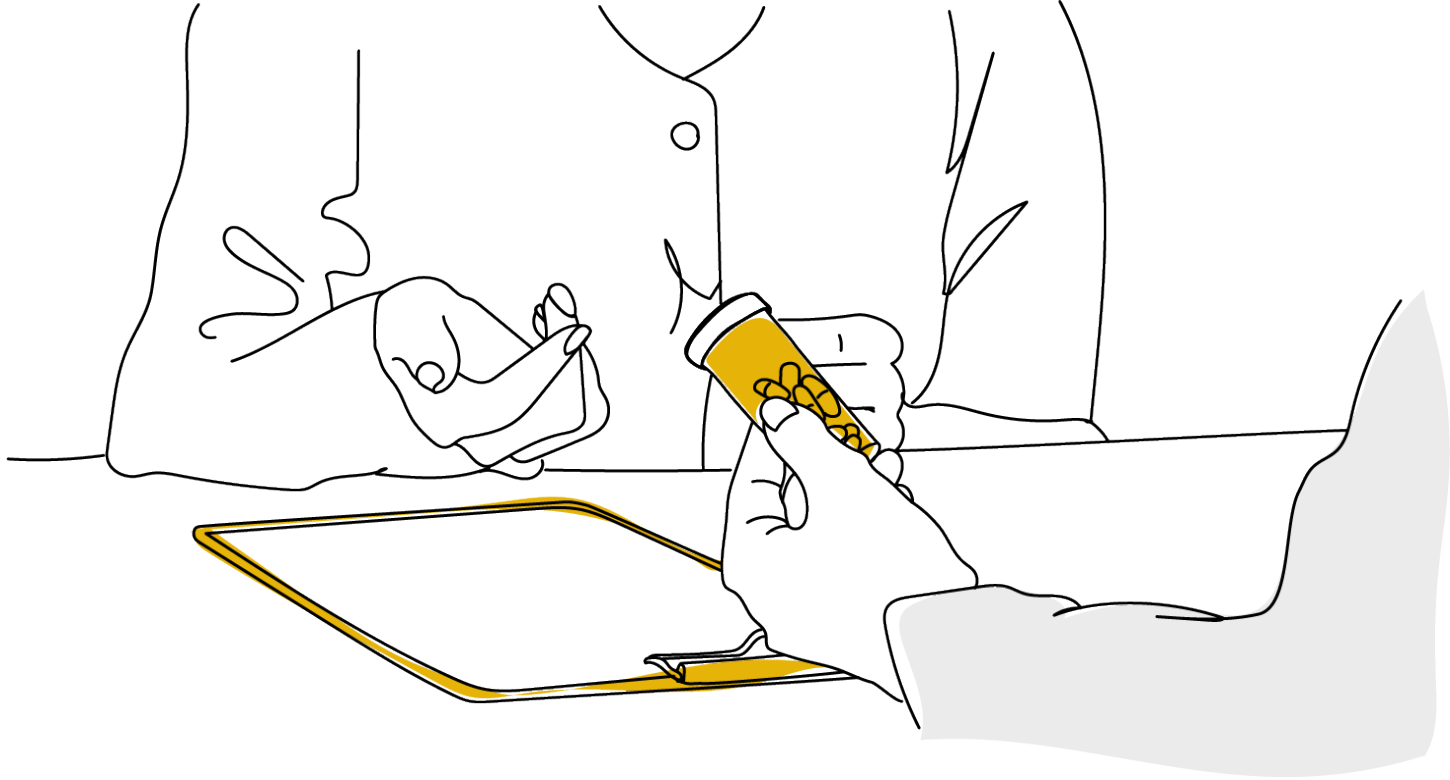
Document

Document the specific barriers you identify with the patient on the **Adherence Barriers and Interventions Log**.

