POSITIVE SPIN
FACILITATOR’S
GUIDE

Thanks to advances in HIV treatment, people living with HIV who are diagnosed early, linked
to care, prescribed antiretroviral therapy (ART), and stay adherent to their medication are living
healthy lives and reducing the risk of spreading the virus to others.

In his 2013 Executive Order establishing the HIV Care Continuum Initiative, President Obama called
upon Federal agencies implementing the National HIV/AIDS Strategy to prioritize addressing
the continuum of HIV care, including by accelerating efforts to increase HIV testing, services,
and treatment along the continuum. In 2013, AIDS.gov developed two videos to help educate
Americans about the continuum of HIV care: The HIV Care Continuum Initiative of the National
HIV/AIDS Strategy and HIV Continuum of Care.

Encouraged by the White House to update those videos, AIDS.gov developed Positive Spin to
continue to raise awareness and increase understanding of the HIV care continuum. Given the
disproportionate impact of HIV on young Black gay, bisexual and other men who have sex with
men (MSM) and our ongoing commitment to using new media tools in HIV efforts, we developed
a series of videos featuring the personal stories of Black MSM who have successfully navigated
the continuum from initial diagnosis to achieving viral suppression as a way to explain what the HIV
care continuum is and demonstrate its importance.

WHAT IS POSITIVE SPIN?

Positive Spin features 25 brief videos that share the personal experiences of five HIV-positive,
gay black men who have successfully navigated the care continuum from diagnosis to viral
suppression. Positive Spin focuses on these stories, initially, because black gay and bisexual men
currently experience the greatest impact of the domestic HIV epidemic.

Positive Spin uses digital storytelling videos because we believe in the power of compelling
personal stories to communicate important messages across communities and populations.
Stories for some can address the misconceptions, stigma, and discrimination that continue to
present significant barriers to accessing HIV testing and treatment. The stories of the men featured
Positive Spin is an educational resource and provides health information for your general knowledge. It is not intended to be a substitute for professional medical advice, diagnosis, or treatment. Always seek the advice of a physician or other qualified health provider with any questions regarding a medical condition.

What is the HIV Care Continuum?

The HIV care continuum is the series of steps from the time a person is diagnosed with HIV through the successful treatment of their infection through the use of HIV medications. The ultimate goal of HIV treatment is to achieve viral suppression, meaning the amount of HIV in the body is very low or undetectable. This is important because it helps people with HIV to stay healthy, live longer, and reduce their chances of passing HIV on to others.

The HIV care continuum requires of several steps for a person living with HIV to achieve viral suppression:

- Diagnosed with HIV infection
- Linked to care, ideally meaning they visited a healthcare provider within three months after learning they were HIV-positive
- Engaged or retained in care, meaning they received medical care for HIV infection
- Prescribed antiretroviral therapy to control their HIV infection
- Virally suppressed, meaning that their HIV viral load – the amount of HIV in the blood – is at a very low level

To learn more and access the latest information on the proportion of people living with HIV engaged at each stage of the continuum, visit the AIDS.gov HIV Care Continuum page at: https://www.aids.gov/federal-resources/policies/care-continuum.
Who Should Use this Facilitator's Guide?
The Positive Spin videos and website were created with a variety of audiences in mind. Namely:

- People living with or at risk for HIV
- Case workers
- Support group facilitators
- Providers new to HIV
- Federal workforce

When used in conjunction with this guide and facilitated discussion, Positive Spin aims to help health professionals and people living with or at risk for HIV:

- Describe the five stages of the HIV care continuum
- Identify strategies to address the potential challenges and barriers encountered along the continuum
- Connect people living with HIV to federally funded programs and resources to support them along the continuum.
POSITIVE SPIN FACILITATOR’S GUIDE

INDIVIDUALS FEATURED IN POSITIVE SPIN

Positive Spin features the personal experiences of five HIV-positive, gay black men who have successfully navigated the care continuum from diagnosis to viral suppression and are now living healthy with HIV.

These stories represent the individuals’ own personal experiences and are not intended to be inclusive. By by sharing these stories, AIDS.gov hopes to inspire more people with HIV to get tested, get connected with care, start HIV treatment, and stay in care, so that they can live longer, healthier lives and reduce transmission of the virus.

GUY ANTHONY

Guy learned he was HIV-positive in 2007. After a negative experience with a provider, he fell out of care for two years. But deciding he needed to take control of his health, he started volunteering at an LGBT support center in hopes they would help connect him to a provider better suited to his needs. It worked. He was linked to a nurse practitioner who communicated the message he most needed to hear: "you're worth it." Today, he has an undetectable viral load and receives ongoing mental health care, which helps him stay healthy. An HIV activist and peer counselor, Guy is the author of Positively Beautiful: A Book of Affirmations + Advice & Advocacy.

