

# Positive Living Group Guide



## About this guide

The Positive Living Group addresses literacy about why medications are important to take and the importance of seeing your healthcare provider at least twice a year, feelings about living with HIV and taking medications, how to obtain emotional, informational and practical support about fully engaging in HIV care (including referral and retention in care and adherence to HIV medications), dating and disclosure of HIV status to others, relationships and sex, and how to prepare for and get the most from visits to a medical provider. Confidentiality is stressed.

# Contents

About this guide .....	1
<b>Preface: Tips for Facilitators .....</b>	<b>3</b>
<b>Before the Meeting.....</b>	<b>5</b>
<b>Welcome/Introductory Remarks/Ground Rules.....</b>	<b>6</b>
Ground Rules .....	6
Confidentiality.....	7
<b>Introduction of Participants: Commonalities.....</b>	<b>9</b>
Commonalities Exercise:.....	9
<b>Background: Why Are So Many Black Same-Gender-Loving Men Living with HIV?</b> <b>.....</b>	<b>10</b>
Discussion.....	12
<b>Two Lies and a Truth? .....</b>	<b>13</b>
Discussion.....	20
<b>Step It Up .....</b>	<b>22</b>
Discussion.....	24
<b>Ring That Bell .....</b>	<b>26</b>
Scenarios 1-8: .....	27
<b>Medications and HIV .....</b>	<b>35</b>
Discussion: What are the benefits of taking medications? .....	35
Discussion: Why do we miss taking our meds? .....	37
<b>Supporting Our Brothers Living with HIV and Getting Support for Ourselves.....</b>	<b>41</b>
<b>Encouraging Friends and Becoming More Involved with the M+ for Men Living with HIV .....</b>	<b>45</b>
<b>Invitation to Become Involved with M+ .....</b>	<b>46</b>

# **Preface: Tips for Facilitators**

## **Be engaged with each other and with the group**

For group meetings to be most successful, the discussion leader and co-facilitators must work together as a team – assisting one another, supporting one another, playing off each other’s comments. The team might agree on a system of nonverbal communication for use during the meeting to signal to the other one’s needs and preferences. Two important messages are:

“Help! Say something to get the discussion going.”

“We need to move to the next section.”

The facilitators should express enthusiasm and confidence in the group’s activities. Doing so will put the participants at ease – reassure them by how you act that everything that happens in the group will be fun and/or meaningful for them. Also, be aware of your body language (e.g., how you are sitting, the position of your legs and arms, your facial expressions). Try to communicate that you are relaxed, interested, friendly, and sensitive.

## **Stay on time**

At the beginning of each section of this guide, a recommended time frame for covering the material is provided. It’s very important to keep things moving and not spend more time than is allotted. There’s a lot to cover in each meeting; the facilitators should pace themselves and help each other keep within the allotted time periods. It is very important not to spend too much time in the early sections because the latter sections are the most important.

It is not necessary to memorize the narrative or deliver it exactly as written, but it can serve as a guide for covering the material quickly. In addition to the narrative, reminders and instructions for the discussion leader

regarding the conduct of the meeting are provided throughout this guide. Those portions should not be read aloud to the participants.

## **Agenda Outline**

180 minutes

Welcome/Introductory Remarks/Ground Rules .....	<b>10 min</b>
Introduction of Participants: Commonalities.....	<b>15 min</b>
Background: Why Are So Many Black Same-Gender-Loving Men Living with HIV? .....	<b>10 min</b>
Two Lies and a Truth? .....	<b>30 min</b>
Step It Up .....	<b>20 min</b>
Break .....	<b>15 min</b>
Ring That Bell.....	<b>20 min</b>
Medications and HIV .....	<b>20 min</b>
Supporting Our Brothers Living with HIV and Getting Support for Ourselves .....	<b>20 min</b>
Encouraging Friends and Becoming More Involved with the M+ for Men Living with HIV .....	<b>10 min</b>
Invitation to Become Involved with M+.....	<b>10 min</b>

# Before the Meeting

Gather all materials you will need during the meeting. Make sure that these materials are conveniently accessible to the facilitator who will be handing them out or using them.

- Refreshments
- Ground rules, posted in room
- Writing instruments and paper for participants
- Copies of confidentiality agreement
- White boards or flip charts (2)
- Marking pens
- Copies of the pamphlet "How to Talk with Your Provider"
- Bells (2)

The pre-meeting period can be very awkward and tense for some participants who may not know anyone in the room or are nervous about coming to a group specifically about living with HIV.

Participants will feel more at ease and welcome when the co-facilitators personally greet them and thank them for coming. Make small talk, introduce the participants to one another, invite them to have refreshments, let them know where the bathrooms are located, and so forth.

Remember to be well prepared in advance (this is not the time for last-minute organizing and improvising).

If members of the group have questions that the facilitators cannot answer, let them know that you will investigate and try to provide answers.

# Welcome/Introductory Remarks/Ground Rules

## Objectives:

- To provide the participants a general idea of what to expect.
- To present ground rules for the meeting to the group.

(10 minutes: 11:00-11:10)

[Facilitators introduce themselves.]

### **MODERATOR**

What is M+? M+ is “Red Carpet Treatment,” a way to provide excellent services for men living with HIV.

This group, Positive Living, is about protecting and supporting one another.

The Positive Living Group focuses on issues facing men who are living with HIV, and how we can get what we want and help one another through these challenging times.

This group can help build a support system for you and your friends who are also living with HIV.

## **Ground Rules**

We want to create a safe space for us to talk about things we may not often get to talk about, especially with a group of men we don't know very well who are living with HIV. Following these ground rules will help make this a safe space.

## **Confidentiality**

While we encourage you to talk with your friends about what happens at this group, especially your friends who are living with HIV, please don't tell anyone who was here. It is really important to keep this confidential!