TALKING POINTS

- Thank you for coming in today. How are you?
- **What issues would you like to be sure we talk about today?**
 - *Address questions and/or note for discussion before the session ends*
- **How are things going with the plans that we discussed last time?** Have you faced any challenges? If so, what challenges have you faced? *Probe for the following as relevant:*
 - **Side effects:** Which? Questions?
 - **Doctor-client communication:** Any issues/challenges?
 - **ART drugs, regimen, and schedule:** Any issues with taking meds on time? Missed doses? Obtaining meds? Keeping appointments?
 - **Social support and disclosure:** Disclosure? Adherence issues?
 - **Violence:** Physical? Verbal? Other?
 - **Substance use:** Challenges to adherence?
 - **Plans for travel:** Any plans? How will they obtain meds?
- Let's explore the **challenges** you mentioned that affected your ability to stay on treatment by looking back at your plan. We might have to make some revisions together. **How does that sound to you?**

18. Returning to care after having stopped treatment

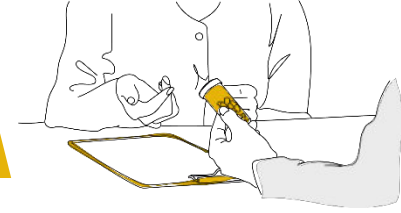


Welcome back!

Returning here shows you are committed to protecting your health.

Together we will explore ways to help you stay healthy.

18. Returning to care after having stopped treatment (1)



KEY MESSAGES

- Welcome back! Returning here shows you are committed to protecting your health.
- Together we will explore ways to help you stay healthy.



Provider Instructions

- **Use open-ended questions**
 - Affirm! Avoid having the client feel like they have failed.
 - Reframe: *You made an effort and faced some challenges. Coming in today shows how much you want to take care of yourself.*
- **Go the appropriate cue cards in the Adherence Planning section to develop or review their plan and adjust as needed**



Document

Document the specific barriers you identify with the patient on the **Adherence Barriers and Interventions Log**.

TALKING POINTS

- Thank you for coming in today and taking charge of your care.
- Tell me about your experience taking your meds so far.
 - What meds were you taking? How were you taking them? What were the effects? When and what were the reasons that made you stop?
- Let's explore the **challenges** that affected your treatment.

BARRIERS	PROBING QUESTIONS TO ASSESS BARRIERS
Knowledge deficit	Can you tell me the names of your meds? What is your schedule/plan to take your ARVs (e.g., what time of day, how many [if pills])? What is your understanding of the purpose of your meds?
Side effects	Have the meds affected the way you feel? Please describe what problems they cause (e.g., nausea, diarrhea, sleep disturbance).
Forgot	Have you ever forgotten or do you often forget to take your meds? Do you take them at a set time of day? What is your method of remembering to take your meds?
Felt better	Do you take your meds even when you are feeling well?
Illness	Have you had illnesses that have prevented you from taking your meds?
Substance use	Do you use alcohol? Do you use drugs? Do you feel this may be affecting your ability to take your meds?
Depression	How is your mood in general? Have you been feeling sad or confused? If yes, has this affected your ability to take your meds?
Health beliefs	Do you believe that taking your meds everyday is beneficial for your health? Have you ever tried other remedies for treating HIV? If so, what?

19. Returning to care after having stopped treatment (2)



19. Returning to care after having stopped treatment (2)



KEY MESSAGES

Let's continue exploring ways to help you stay healthy and happy.



Provider Instructions

Summarize what was learned from the client about any specific barriers identified on this card.

A: Affirmations, for example:

- *I appreciate that you are able to be honest about the way you take your meds.*
- *You are clearly a resourceful person to manage so many challenges.*
- *You've worked really hard to take your medications despite these challenges.*



Document

Document the specific barriers you identify with the patient on the **Adherence Barriers and Interventions Log.**

TALKING POINTS

- How has your experience with the health center been?
- Let's continue to explore any challenges you have faced in staying on treatment.