URIAH BELL

Uriah was diagnosed with HIV in 1987 when he was 17 years old. In denial, he ignored his HIV diagnosis for five years. But when he got very sick with tuberculosis, he couldn't deny it any more. By the time he was connected to care, he had four T-cells and a viral load of 759,000. With proper care and treatment, he was prescribed antiretroviral therapy (ART) and his T-cell count rose. A poet, author, and activist, Uriah has stayed in care and today his T-cell count is above 650 and his viral load is undetectable.
PAUL GLASS

Paul was diagnosed with HIV in 1987, a time when doctors and researchers were still learning about HIV and how to treat it. He found a great primary care doctor who monitored his condition and eventually referred him to an HIV specialist. Paul started antiretroviral therapy (ART) in 2002 and stayed adherent. Today, his CD4 count is 462 and his viral load is undetectable. An HIV activist and advocate, husband, father, and grandfather, Paul says “I feel like I’ve got a lot of years ahead of me. I’m extremely happy.”

PATRICK INGRAM

Patrick was diagnosed with HIV in 2011 after making what he calls “one of the most adult decisions of my life”—the decision to take an HIV test. After he found out he was HIV-positive, a close friend drove him to an HIV clinic. There, a caring doctor examined him and talked to him about the importance of antiretroviral therapy (ART). Patrick started ART and uses mobile apps and other tools to make sure he takes his meds every single morning. Today, strong and healthy, with an undetectable viral load, Patrick blogs and speaks publicly about living with HIV.

KEN WILLIAMS

Ken was diagnosed with HIV in 2010 and was linked to HIV care immediately after his diagnosis. He learned how antiretroviral therapy (ART) could keep him healthy and reduce his risk of transmitting HIV to others, so he decided to start treatment as soon as possible. He took his first dose four months after he tested positive for HIV and says he “hasn’t looked back since.” A prominent video blogger, Ken sees his health care provider regularly and is living a happy, healthy, and full life with HIV.
DISCUSSION QUESTIONS

The discussion points offered in the following pages include a quote or comment from each video, followed by questions that can be posed to a group or individual to help them better understand that particular stage of the HIV care continuum. Because the discussion points refer to specific individuals, we have provided their names and photographs as a reference.

It should be noted that this is not a complete list of discussion points, nor will all of the questions be relevant to all audiences. We encourage you to tailor the points and the language used to the needs of your particular audience.

While we have provided specific questions and discussion points for each stage and each individual, each video and each story addresses overcoming challenges. The following universal questions can also be used to facilitate discussion across all the videos.

- How do you feel that the experiences in this video relate to your own personal experiences?
- What challenges were faced? What are some strategies you have used to overcome these challenges?
- What support systems were in place? What are some strategies to ensure that these support systems are in place for everyone living with HIV?

Know Your Status

SUMMARY

You can’t rely on symptoms to know whether you have HIV. You can look and feel perfectly healthy and still have HIV.

Getting tested for HIV gives you the knowledge you need to protect yourself and your partners. If you learn you are HIV-positive, you can start treatment that will help you stay healthy and live longer. You can also take steps to reduce the risk of passing HIV on to others.

The five videos in this section describe each men’s experience of finding out his HIV status. Each man’s experience is unique. Below are discussion points for each video.
GUY

*Diagnosed with HIV in 2007 when he was 19 years old.*

When Guy reflects on receiving the news that he was HIV positive, he says,

> They came and told me that I was HIV-positive, and I just sat there. I was emotionless.

- If you are HIV-positive, what do you remember about learning your HIV status? What emotions did you have?
- If you are a healthcare worker, what emotions have you witnessed in others upon learning their HIV status? How did you respond and why?
- What resources exist in your community to help a person manage their emotions? What resources are missing? How have you tried to fill any gaps that exist?

Guy says,

> I was 19 years old and my life had changed.

- If you are HIV-positive, how did your life change when you found out you were diagnosed with HIV?
- Or, how might your life change if you received this diagnosis?
KEN

*Diagnosed with HIV in 2010 when he was 26 years old.*

In his video, Ken says,

> HIV can happen at home.

■ What does this mean to you? Where else can HIV “happen”?

When Ken’s HIV diagnosis was confirmed, he says,

> I sat at my desk, and I cried.

■ If you are HIV-positive, how did you react when you found out your status? How did you feel?