A lot of men who are living with HIV have to deal with discrimination against people who are living with HIV. Fear about this discrimination in the Black community and the Black, same gender-loving community, is a *huge* issue among many men who are living with HIV.

There are many ways that this discrimination can be expressed. For example, there is a LOT of gossip in the gay men's community about who is living with HIV – as you know.

So it's very important that no one here tells others who was here. Keeping other people's business confidential, that is, PRIVATE, is so important that we're passing out a confidentiality agreement that we'd like for each of you to sign. We will keep these in our locked cabinets.

### **Speak from Your Experience**

Try to speak from your own experience. Be as personal as you feel comfortable being and feel free to say whatever is on your mind. That's how we can learn from each other.

But we know that sometimes you might not want to reveal to others here that you feel a certain way or have done a certain thing. It's fine here to say that you've heard friends say something or have known of friends who have done certain things, rather than saying that this is what you feel or have done.

### **Mutual Respect**

We are here to support and learn from each other. Please don't judge anything you hear someone else say, even if you disagree with him. There are no 'right' or 'wrong' answers; everyone is entitled to his own opinions. We've all had different experiences.

## **Have a Good Time!**

Be creative, playful. Try to participate as fully as you can with one another.

Please turn off your cell phones or put them on vibrate. If you need to need to take a call, please step outside, or better yet, wait for the break.

# Introduction of Participants: Commonalities

## Objectives:

- To introduce participants to one another.
- To help participants feel comfortable talking in the group.

(15 minutes: 11:10-11:25)

[Need 2 dry-erase boards or flip charts and markers.]

### **MODERATOR**

This is a get-to-know-everyone exercise. The assignment will be to find 5-10 things you have in common with others in your group. These commonalities cannot be something obvious like “we are all wearing pants,” or “we all have 2 arms” – it can’t be a body part. So dig deeper and go into topics like hobbies, interests, and more meaningful topics.

To begin finding your commonalities – your first question to answer as a group will be: What is your name, and do you prefer to be called he or him or she or her.

### **Commonalities Exercise:**

- Break into 1 or 2 groups
- Have them write their commonalities on white boards.
- Have them meet for 10 minutes to brainstorm. Let them talk it out, don’t facilitate this.
- Ask them to identify someone who will report back to the facilitators what commonalities they discovered.
- Ask if they learned anything from this exercise.

# Background: Why Are So Many Black Same-Gender-Loving Men Living with HIV?

## Objectives:

- To get participants to know why there are disparities in the rates of groups of men contracting HIV.
- To let participants know specifically why Black same-gender-loving men are contracting HIV, and that it has nothing to do with shameful things.

(10 minutes: 11:25-11:35)

### **MODERATOR**

Now we're going to talk about why so many Black same-gender-loving men are living with HIV by comparison with other groups of men.

Is it because Black same-gender-loving men have riskier sex and more sex partners than other racial groups? Do we sleep around more than men from other groups?

[Facilitator should present these points in his/her own words.]

- Black men don't have riskier sex than men of other racial or ethnic groups, and they also don't have more sex partners than others. In fact, Black men generally are less risky and have fewer sex partners than other ethnic or racial groups of gay men. So what's going on?
- We're connected and intertwined with each other. We have a lot of friends and acquaintances who know each other. These are called "social networks." Have you noticed that it seems like almost

everyone knows everyone around here? Have you ever made the acquaintance of anyone here?

[Give participants a chance to respond.]

- OK, there are also “sexual networks.” Black men typically have sex with other Black men. There are fairly small sexual networks of men who have sex with each other – that is, you have sex with one guy, who has sex with another guy, who has sex with yet another guy – and then you have sex with him. Sexual networks play a huge part in the spread of HIV.
- A lot of men in Black sexual networks don’t know that they have HIV. This increases the chances of having sex with someone who is living with HIV, but doesn’t know it. One reason for this is that many Black same-gender-loving men don’t get tested as often as they should – it’s been figured out that HIV-negative men should get tested at least every 6 months.
- The other major reason for high rates of HIV among Black same-gender-loving men is that many of us who are living with HIV aren’t taking HIV medications at all, or aren’t taking them as regularly as other groups of men.
- And we now know that if you take all your medications every day, most of the time you’ll be told by your healthcare provider that your HIV is “undetectable,” which means that you aren’t likely to pass HIV to another person. We’ll talk more about this later.
- So what this all means is that Black men who are HIV negative just have a greater chance of coming across someone who has HIV that can be passed to someone else.
- Here at APEB, we reject the idea that men living with HIV should feel badly or ashamed of themselves. Nobody living with HIV is “dirty” or “sick” or “immoral” just because they have HIV.

## **Discussion**

[Keep it short!]

### ***MODERATOR***

What do you think? How many of you thought that the reason we have high rates of HIV are for other reasons?

# Two Lies and a Truth?

## Objectives:

- To get participants to think about common misconceptions about HIV medications, medical appointments, and living with HIV.
- To help participants feel comfortable talking in the group.

(30 minutes: 11:35-12:05)

### **MODERATOR**

Now we're going to play a game called "Two Lies and a Truth." Your job is to figure out from three statements which one is true and which ones aren't true, and to explain why you think that.

I'm going to read aloud sets of three statements. One of the statements will be true (correct), and the two other statements will be false (incorrect). The group has to decide which one is the "most true" statement.

[Read each statement, one after the other, with a short pause between statements. The statement marked with asterisks (\*\*) is the correct statement.

Remember to get participants to explain why they chose the answer they did. In instances in which they choose the wrong answer, thank them for their answer, and then ask the group, "What does anyone else think? Does someone else have a different idea about which statement is true?" Again, get them to explain their choice.]

### **MODERATOR**

OK ... first set of statements:

- a. If you're living with HIV and on medications (meds), you can live as long as someone without HIV.\*\*

- b. Having HIV means you are going to die at a much younger age than people without HIV.
- c. Having HIV isn't a big deal any more.