BARRIERS	QUESTIONS TO ASSESS BARRIERS
Pill burden	Is the number of pills or amount of liquid a challenge for you?
Lost/ran out of pills	Have you lost or run out of your meds?
Transportation problems	Do you have difficulty getting to the health center to collect your meds? If yes, what are the reasons (e.g., long distance, expense, job)?
Scheduling difficulty	Have you been too busy to take your meds? Have you traveled outside of your province/district for work or another reason for long periods of time?
Share with others	Have you ever shared your meds with others?
Fear of disclosure	Have you disclosed your HIV status to your family or your partner? If not, what are your concerns about disclosure? Has your family or partner been non-supportive or kept you from taking your meds? Have you experienced any form of violence, including physical, sexual, or verbal, or are you afraid of potential violence if you disclose your status?
Family/partner relationships	
Inability to pay	Have clinic or other fees kept you from taking your meds?
Food insecurity	Has a lack of adequate food ever been a problem for taking your meds?

20. Returning to care after having stopped treatment (3)



20. Returning to care after having stopped treatment (3)



KEY MESSAGES

Let's continue exploring ways to help you stay healthy.

Provider Instructions



Summarize what was learned from the client about any specific barriers identified on this card.

Use reflective listening, for example:

- *You're wondering* if it matters if you take your meds.
- *So you said you feel angry* when you think about taking your ARVs and that makes it really hard.
- *What I hear you saying is* you are so overwhelmed, your health is the least of your problems right now.

Document



Document the specific barriers you identify with the patient on the **Enhanced Adherence Plan Tool**.

TALKING POINTS

- Let's continue to explore any challenges you may be facing when taking your meds.

BARRIERS

QUESTIONS TO ASSESS BARRIERS

Drug stock-out

Have you ever come to the health facility and found that there were no meds available, or you were only given a small supply?

Long wait times

Have you ever left the health facility before receiving your meds because of long wait times?

Stigma and discrimination

Are you fearful that people in the community will find out about your HIV? Does that prevent you from coming to clinic or taking HIV meds?