■ Or, how have others you have known reacted to learning their status? How did you respond to them?

■ What actions can you take to help yourself feel better? What resources are in the community?

When asked what advice he would give himself before he was diagnosed with HIV, he says that he would tell himself,

> Go ahead. Live.

■ If you could go back in time to before you were diagnosed with HIV, what advice would you give yourself?

■ Or, what do you think some of the individuals you know who are HIV-positive would tell themselves if they could go back in time?
PATRICK

Diagnosed with HIV in 2011 at age 23.

Patrick says,

“I made one of the most adult decisions of my life, and that was to get tested.

■ Why do you think Patrick considers to decision to get tested, “one of the most adult decisions” of his life? What inspired (or could inspire) you to make a similar decision?

When talking about waiting for his test results, Patrick says,

“Those were the longest 20 minutes of my life.

■ Do you remember this waiting period? What was it like for you?

Patrick says that after telling his family about his HIV status, they said,

“Regardless of whatever you’re going through, we’re still going to love you and be there for you.

■ What do you think are some of the challenges people living with HIV face in telling their friends and family members about their HIV status?

■ Do you think Patrick’s story is typical? Why or why not?

■ How do you think Patrick’s family’s response may have contributed to his eventually being able to access HIV treatment and care?

■ How would you support a friend who disclosed to you?
PAUL

Diagnosed with HIV in 1987 when he was 37 years old

Paul received his diagnosis in a rather abrupt and uncaring manner.

- If you are HIV-positive, what was the manner of the person who delivered the news to you? How did this affect your ability to make it to the next stage of care?

Paul says that after he was diagnosed with HIV, he thought,

“Who should I tell? Who can I tell?”

- If you are HIV-positive, to whom did you disclose your status? Did you feel comfortable doing so? What were some factors that made you feel comfortable with some people and (potentially) uncomfortable with others?

- If you are a healthcare worker, have you had discussions about disclosure with individuals who were newly diagnosed? How did these conversations go?

- Do you know the laws regarding disclosure in your state? Where could you find this information?

After Paul told his family and teenage son, he said,

“it turns out that it was OK.”

- If you are HIV-positive, to whom have you disclosed your status? How did it feel?

- How do you think Paul’s family’s response may have contributed to his eventually being able to access HIV treatment and care?
UIRATH  
_Diagnosed in 1997 when he was 18 years old_

After Uriah received his HIV diagnosis, he said,

“I walked out of the office and ignored it for five years.”

■ What do you think are some reasons why Uriah chose to ignore his status? What are some of the consequences of this choice? Have you ever wanted to ignore your status?

■ What advice would you give to a newly-diagnosed person who was considering ignoring their status?

Once he accepted his HIV status, Uriah said,

“It has been a blessing, in hindsight, ever since.”

■ How might having HIV be a blessing? Why would someone say that?

■ Have you ever felt that your HIV diagnosis was a blessing?
CONNECT TO CARE

SUMMARY

After you are diagnosed with HIV, it’s important to get connected to an HIV provider as soon as possible because with proper care and treatment, you can stay healthy, live longer, and reduce the chances of transmitting HIV to others. Your provider will conduct a complete health evaluation and conduct lab tests to set up a treatment plan to help you stay healthy.

Some of the men in the videos connected to care immediately following their diagnosis, while others did not. The following quotes and questions are meant to guide a discussion about the importance of connecting to care, as well as the potential challenges.

GUY

Once Guy found a provider that he felt truly listened to him, he said.

“That’s where I felt empowered the most, because he asked me questions that the previous provider didn’t.”

■ If you are HIV-positive, do you feel empowered by your provider? Why or why not? (Or, if you are a healthcare worker, how do you help your clients feel empowered?)

■ What questions do you wish your provider would ask?

■ What can people with HIV do to feel more empowered?

Guy mentioned that he also suffers from depression and that his care team,

“cared about me holistically.”

■ What does caring holistically mean to you? How does this make a difference in supporting people with HIV to achieve the goal of viral suppression?
KEN

Ken’s provider told him,

“This is completely human. We’re going to get through this.”

- If you are HIV-positive, has your provider said things to you that made you feel like he/she was going to help you get through your HIV diagnosis? If so, what did they say? Why was that significant?

- Or, if you are a healthcare worker, have you said something similar to your clients? How did they respond?

When referring to getting medical care, Ken says,

“It’s about going where you are celebrated. Not just tolerated.”

- What does this mean to you? What does being celebrated mean? What does it look like? How does it feel to be ‘just tolerated?’ What does that look like?