[Follow up.]

Your thoughts on these?

[Make sure these points are covered.]

- So what this all means is that Black men who are HIV negative just have a greater chance of coming across someone who has HIV that can be passed to someone else.
- That's right. These days, if you are living with HIV and taking medications, you can live as long as someone without HIV – the medications are really effective!
- What about saying HIV isn't a big deal anymore? For some people, it still IS a big deal, or as someone said, it's a "little big deal" – but certainly not like it used to be.

## **MODERATOR**

OK ... next set of statements:

- a. HIV meds are very toxic and harmful.
- b. If you are taking HIV medications, drinking alcohol, smoking weed, or using substances such as molly, coke, or meth do not interfere with your meds.\*\*
- c. If your HIV is undetectable or suppressed, that means you are cured of HIV; there is no more HIV in your body.

[Follow up.]

Your thoughts on these?

[Make sure these points are covered.]

- People should continue to take their meds even if they drink, use weed, or do drugs. It is not a problem. A lot of men think that if they

are going out to get high, they shouldn't mix their meds with alcohol or drugs and so they skip taking their meds. This is incorrect – in fact, you can even take your meds with a cocktail! Questions?

- Although some meds can cause side effects, not all do, and the meds these days aren't considered "toxic."
- About the last statement – unfortunately, even if your HIV is undetectable or suppressed (which means the same thing – the HIV in your body is suppressed, so it's not making more copies of itself in your body) – you're not cured of HIV.

### **MODERATOR**

OK ... next:

- a. It is best to wait as long as possible before you start taking HIV medications.
- b. Today's HIV medications affect how you look.
- c. HIV medications are very effective these days, and are even more effective than they were just 5 years ago.\*\*

[Follow up.]

Your thoughts on these?

[Make sure these points are covered.]

- There have been some real breakthroughs in HIV treatment in the past few years, and the medicines are getting more and more effective, with fewer side effects. Although some side effects still do happen.
- What about the other statement – about waiting as long as possible until starting meds? [Pause for answers.]
- The recommendation these days is that people start taking HIV meds right away when they learn they are HIV positive so that the virus doesn't damage our bodies. HIV affects nearly every internal

organ in our body and that's why you want to take meds very consistently, because you want to stop it from impacting your body.

- What about the other statement – about meds affecting how you look? [Pause.]
- Today's medications don't negatively affect how you look. These days, nobody can tell by looking at you that you are taking medications for HIV. It used to be that the medications did affect how you look, but thankfully that's not the case anymore.
- Unfortunately, if you did start taking medications several years ago and had some body changes, those aren't likely to change. But if you've just started in taking medications in the past few years, or very recently, then you won't get body changes.

## **MODERATOR**

OK ... next set of statements:

- a. When you are seeing a doctor about HIV, the best thing to do is sit quietly and just listen to what he or she has to say to you.
- b. Doctors are in a rush when they are seeing patients, so it's best not to ask them many questions and take up more time.
- c. Doctors sometimes get a little irritated when you ask them too many questions.\*\*

[Follow up.]

Your thoughts on these?

[Make sure these points are covered.]

- While it's true that doctors are often in a rush, it's still best to ask all the questions you may have while you're there, even if they get a little irritated. This is about YOU getting the care YOU need. The provider is there for YOU! It's your care. And in the long run, most doctors really do want to hear your questions.

- It can really help to think through any questions you have for your doctor, and then write them down and carry the questions to your appointment so you don't forget or get flustered!
- We have a pamphlet here that we'll be distributing to each of you at the end of the group, about ideas concerning how to talk with your healthcare provider, and plan ahead for meeting with him or her. It gives some really good tips about how to prepare for your doctor visits and information you should share with your doctor.
- You are in charge of your own care, and you can talk about any issues that are important to you. If you are not comfortable talking to your provider, you may want to change providers.

### **MODERATOR**

OK ... next set of statements:

- a. If you've been having condomless sex with various men, there is no need to get tested for sexually transmitted infections (STIs – what used to be called STDs) unless you're having symptoms (for example, genital itching, discharge, burning when you pee).
- b. STIs can have a negative impact on someone who is living with HIV.\*\*
- c. There are no programs available for people to obtain HIV medications if they don't have insurance.

[Follow up.]

Your thoughts on these?

[Make sure these points are covered.]

- Some men who are living with HIV and are undetectable are having condomless sex in certain situations (such as with other men who are also living with HIV or with men who are on PrEP). But condomless sex leaves you open to catching an STI, and STIs can

affect the immune system of people living with HIV. It's important to consider this possibility when deciding to use or not use a condom.

- Do STIs always cause symptoms? [Pause.]
- STIs often cause symptoms, burning when peeing, a drip or discharge – but not always. So if you're having condomless sex, you should be getting tested for STIs every 3 to 6 months. Some STIs are really serious.
- For example – you can catch HPV, human papillomavirus. If you're having anal sex, it is really important to get an HPV vaccine. Has anyone heard of this? [Pause for answers.] HPV is dangerous because it can lead to anal cancer. The good news is that you can get vaccinated for HPV right here at APEB if you want. Just tell your doctor.
- As to the last statement, yes there are programs to help men to get onto medications if they don't have insurance. In fact, I (Raymond) can help you with that, because I not only lead this group and the group called HAPI, I am also a case manager and can help you with that. Sometimes, I might have to refer you to someone else here named Cory. So pretty much, people with HIV CAN receive help to get on medications.

## **MODERATOR**

OK ... next set of statements:

- a. Sometimes you have to change HIV medications to find the right one or ones.\*\*
- b. You just have to stick with the medication the doctor first prescribes for you, no matter how it affects you.
- c. Cigarette smoking doesn't have much of an effect on someone with HIV.

[Follow up.]