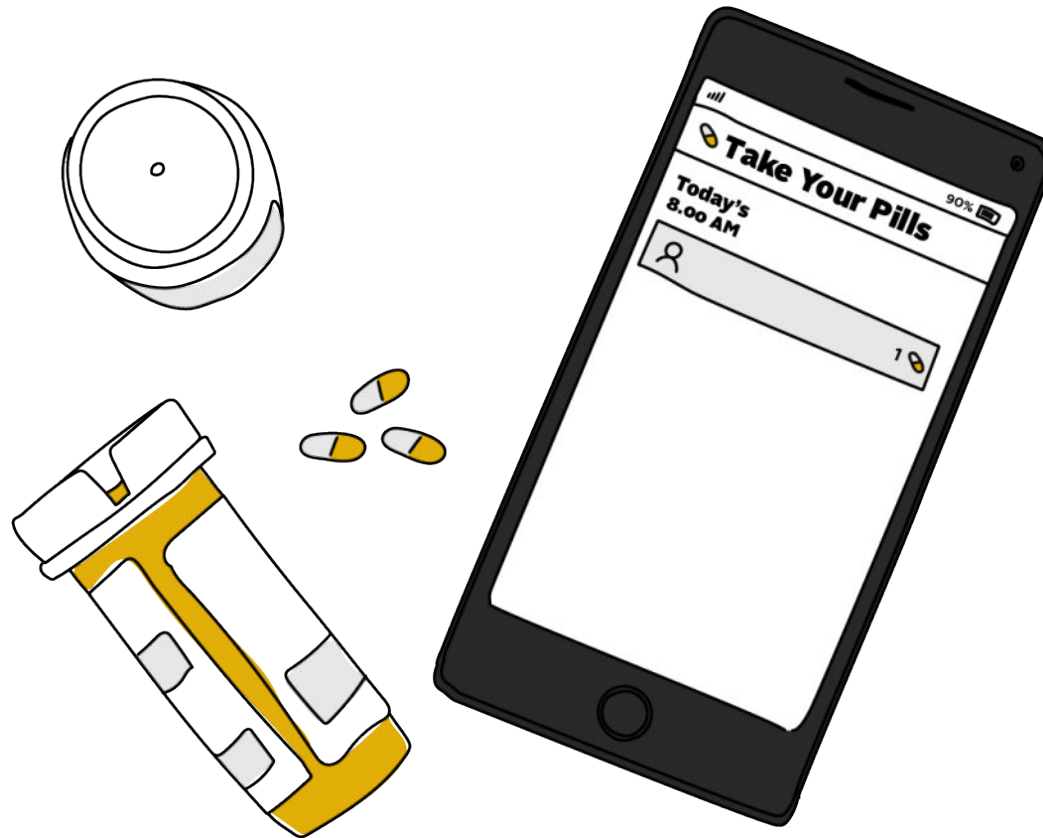
Political crisis/war/natural disaster

Is it ever unsafe for you to pick up your meds from the health facility?

Use summary statements, for example:

- *Let me see if I understand so far.* You are struggling to take your meds because you want to be well and healthy, but you also have other problems in your life that make it difficult to focus on your health.
- *Here's what I've heard you say, let me know if it is right.* You feel fine when you miss a dose and are feeling really uncertain about whether the meds are necessary to keep you healthy.

21. Tips to improve taking meds



Together we will find ways to make it easier to take your meds.

21. Tips to improve taking meds



KEY MESSAGES

Together we will find ways to make it easier for you to take your meds.

Provider Instructions



After giving a tip, ask if it seems helpful or if there are questions:

- How likely do you think it is that this will help you?
- How likely are you to try...?
- What questions do you have about...?

Document



Document the specific barriers you identify with the patient on the **Adherence Barriers and Interventions Log**.

TALKING POINTS

- You are taking your health seriously by talking about challenges you have faced taking your meds. *[Summarize main challenges and barriers].*
- What might be the outcome if you regularly miss your doses? *[Use ASK-TELL-ASK if the client does not provide accurate information].*
- Let's explore ways in which we can make it easier for you to take your meds. How might you address some of the challenges you raised?
 - *[Use client's ideas and the tables on next three cue cards, or the Adherence Planning cue cards (D), to come up with solutions.]*

BARRIERS	INTERVENTIONS TO ADDRESS BARRIERS AND IMPROVE ADHERENCE		
Knowledge deficit	<ul style="list-style-type: none"> • Individual counseling for basic HIV/ARV education 	<ul style="list-style-type: none"> • Group counseling/peer support group 	<ul style="list-style-type: none"> • Written instructions
Side effects	<ul style="list-style-type: none"> • Nausea → take with food (refer to physician if persists) • Headache → paracetamol (refer to physician) 	<ul style="list-style-type: none"> • Diarrhea → refer to physician • Fatigue → refer to physician 	<ul style="list-style-type: none"> • Anxiety/depression → take before bed; refer to physician if persists
Forgot	<ul style="list-style-type: none"> • Medication organizer (i.e., pillbox) • Treatment buddy or supporter • Directly Observed Therapy 	<ul style="list-style-type: none"> • Visual schedule (calendar, journal) • Announced pill count at next session 	<ul style="list-style-type: none"> • Reminder devices (e.g., phone calls, SMS, alarm) • Take pills late; do not skip dose
Felt better	<ul style="list-style-type: none"> • Basic HIV/ARV education 		
Illness	<ul style="list-style-type: none"> • Refer to physician 	<ul style="list-style-type: none"> • Directly Observed Therapy 	<ul style="list-style-type: none"> • Treatment buddy

22. Tips to improve taking meds



Together we will find ways to make it easier to take your meds.

22. Tips to improve taking meds



KEY MESSAGES

Together we will find ways to make it easier to take your meds.

Provider Instructions



Collaborate to come up with solutions, for example:

- What have you already tried?
- You have thought a lot about this; what are other ways to solve this challenge?

Document



Document the specific barriers you identify with the patient on the **Adherence Barriers and Interventions Log**.

TALKING POINTS

- Let's continue to explore ways in which we can make it easier to take your meds.