- How do you think an atmosphere that celebrates, not just tolerates contributes to helping people with HIV to achieve the goal of viral suppression?

PATRICK

After a week of trying to connect to care Patrick found a friend who helped advocate on his behalf and got him into care. At that point he said,

“I was sick. I was tired. My energy levels were low. And I didn’t care anymore.”

- If you are HIV-positive, have you ever felt this way? If yes, how did you cope with it? Is there someone who you can identify that can and will advocate for you when you don’t have the energy?

- If you are a healthcare worker, how can you support your clients who feel this way?
One of the first things Patrick’s provider says to him is,

“\[quote\] What do you know about HIV? You need to know more. [quote]”

- Why do you think Patrick’s provider said this to him? How or why do you think it supported Patrick in eventually achieving the goal of viral suppression?
- If you are HIV-positive, where can you learn more about HIV/AIDS?
- Is there ever a point where you know enough about HIV?

As a result of Patrick’s provider encouraging him to learn more about HIV, he said that now,

“\[quote\] Every time I have to go to a new provider, I want to make sure that I am going to a doctor who is knowledgeable about HIV. [quote]”

- If you are HIV-positive, how can you find out if your provider is knowledgeable about HIV? What questions can you ask?
- Have you ever been to a provider who didn’t seem to be very familiar with HIV? How did this influence your care and/or relationship?
- If you are a healthcare worker, do your clients ask you about your knowledge of HIV? How do you typically respond?

PAUL

When Paul connected to care, his provider told him,

“\[quote\] Relax. Fill out these forms. The doctor will get the chance to talk to you. [quote]”

- How do you think Paul felt when he heard this? What can a provider say or do to help a person with HIV feel more at ease?
Once Uriah connected to care, he realized,

"It wasn’t just me that I had to live for.

■ Why was that realization important for Uriah?

■ In addition to yourself, who else do you have to live for? How does that make you feel?

■ How do you think the idea having “someone to live for” helps people connect or re-engage in care? What about people who don’t have this same feeling? How can you support them in connecting to care?

Uriah’s provider assured him that,

"With lifestyle choices, I could take complete control of this.

■ What lifestyle choices can help an individual take control of their HIV?
START HIV TREATMENT

SUMMARY

Talk to your HIV care provider about getting started on HIV treatment. It’s called antiretroviral therapy (ART). HIV Treatment will help you stay healthy.

ART is the use of HIV medicines to fight HIV infection. It involves taking a combination of HIV medicines every day. These HIV medicines are lifesavers and will help you stay healthy. ART is recommended for all HIV-positive people, even if you feel fine. ART can’t cure HIV, but it can control the virus so that you can live a longer, healthier life and reduce the risk of transmitting HIV to others.

The following quotes and questions are intended to trigger discussion about the benefits, challenges, and strategies for starting HIV treatment.

GUY

Once Guy started treatment, he said.

“I felt empowered and I felt confident again.”

- If you are HIV-positive, how did you feel when you started treatment?

- What might help you (or your client) feel more empowered and more confident about being on ART?

Because Guy was also taking antidepressants, it took some time before his provider felt comfortable prescribing him a one-pill-a-day regimen. Once he did, he said,

“I just remember being so excited that after 7 years, I was able to get on a one-pill-a-day regimen.”

- If you are HIV-positive, how do you feel about your regimen? Is it manageable? Is there anything that you could do to make it more manageable?
Before Ken started treatment, he asked himself,

*Are you ready to do it? Because this is a lifelong process.*

- If you are HIV-positive, did you feel ready when you started treatment? Do you feel ready now? Why or why not?

- What can people living with HIV do to get ready to start treatment? How can you support them in this process?

Ken says,

*I think starting treatment is a sign of acceptance in itself.*

- Do you agree with this statement? Why or why not?

- What does it mean to accept yourself? In addition to starting treatment, what are some other signs that a person has accepted living with HIV?

When Patrick started taking his medication, his provider told him,

*This is going to determine how long you live, and your health.*

- How does this statement make you feel? What other things determine how long a person with HIV lives and stays healthy?
When Patrick first started treatment, he had side effects such as diarrhea, weakness, and stomach pain, but these subsided over time. Now, he said.

"I really don’t have that many side effects.

- If you are HIV-positive, did you experience side effects? Do you still? If so, how do you deal with them?

- Do these side effects impact how/if you take your medication? What kind of things can you do to help deal with these side effects?

- If you are a healthcare worker, what kinds of side effects have your clients experienced and how have you helped them manage these side effects? Did they affect how/if your clients took their medication?