Your thoughts on these?

[Make sure these points are covered.]

- Sometimes a medication might not work so well to reduce the amount of HIV in your body, or perhaps it may give you overly vivid dreams or other side effects. In such cases it may be necessary to go back to your doctor to find another medication that works better. This is where you need to advocate for yourself – if you are having any kind of side effects, make sure to tell your doctor about them!
- And the other two statements are FALSE – there are quite a few treatment options, so if you are having bad side effects, your doctor may be able to make adjustments, and cigarette smoking really does have a big negative effect on people living with HIV.

### **MODERATOR**

OK ... last set of statements:

- a. There isn't much of a need to see HIV providers more than once a year as long as you feel well.
- b. It's important to go see your healthcare providers and get lab tests at least twice a year regardless of how you feel.\*\*
- c. It doesn't do any good to start taking medications right away. It is best to wait to take medications until you are beginning to feel poorly.

[Follow up.]

Your thoughts on these?

[Make sure these points are covered.]

- Regular doctor visits can help keep you stay healthy, because they keep track of your viral load and something called CD4 cells. Viral loads are the most important thing to track, but usually CD4s are monitored too. What are CD4s? [pause]

- They are helper cells. If they go down very low, it means that there is damage occurring to your immune system. So basically, as your CD4 numbers go up, your immune system is working better and your viral load will go down. If your CD4 count goes down, then your viral load will increase. So at your doctor's visits, you are monitored to see that these are working right. And you get a chance to talk with your provider about any concerns you have.
- Taking medications right away reduces swelling of organs in your body and the meds keep HIV from producing new HIV cells. It's recommended that, once you know you are living with HIV, it's best to start medication right away.

## Discussion

### **MODERATOR**

Sometimes people don't want to go to a doctor because they feel uncomfortable at the doctor's office or the clinic.

Has anyone here ever had an uncomfortable experience at their doctor's office when they were going in for HIV care?

[If someone says yes, ask him to describe it, if he feels comfortable doing so.]

[Ask what he did so that it would be better next time.]

[Ask others if they might have ideas about what to do so that it is more comfortable.]

Has anyone here – or anyone you know – ever felt that they weren't treated well at a doctor's office or clinic because they are same-gender-loving or because they are Black?

[If someone says yes, ask him to describe it, if he feels comfortable doing so.]

[Ask what he did so that it would be better next time.]

[Ask others if they might have ideas about what to do so that it is more comfortable.]

[Remind the participants that they can get care here at APEB that is really tuned-in to who they are.]

OK, so this is the end of Two Lies and a Truth – thank you, I think we came up with a lot of great ideas about how to approach these issues!

# Step It Up

## Objectives:

- To get participants to think about how they feel about HIV stigma, that is, negative attitudes and discrimination against people living with HIV.
- To help participants consider whether they have internalized HIV stigma, that is, do they feel poorly about themselves because of having HIV stigma themselves.
- To help participants to consider actively fighting against internalized HIV stigma.
- To help participants to analyze how they can get emotional support for internalized stigma, and in general.

(20 minutes: 12:05-12:25)

### **MODERATOR**

In this activity, we're going to get up and move around. First, everyone should get up and let's clear the furniture to the side to the room.

[Pause while the furniture is moved.]

Everyone please go to the center of the room, and stand in a line next to each other. I am going to read a statement that you may agree or disagree with. If you feel that the statement can be answered yes, that it is descriptive of you, then take a step forward. If it is untrue for you, then take a step back.

Let's try the first one ... If it's true that the online dating profile that you used most recently includes your HIV status, then take a step forward. If it's not true, then take a step back. If you don't have an online dating profile, then don't move forward or back, just stay in place.

[Pause for a few seconds to give people a chance to move and look around. After people move in response to each question, give them some time to look around.]

OK, go ahead and get back in line. So let's do the same for the rest of the statements:

1. I am not concerned whether people gossip about me living with HIV.
2. I talk with a friend when I'm feeling down about some aspect of living with HIV.
3. I've walked into a social situation (such as a bar or someone's home) and realized that others were gossiping about my living with HIV.
4. I rarely feel ashamed that I have HIV.
5. I remind myself that I'm a good person.
6. I get why some may think people living with HIV are "nasty."
7. I have told a close friend that I am living with HIV.
8. I refuse to believe that HIV is a punishment sent by God.
9. I have told a family member that I am living with HIV.
10. I remind myself that there's no shame in having HIV.
11. If I were in a situation in which men were gossiping about someone's HIV status – I would do something to stop the gossiping.
12. All of my online dating profiles include my HIV status.

OK, great. Thank you. Take a look around you, and you'll see that you have had a variety of experiences. Some of you have had an easier time and others have had a harder time about living with HIV, both in terms of your feelings about yourself, and from your family or friends.

Now hold onto your thoughts, let's put the furniture back in place, and then talk about it.

[After furniture has been moved back, begin discussion.]

## Discussion

### **MODERATOR**

So, how was that exercise for you? Do you have any thoughts after doing this?

What surprised you about your responses versus others' responses to particular issues?

[You may want to re-read some of the statements that seemed to get the most reaction from the group, or ones for which there was a lot of variation in how participants responded.]

- What stood out for you?
- Have you been able to come out about your HIV status to your family? To your friends? Are there certain family members that have been easier to come out to than others?
- How does gossip in the community affect you?
- Have you ever considered doing something to stop men from gossiping about HIV status? If so, what did you think about doing?
- How often do you feel badly about having HIV, if ever? Has this changed over time?

There are good things you can do for yourself too!