BARRIERS	INTERVENTIONS TO ADDRESS BARRIERS AND IMPROVE ADHERENCE		
Depression	<ul style="list-style-type: none"> • Referral to mental health professional 	<ul style="list-style-type: none"> • Individual counseling • Peer support group 	<ul style="list-style-type: none"> • Treatment buddy
Pill burden	<ul style="list-style-type: none"> • Refer to physician to change to fixed-dose combination if available 		
Lost/ran out of pills	<ul style="list-style-type: none"> • Extra supply of pills 	<ul style="list-style-type: none"> • Community adherence group (to pick up/support taking drugs) 	<ul style="list-style-type: none"> • Educate patient to alert facility if it occurs
Transportation problems	<ul style="list-style-type: none"> • Community adherence group (to pick up/support taking drugs) 	<ul style="list-style-type: none"> • Multi-month dispensation (3-6-month supply when feasible) 	<ul style="list-style-type: none"> • Treatment buddy who can pick up drugs
Health beliefs	<ul style="list-style-type: none"> • Individual counseling for basic HIV/ARV education 	<ul style="list-style-type: none"> • Group counseling 	<ul style="list-style-type: none"> • Peer support group
Scheduling difficulty	<ul style="list-style-type: none"> • Education (combine with daily routine such as bedtime or brushing teeth) 	<ul style="list-style-type: none"> • Reminder devices (e.g., phone calls, SMS, alarm) • ART group 	<ul style="list-style-type: none"> • Treatment buddy • Keep a few doses in different locations for easy access
Alcohol or drug use	<ul style="list-style-type: none"> • Opioid substitution therapy • Individual counseling 	<ul style="list-style-type: none"> • Directly Observed Therapy 	<ul style="list-style-type: none"> • Peer support group

23. Tips to improve taking meds



Together we will find ways to make it easier to take your meds.

23. Tips to improve taking meds



KEY MESSAGES

Together we will find ways to make it easier to take your meds.

Provider Instructions



Offer suggestions to overcome specific barriers that have been identified.

Document



- Document interventions and any needed referrals on the **Adherence Barriers and Interventions Log**.
- Summarize the plans.
- Ask the client if they have any questions.
- Discuss the next follow-up date and its purpose.

TALKING POINTS

- Let's continue to explore ways in which we can make it easier for you to take your meds.

BARRIERS	INTERVENTIONS TO ADDRESS BARRIERS AND IMPROVE ADHERENCE		
Sharing meds with others	<ul style="list-style-type: none"> • Individual counseling for basic HIV/ARV education 	<ul style="list-style-type: none"> • Group counseling 	<ul style="list-style-type: none"> • Facilitate enrollment into care /PrEP for family members
Fear of disclosure	<ul style="list-style-type: none"> • Individual counseling • Treatment buddy • Couples counseling and testing 	<ul style="list-style-type: none"> • Group counseling • Unmarked pill bottle 	<ul style="list-style-type: none"> • Peer support group • ART group
Family/partner relationships	<ul style="list-style-type: none"> • Group counseling 		
Inability to pay	<ul style="list-style-type: none"> • Refer to social worker, peer worker, or NGO 		
Food insecurity	<ul style="list-style-type: none"> • Refer to social worker, peer worker, or NGO 		
Long wait times	<ul style="list-style-type: none"> • Nurse-led or community-based care 	<ul style="list-style-type: none"> • Three month supply where feasible 	<ul style="list-style-type: none"> • ART group
Stigma and discrimination	<ul style="list-style-type: none"> • Individual/group counseling 	<ul style="list-style-type: none"> • Peer support group 	<ul style="list-style-type: none"> • ART group
Political crisis, war, natural disaster	<ul style="list-style-type: none"> • Individual counseling 	<ul style="list-style-type: none"> • Case management 	