- What about deliberately reminding yourself that you are a good person whether or not you have HIV? [pause]
- Sometimes people feel that living with HIV requires them to develop strength and the ability to deal with ups and downs in their lives? Have you felt this way? [pause]
- Are there other good things that have happened to you as a result of living with HIV? [pause]

**Break (15 minutes) 12:25-12:40**

# Ring That Bell

## Objectives:

- To get men to think about how to avoid passing HIV to other men.
- To understand what it means to be virally suppressed.
- To highlight the seriousness of getting some STIs.
- To clarify what is pre-exposure prophylaxis (PrEP).

(20 minutes: 12:40-1:00)

[Need bells for exercise.]

### **MODERATOR**

OK, for this activity, we are going to play Ring That Bell. Please count off: 1, 2, 1, 2, 1, 2.

[Wait for the participants to count off.]

All the 1s go here and the 2s go there. This exercise is about what you can do to avoid passing, or “transmitting,” HIV to other men in a variety of different situations. This isn’t a competition, though it might feel that way! It’s an opportunity for men to hear about different perspectives on the same situation.

We’re going to present different scenarios of having sex. You and your team have to figure out if in each scenario, you can have condomless sex or if you should use a condom. In some situations although you could have condomless sex and not pass HIV to your sex partner, there’s a reason why you might use a condom. In these cases, we say, “It’s complicated.”

So, your team’s answer can be: condomless, use a condom, or it’s complicated. And then the team needs to explain its answer.

The scenario will also tell you about your HIV viral load – whether you are detectable or undetectable, or you might need to figure it out.

When you know the answer, your team should ring your bell and your team should be prepared to explain it.

Now of course, the answer to every question could be to use a condom. It is never wrong to use condoms! We're talking here about when you might be able to go condomless and not spread HIV to someone or risk catching an STI.

So, although sometimes we say here that condomless sex is OK, it is important to remember about STI prevention as well. And the research is clear – many men who are having condomless sex these days are also catching and spreading a LOT of STIs!

Any questions before we start the game?

OK, let's start.

Note: The answers that are highlighted below are acceptable responses – remembering that using a condom is never incorrect.

## **Scenario 1:**

The last few times you've seen your HIV doctor you've been told your viral load is undetectable. You're checking out who's online because you feel like having sex. You're a total bottom. This super-hot guy catches your eye and you see in his profile that his HIV is undetectable too. You like having sex with other men who are living with HIV and you think you've found your man for the night.

- What kind of sex do you have? condomless / use a condom / it's complicated

## **Discussion**

[Make sure these points are covered.]

- Condomless sex is OK in this situation. However, all three of the available options are appropriate choices. It all comes down to personal preference.
- But clearly, since both partners are already living with HIV, there's no risk of transmitting HIV to each other, so condomless sex is OK.
- Additionally, the risk of passing along a different strain of HIV is very, very small. This used to be a concern, but HIV medications are so strong now, this is no longer a worry.

### **MODERATOR**

OK, so we've briefly referred to "undetectable," or "virally suppressed" – what does this mean?

[Wait for responses.]

OK, viral load is how much HIV you have in your blood. If the medications you're taking work really well, then they suppress your virus – meaning that there is very little HIV circulating in your body. A viral load test examines how much virus you have. If your virus is suppressed or "undetectable," that means the virus is no longer spreading in your body and in fact, is at a very, very low level, so much so that they can't find it on the test – it can't be detected – so it's undetectable. The virus is completely suppressed.

To get to an undetectable level, you have to take your medications every day, regularly. And you should see your doctor about twice a year to be sure that the medications are working really well.

HIV is still there, but in very, very low levels. If your HIV is undetectable or virally suppressed, this means you are helping your health in the best way possible, and it means that you are VERY unlikely to pass HIV to others if you have condomless sex.

But you are very much at risk of catching an STI, or passing an STI to your sex partner if you have one.

## Scenario 2:

You've been living with HIV for 3 years. You've been feeling fine and have decided that at least for now, you're not going to start taking medications. You start talking with this guy online who says he's on PrEP. He sends you a picture of his fine, round ass. You'd tap that for sure.

- What kind of sex do you have? condomless / use a condom / it's complicated

OK, let's discuss PrEP for a moment. What is PrEP?

[Wait for responses.]

PrEP is a pill that HIV-negative men can take once a day that lowers the risk of catching HIV infection by up to 96% – if they are taking PrEP regularly.

But men have to be really regular in taking their PrEP pills for it to work. Someone can be on PrEP, but if they aren't taking it regularly, it might not be protective.

### Discussion

[Make sure these points are covered.]

- All three answers could be appropriate, but it depends on the people involved. If the guy is on PrEP and has been taking it consistently for long enough, then he's protecting himself from getting HIV, but a condom can make it even safer.
- The best thing would be to disclose to him – tell him – that you are living with HIV but not on meds, and see what he wants to do. He can make the best choice for himself since he knows if he has been taking PrEP regularly or not.
- If he's not been taking PrEP regularly, he might not be totally protected. That's good information for you to have too. Just because he's on PrEP doesn't mean that he knows everything about it. He might think he's protected because he started taking it yesterday, but

that's not enough time for it to start working. Or, he might have missed his last 5 doses, and he might not be protected then either.

### **Scenario 3:**

Six months ago your doctor told you that your HIV was undetectable, that is, your virus is suppressed. You've been consistently taking your medications ever since. While checking out online, you start chatting with this guy who is just your type. He sends you a pic of his ass and you totally want to fuck him. His profile says he's on PrEP.

- What kind of sex do you have? condomless / use a condom / it's complicated

### **Discussion**

[Make sure these points are covered.]

- This is the safest situation in terms of HIV transmission between someone living with HIV and someone who is HIV negative. If you are undetectable, which means HIV is suppressed in your body, you're very unlikely to be infectious. And he is HIV negative, but protected by PrEP.

### **Scenario 4:**

A year ago you found out you are living with HIV. You started taking medications, but after a few weeks you decided that you just didn't feel like doing that right now. So you stopped. You have a fuck buddy who you haven't seen for a few months and in the past he's told you that he's negative. He texts you a picture of his dick and says he's in the neighborhood.

- What kind of sex do you have? condomless / use a condom / it's complicated

## Discussion

[Make sure these points are covered.]

- For this situation, since your virus is not suppressed and you are with someone who is negative or thinks he is negative, it would be best to use a condom.
- This would be a good situation to talk with him about his and your status. Perhaps he is on PrEP and is very regular in taking his medications.

## Scenario 5:

You've been living with HIV for about 2 years now but so far you just haven't wanted to take HIV meds because you feel pretty great. You've been on two dates with this guy you really like, who's also living with HIV. He's on Atripla and he's talked to you about you getting on medications. You're having him over for dinner this weekend and hope you get down to business.

- What kind of sex do you have? condomless / use a condom / it's complicated

## Discussion

[Make sure these points are covered.]

- You are both living with HIV, so having condomless sex is very low-risk. However, if you are going to have condomless anal sex, what should you do about making sure you don't have an STI or are transmitting one?

[Wait for responses.]

- Get checked for STIs whenever you have a funny drip or discharge, burning when peeing, a genital itch, discomfort – but what do you do about STIs that don't have symptoms?

- Get tested for STIs at least every 3 to 6 months, don't rely only on noticing symptoms.

## **Scenario 6:**

You just saw your doctor about a month ago and you were told that your viral load was undetectable. You take your meds regularly, and so you can assume that your viral load is still undetectable. It's a Thursday night and you're totally free ... you have no plans. You feel horned up and decide to see what your favorite bathhouse has to offer. You find yourself in a room with a hot guy. You take turns sucking each other and then he turns around and presses his ass up to your dick.

- What kind of sex do you have? condomless / use a condom / it's complicated

## **Discussion**

[Make sure these points are covered.]

- A case can be made for any of the three options. Taking your meds regularly and having an undetectable viral load can allow for condomless sex.
- However, you should consider the possibility of catching an STI, and so using a condom is entirely appropriate here too.

## **Scenario 7:**

You have been living with HIV for 6 years now and go to the doctor regularly. With every visit, you're told that your HIV is undetectable/suppressed. You take all your meds every day. You go out to the club and see this hot dude you've noticed around town. You see him getting a drink and he notices you too. You make eyes at each other and after a while you introduce yourself. You end up going back to your place. You start making out and you feel his dick pressed up against you. Very quickly you're both rolling around naked. It's not clear who will get fucked

but someone definitely will be taking dick tonight. He tells you he's negative.

- What kind of sex do you have? condomless / use a condom / it's complicated

## **Discussion**

[Make sure these points are covered.]

- This seems like "it's complicated." It's possible that the guy told you he is negative because he wants you to use a condom if you are living with HIV.
- The best thing might be to discuss your status and his status, so he knows what's up and you two can make the best choice together.
- It's also possible that even though your HIV is undetectable, you may not want to discuss your status with someone you just met at the club by disclosing that you are living with HIV and have an undetectable viral load. So in that case, you may want to use a condom.

## **Scenario 8:**

You have been taking HIV medications for 2 years or so, and at the past few visits your doctor has told you that that your HIV is not undetectable; you have a viral load of 100,000. In the past few weeks you've been super busy and forgot to take a bunch of your pills. It's Thursday night and a guy who you've met a few times texts you and asks if you want to get together. You get together to watch a movie and start messing around. He hasn't said anything about his HIV status and doesn't ask you about yours. It's obvious that he wants to fuck you and you are horny as hell.

- What kind of sex do you have? condomless / use a condom / it's complicated

## **Discussion**

[Make sure these points are covered.]

- Sometimes, HIV remains detectable in your blood even though you are taking HIV medications.
- Why does this happen? [Make sure these points come up.]
- Sometimes people don't take their medications regularly and then HIV levels increase in the blood (and in cum or semen).
- It's important not to skip doses. When you miss a dose, HIV can begin to increase again. That's bad for your health and it means you can transmit HIV to other people, much more than if you were taking your medications regularly.
- It's possible that these medications aren't working so well for you, and so you may need to try some other medications.
- Would it be safe if you were the bottom and he was the top? [Pause.]
- No, this still wouldn't be safe since a top, someone doing the fucking, can get HIV from the bottom, the guy getting fucked.
- If you end up having condomless anal sex and your partner is HIV negative, you can recommend that he try to get onto PEP (post-exposure prophylaxis), which is a medicine someone who is HIV negative can take to avoid becoming infected after a possible exposure to the virus.
- But in order to work, PEP has to be taken within 72 hours – that is, 3 days – after having sex. And the guy would have to take PEP for about 1 month. People can get PEP here at APEB.

# Medications and HIV

## Objectives:

- To consider good reasons to take medications.
- To help participants come up with ideas about how to remember to take their medications.

(20 minutes: 1:00-1:20)

[A flip chart or white board and marking pens will be needed.]

### **MODERATOR**

OK, now we're going to do some brainstorming about HIV treatment and medications.

We're going to talk about treatment for HIV. So first, what are the benefits of taking medications?

## **Discussion: What are the benefits of taking medications?**

[Make sure these points are covered.]

- If we aren't taking medications when we are living with HIV, is it likely we will eventually get sick? HIV and AIDS are on a continuum – at one end of the continuum is having HIV and at the other end is being diagnosed with AIDS. When we first become infected with HIV, we're on one side of the continuum.
- But over time, if we aren't on treatment, our health worsens. For some people this happens right away, but for others, we might seem to be OK for a while – even for many years. Our immune system – which is what fights infections in our bodies – tries to fight HIV but eventually it loses and we become sick if we aren't taking

medications. So we move along the continuum as we become sick and we eventually develop AIDS unless we're taking medications.