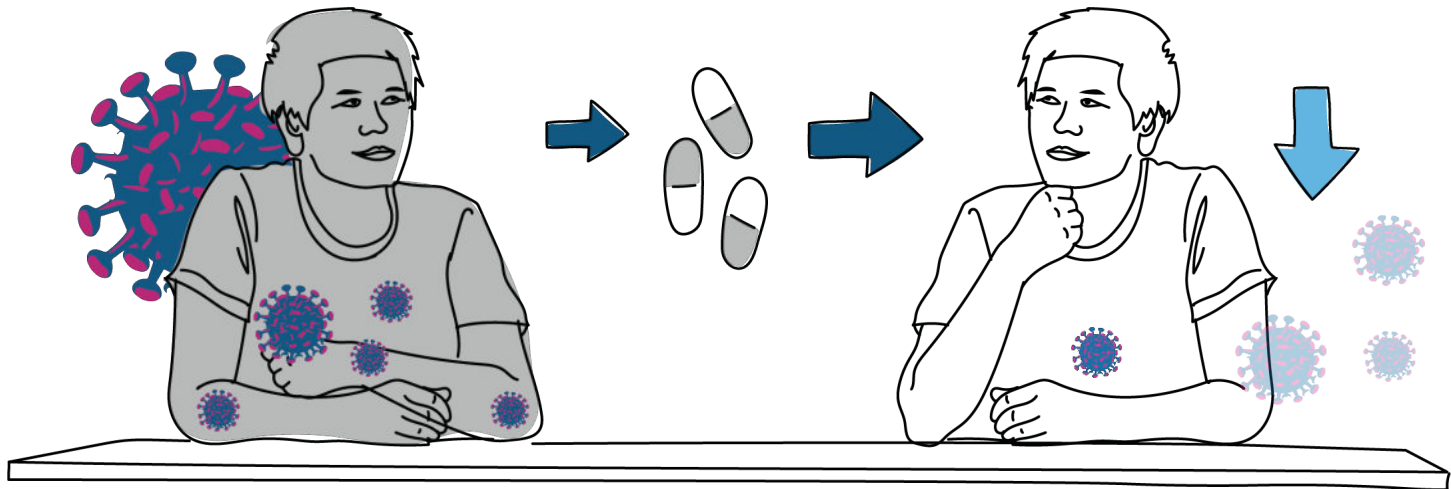
24. You have a suppressed viral load

A suppressed viral load means you are adhering to your medications and they are working.

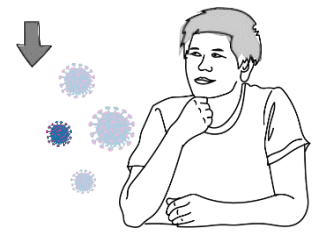
This does not mean your meds can be stopped.

Until your viral load is below 200ml, you can still sexually transmit HIV to your partners.

Continue to take your medication every day.



24. Your viral load is suppressed



KEY MESSAGES

- A suppressed viral load means you are taking your ARVs well and they are working.
- This does not mean ARVs can be stopped.
- Continue to take your ARVs everyday.



Let's Review

- What does a suppressed viral load mean?
- Why is it important to continue taking your meds every day?
- When will the next viral load be checked?
- What medicines do you take and when?