- When people have HIV and don't take medications, HIV multiplies and spreads throughout the body. As it does this, it damages many organs in the body. Most people who are living with HIV and don't take medications are eventually diagnosed with AIDS.
- Taking medications regularly, every day, means that you won't develop AIDS. In fact, you really don't hear much about AIDS anymore because the medications work so well.
- Taking HIV medications means that we can live as long as people who don't have HIV.

It used to be that when people found out that they had HIV, it was recommended that they wait a while before starting to take medications, until there were signs that they were becoming ill. But now, we start taking medications immediately after we find out that we are living with HIV. Nip it in the bud before it spreads throughout your body! HIV medications will do that.

Any thoughts on this?

[Let the participants speak, but keep it short.]

- The other benefit of taking HIV medications is that they can help you avoid passing HIV to others. That's a huge benefit.

Alright. Despite the fact that HIV medications are really effective at reducing the amount of virus in your body – almost everyone misses a dose now and then. Some people miss doses for a day, two days, even a few weeks. Let's explore that together and try to understand why it happens.

### **MODERATOR**

What are the reasons we sometimes miss taking our HIV meds? These can be your own reasons or someone else's reasons – and you don't need to

tell us which describes YOU! We are going to write these reasons on the flipchart here.

[Board Activity]

Write the reasons identified below for missing doses on the dry erase board. (Have one coordinator write and the other lead the discussion.)

On the left side, write reasons in one color. Leave room on the right side of the paper to write possible solutions to the particular issues, in a different color.

So on the left side are the challenges to taking medications regularly, and on the right side are the solutions.

Have them match up on each side.

## **Discussion: Why do we miss taking our meds?**

[Make sure these points are covered.]

- When you hear people murmur or indicate that a reason is quite familiar, say, **“Hmm, I hear a lot of agreement here, how many of you have experienced this?”**
- When attendees begin to run out of ideas, it helps to read the whole list to them and then ask: **“What other reasons can you come up with?”**
- Ask occasionally, “Which of these resonate for you – are they your reasons too?”
- Make sure that depression gets mentioned, and name it (e.g., “Feeling down – that is, being depressed – can be a major factor for to people miss doses of their medications! And sometimes people who are depressed don’t just seem sad, but can be apathetic, don’t seem to care about their health, or can be irritable a lot. All these can be signs of depression.”)

- Sometimes, it helps to prod people to analyze more deeply why something happens, saying, “**And why does that happen?**” or “**What causes that?**”
- Make sure to discuss the fact that using substances such as weed, alcohol, and other drugs, can make it harder to remember to take medications.

OK, so we’ve heard a lot of different reasons for why we sometimes don't take our HIV meds! We know that it is in your body’s best interest to keep taking your medications every day – to keep your immune system at its strongest.

What are some things we can do to help us so that we don’t miss taking our meds? Let’s brainstorm about what can be done that can help with each issue! Let’s help each other to come up with new solutions!

- Write these on the flip chart (remember that sometimes it helps to read the whole list to attendees and then ask, “**What other ideas can you come up with to prevent or avoid missing meds?**”)
- Occasionally, ask or comment, “Hmm, I hear a lot of agreement here. How many of you have found this to be helpful?”
- Also, occasionally ask for more information, “**That sounds like a really good approach – how would you actually do that?**” You want to push so that people feel they have the capability of doing these things (i.e., increase their self-efficacy beliefs that they can achieve these goals).
- Make positive, affirmative comments (e.g., “Oh, these are great ideas!” or “I’ll bet that would be very helpful!”)
- In response to depression being a reason for missing medication doses, you can say, “It can be really hard dealing with depression!” and “If you do feel like you are dealing with depression – or you know someone else who you feel is suffering with depression – talk with one of the coordinators in the program and we can provide you with

referrals who can help. Depression can be treated! If you have it, don't just live with it – try to get help! It will help your whole life be better. Talk with us here at APEB and we can assist you with finding a counselor.”

- If no one mentions depression-related reasons, make sure to raise the issue yourself, such as by asking, “**Has anyone experienced that feeling really down or depressed can make it hard to take medications regularly?**” and then going into the statement above.
- In response to the reasons for missing doses that are associated with substance use, remind participants that it is not problematic to take medications while high on various substances, and therefore, there is no reason to skip doses.
- Suggest that, if they are planning on getting high, perhaps they can plan to make sure they don't skip taking medications.
- Make sure that mention is made of getting support from a friend or family member to take medications. Ask specifically how a friend or family member can provide support.

So one thing that has come up a few times is the idea of getting what is called "social support." This is the kind of support that can help you with taking medications, or seeing your healthcare provider regularly, or simply to cope with living with HIV.

Great, that was excellent! Now we can see all the reasons why we might miss taking our medications, but we can also see lots of things that we can do to make sure we take doses regularly.

But there's one last thing I want to add here – all of us miss doses once in a while, no matter how hard we try to take all our medications. That's OK, just get back to taking them as soon as possible. We need to forgive ourselves if we miss sometimes and not let that be a reason to give ourselves a really hard time.

[Make sure the following points were mentioned and discussed.]

- Just remember at a certain time of day (set a timer, perhaps set it to go off several times with a few minutes in between).
- Associate taking your meds with something else you do regularly, such as brushing your teeth or taking a shower, and incorporate that into your daily routine.
- Plan ahead if you might not sleep at home one night and carry the meds with you.
- Ask a friend or two to call or text you every day, and you can come up with a buzzword that reminds you to take your meds.
- Put the meds in a place where you will see them every day.
- Keep some extra meds with you so that if you realize you forgot to take them at home, you have some right there to take.
- Put a sticker on the inside of your front door so that you see it before leaving home.
- Put a sticker on the mirror to remind you.

# Supporting Our Brothers Living with HIV and Getting Support for Ourselves

## Objectives:

- To motivate participants to talk with their friends about:

Supporting our brothers who are living with HIV to take their medications regularly and see their healthcare provider at least twice a year.

- To discuss the most effective ways for participants to talk with friends.
- To give participants practice in supporting their friends about these issues.
- To give participants practice in talking with friends.

(20 minutes: 1:20-1:40)

## **MODERATOR**

OK, in this next activity, we will talk about how we can support our friends who are living with HIV, and how we can get support for ourselves.

- We probably all have friends we care about who are living with HIV. But we know that not everyone who is living with HIV is in care, seeing their healthcare providers and taking their medications regularly. In fact, up to *half* of men drop out of care after they initially start. They don't see their healthcare providers anymore and have stopped taking medications.
- Now that we've attended the Positive Living Group, we have an opportunity and the power to help our friends live healthier lives.
- Sometimes it's so uncomfortable to talk about HIV that we avoid it, but we can't keep doing that. We don't usually talk about these sorts

of things – but we need to start if we're going to help make sure our friends who are living with HIV are as strong and healthy as possible!

- When we encourage our friends to take their medications regularly, we're helping take care of each other.

OK, we're now going to do a few "lightning rounds." We will take turns and go around the room, from person to person, as quickly as we can, speaking out things. Speak truthfully, keep it real.

So, the first topic for a lightning round is this:

**Lightening Round 1: What can you do to help a friend who is living with HIV to take care of himself?**

- This could be asking once in a while if he is keeping his doctors' appointments, or if he needs a reminder of an upcoming one, or help in getting to a doctor's appointment, or if he might want any reminders from you to keep taking his meds regularly.
- Or it could be helping a friend get back into care, someone who you know who is living with HIV but decided not to take medications. You can refer him here, to M+ and APEB.
- So as we go around the circle, the question to answer is, "What can you do to help a friend who is living with HIV to take care of himself?"

[If this goes very quickly, you can ask the group to talk about something else they might do for that friend, or what they might do for a second friend.]

***Discussion***

- How motivated to you feel to do this?
- What are some potential challenges to following through and doing this for a friend?

***MODERATOR***

The second topic for a lightning round is this:

## **Lightening Round 2: If a friend were going to support you about these issues, what would you like regarding support?**

For example, daily texts? Let's go around the circle twice for this one!

### ***Discussion***

[After members of the group respond, here are some questions for discussion.]

- What do you think about all these ways in which you might be able to get support from friends or family members in helping you to be on track in seeing a healthcare provider, and being on medications for HIV?
- Which of these actions really hits you as a great help you'd like?
- What are some ways that friends might try to provide support that would NOT be so useful?
- How can you get a friend or family member to help you in the way you've thought of?

People who give support to others and who get support *from* others do better in terms of taking their medications and staying in care.

So it's important for you and for your friends who are living with HIV to give support to one another and get support from one another – in the way that is beneficial for everyone. It's important to talk to your friends about how they might give support to people living with HIV.

How might you go about asking for support from a friend or a family member? What problems or challenges might come up if you ask for help with remembering to take your medications for example, or about getting a ride to an appointment?

In order to have the most influence with your friends in helping them take care of themselves, here are three tips we want to give you.

1. Emphasize the *positive benefits* of what you're encouraging them to do. So, if you are trying to encourage a friend to remember to take his

medicines every single day, talk about the benefits of taking them in terms of his health and well-being.

2. Use *yourself as an example*. Talk about how you've done this yourself and how you did it. For example, in the scenario we've just discussed, you could tell him about how you've negotiated beforehand that you wanted to have safer sex or perhaps that you put it into your online profile if you have one.
3. *Don't lecture* your friend or be judgmental. Most of the time, we respond better when hearing words of care and support rather than being lectured to, or worse yet, being told we're stupid for doing something. So think about how you're encouraging your friend to take care of himself.

What problems or difficulties might arise in talking with a friend about these issues?

What ideas do you have about how to deal with these problems?

# Encouraging Friends and Becoming More Involved with the M+ for Men Living with HIV

## Objectives:

- To elicit commitments to talk with friends.
- To inform participants about other activities for men living with HIV.

(10 minutes: 1:40-1:50)

[Facilitator asks participants to each make a commitment to talk with friends.]

### **MODERATOR**

Besides inviting men to attend this group, it's also very important to talk with your friends and acquaintances about the issues we've discussed here – and the power they have to make thoughtful decisions about their own health and the health of others.

[Pause for a bit while they think about this. The more they can consider specific people, the better. You are trying to get real commitments here to invite others.]

This can include talking with your friends who are living with HIV about the importance of getting into care, keeping their medical appointments, and taking their medications every day.

# Invitation to Become Involved with M+

## Objectives:

- To let participants know about the variety of ways they can be involved with M+ and APEB activities.

(10 minutes: 1:50-2:00)

[Facilitator asks participants to each make a commitment to talk with friends.]

### **MODERATOR**

We're very excited about M+ and all the services that APEB offers for men living with HIV, and we'd love for each of you to attend those activities that sound of interest to you.

We have HAPI, which is a regular group that you can attend as often as you like. It is held on [day], between xx – yy, right here. Any same gender-loving man who is living with HIV can attend it. We talk about a large variety of topics.

APEB also has Brothaz, which is also a regular group that you can attend as often as you like. It is held on [day], between [time], and is also held right here. It is for men who are same-gender-loving, regardless of their HIV status. So positives, negatives, and guys who don't know their status come together to talk about issues that affect all of us. You don't need to say anything about living with HIV at those meetings.

And finally, we have a lounge for men to come by and hang out, get some snacks, watch TV, and just relax. We call this "The Living Room," and its hours are the same as APEB's, 9:30 a.m. to 4:30 p.m. You're welcome to come by whenever you want.

[Thank participants for attending the meeting.]

[Facilitators might express personal feelings about their own experience with this group and what they got out of the meeting.]

[Invite participants to share their reactions.]