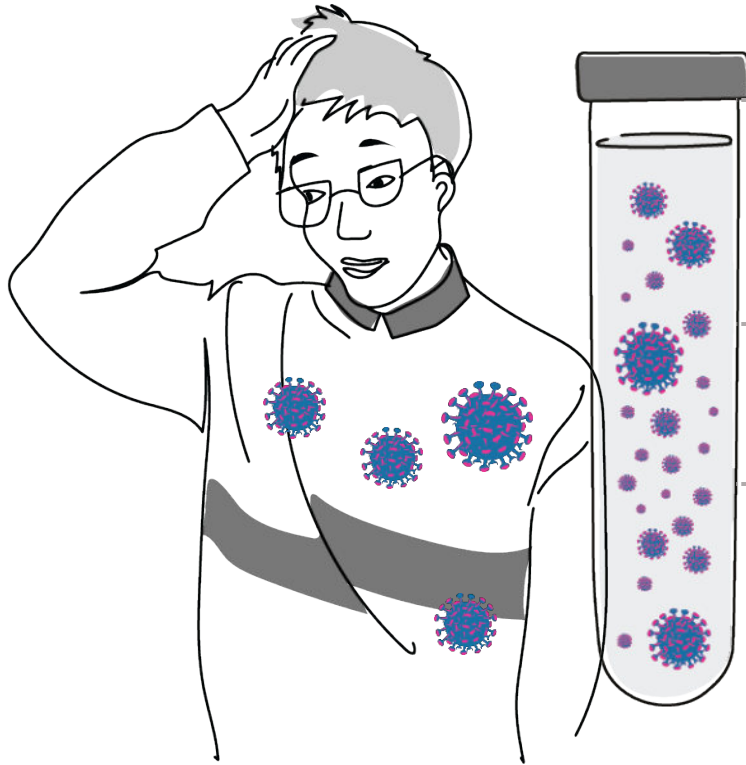
TALKING POINTS

- Your viral load is _____.
- A **suppressed viral load** (<1,000) means you are **taking your meds as prescribed** and they are working. It does not mean you can stop taking your meds or stop using condoms.
- Until your viral load is below 200ml, it is still possible to sexually transmit HIV to your partner.
- A late dose is better than a missed dose.
- Have you experienced any challenges in taking your meds? What has helped you remember to take your meds?

A few reminders:

- It's important to **keep all of your appointments.**
- If you notice that your **meds are running low, come to the clinic** even if you don't have an appointment.
- We will **check the viral load again** in ____ [six months for newly initiated clients and this is first viral load result, or one year for those with more than one low viral load].
- Please let your provider know if there any problems taking your meds in the future, so that he/she can help you address them.
- Your next is appointment is _____. Even if you still have medications, it is important for you to come to your appointment.

25. Your viral load is NOT suppressed



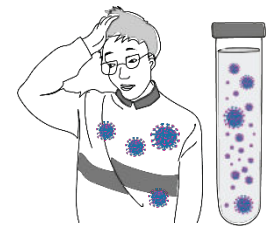
- HIV is making more virus and harming your body.

You may be missing doses of your meds.

Or...

-the virus may have changed and the meds are no longer working.

25. Your viral load NOT suppressed



KEY MESSAGES

- This means that HIV is making more virus and harming your body.
- You may be missing doses of your ARVs.
- The virus may be resistant, meaning it has changed and your meds are no longer working.



Provider Instructions

Remember to use nonjudgmental and respectful language – do not blame or criticize:

- *“I am glad you came to get your viral load results. Now we can help you work toward a low viral load.”*



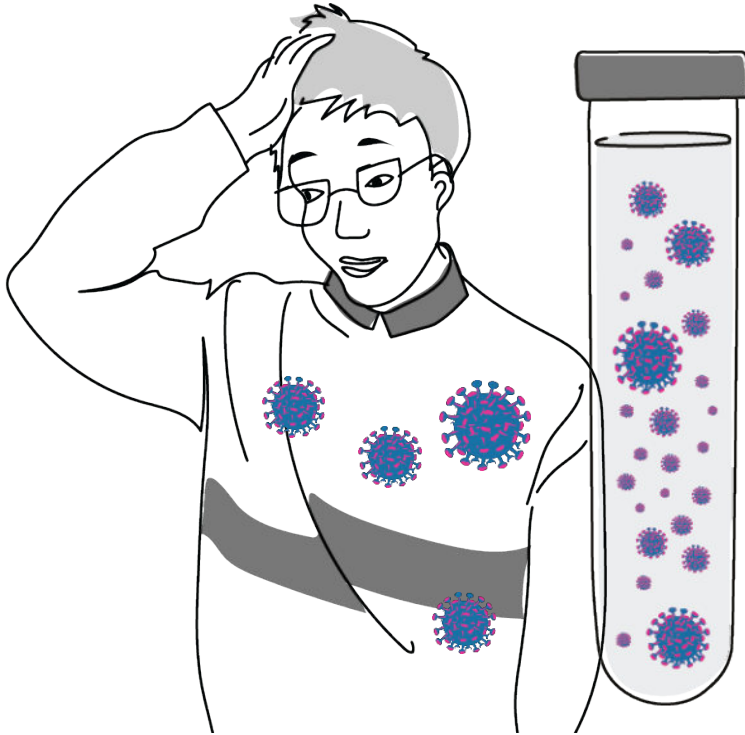
Let's Review

- What are possible reasons for an unsuppressed viral load?
- What can happen when your viral load is not suppressed?
- What is beneficial about having a suppressed viral load? How important is your long-term health?
- What do you think happens if you don't take ARVs regularly?

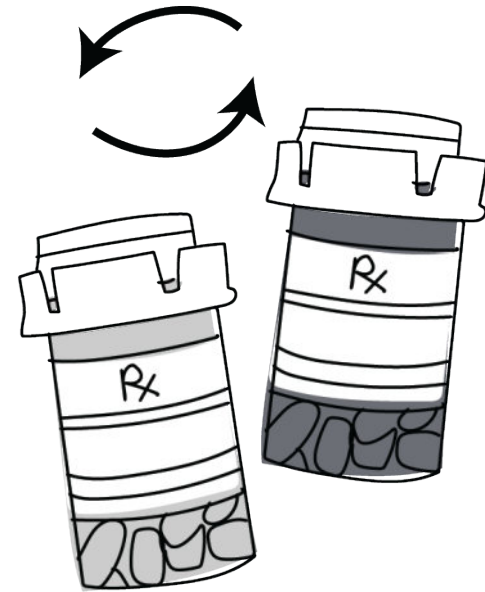
TALKING POINTS

- Your viral load is _____, which is considered unsuppressed.
- The goal is to keep your viral load undetectable, below 200ml.
- Unsuppressed means that **HIV** is making more virus in the body.
- This may be because you are **not taking your meds** as instructed, or because the medicine is not effective for the virus you have.
- With this much virus in your blood, your immune (defense) system becomes weaker. This can affect your brain, heart, liver, and kidneys, and **make you sick**.
- If your meds are not taken properly, the **virus can also change** and become **“resistant” to the meds**, meaning that even if taken properly, they will no longer work.
- With an unsuppressed viral load it's easier to spread HIV to your partner, so it is especially important to use condoms all the time.
- If you were to continue missing doses, what might be some of the outcomes? What is the worst thing that could happen?
- If you were to take your treatment every day, what would you hope would happen?

26. HIV meds are not working well

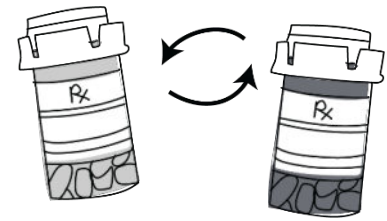


It is likely that the virus has changed and your meds are no longer working.



Switching your medication is recommended.

26. HIV meds are not working well



KEY MESSAGES

- It is likely that the virus is resistant, meaning that it has changed and your meds are no longer working.
- Switching your medication is recommended.

Let's Review



- Can you please tell me what you understand to be the next steps and why your doctor advised changing your medication?
- In your own words, what does resistance mean?
- What are the new meds you are taking, and how will you take them?
- What has helped you to take your meds?
- When is your next appointment?
- We will want to check your viral load again in ____ months to see how the new meds are working.
- Do you have questions?

TALKING POINTS

- Even though you are taking your meds everyday, your viral load result is still high.
- It is likely that the meds are not working well (HIV is 'resistant' to your medication, meaning the medication is not stopping HIV from making copies).
- Your doctor has recommended that you change your medication regimen.
 - *Discuss possible side effects and how to avoid/manage.*
- The new medication should reduce your viral load and keep you well.
- It is important to take your new meds properly.
- Please let your doctor know if you have any trouble so that you can get assistance.
- If you start other medications, such as TB medications, please let your provider know right away.
- Your next appointment is _____.



Provider Instructions

Use relevant cards for adherence assessments and counseling, and explanation of viral load results.



Document

Document new ARVs on the **Enhanced Adherence Plan Tool**.