**Paul**

Paul says,

"I now had a chance to live. And I could begin to make plans again.

- What plans do you have for your future? How can being on HIV treatment help you accomplish these plans?"
If you are HIV-positive, how do you feel about your regimen? Is there anything about your regimen that makes it hard to follow? If so, what can you to do address this?

When he talks about the importance of starting treatment, Uriah says,

“I think the reward is worth it.”

Do you agree with this statement? Why or why not?

If you are HIV-positive, what are some of the rewards of taking your medication?
STAYING IN CARE

SUMMARY
Care and treatment for HIV is a lifelong process. To stay healthy, you need to keep taking your HIV medications and receive regular HIV medical care. By doing so, you can reduce your chances of getting sick from your HIV disease and prevent transmitting the virus to others.

If something is getting in the way of staying in care, talk to your HIV provider so he or she can find ways to help you stay on track. Your life and future are worth it.

The following quotes and questions are intended to inspire discussion about challenges to and strategies to help people living with HIV adhere to their HIV medication.

GUY

Guy is very open about his HIV status and says,

“Pretty much everyone knows my status because I don’t hide it.”

- How do you think Guy’s openness relates to his ability to stay in care?
- If you are HIV-positive, how open are you about your HIV status? Why or why not?

While it can be hard to disclose your status, Guy finds that his friends are very supportive and encouraging. He says,

“If I’m with friends, they say, ‘Hey, did you take your medication?’

- How do you think Guy’s friends’ response relates to his ability to adhere to his HIV medication?
- If you are HIV-positive, are there people in your life (friends, family, co-workers, etc) who can support and encourage you to take your HIV medication? If so, who are they? What can you do to get them to support you?
- If you are a healthcare worker, how can you support your clients in identifying these individuals?
KEN

When Ken talks about adhering to his HIV medication, he says,

“It’s a process for me. I’m still learning and I still have those conversations with my doctor.”

- If you are HIV-positive, what kind of things are you still learning about HIV? What questions do you have for your doctor? Are you comfortable asking him/her?

- If you are a healthcare worker, how do you approach this conversation?

Ken says,

“What inspired me to be adherent is family.”

- If you are HIV-positive, what inspires you to adhere to your HIV medication?

- If you are a healthcare worker, what inspires your clients to stay adherent?

He also says,

“There’s always a reason for taking your HIV medication. Let yourself be the reason.”

- If you are HIV-positive, what’s your reason for taking your HIV medication?

- If you are a healthcare worker, what do you think your clients’ reasons are?
PATRICK

Patrick admits that depending on what he has going on, it can be challenging to stay adherent to his HIV medications.

“I have to be very strategic in the way that I incentivize myself to take my medication every day.”

- If you are HIV-positive, what makes it challenging for you to stay adherent to your HIV medications?
- What are some of the strategies you have used to stay adherent?
- If you are a healthcare worker, what are some of the strategies your clients have used to stay adherent?

Patrick “rewards” himself for being adherent and taking his medications for an entire week by treating himself to a chicken sandwich.

- What are some incentives/rewards might help you stay more adherent?
- If you are a healthcare worker, what are some incentives/rewards might help your stay more adherent?

Patrick uses an app to remind him to take his medication. He says,

“I just try to make it fun and make it interactive.”

- What tools and resources do you know about that would help you (or your clients) stay adherent?
When Paul discusses challenges to taking his HIV medication, he says,

“It was really difficult to wrap my mind around the fact that I needed to take them regularly.”

Do you think this is a typical response? Why or why not?

Was there anything in particular that was difficult for you (or your clients) to wrap your mind around? If so, what? How did you/they finally come to terms with that?

Paul goes on to say that,

“I knew that it was something that I had to contend with and to figure it out.”

If you are HIV-positive, what challenges do you still face with adhering to your medications? What questions to you have?

What are some things you can do help figure out how to deal with these challenges? Whom can you talk to? Where can you learn more?

If you are a healthcare worker, what are some of the ongoing challenges your clients typically face and how do you support them in overcoming them?

Uriah is very proud to say,

“I have not – in these 16 and a half years – missed a dose.”

If you are HIV-positive, what makes you proud about taking your HIV medications? What goals do you have? How do you track your progress?
LIVING HEALTHY WITH HIV

SUMMARY
HIV is a lifelong condition. At this time, there is no cure. But that doesn’t mean you can’t live a long and healthy life! If you are diagnosed early, start taking antiretroviral therapy (ART), and continue to take your HIV meds regularly, you can keep HIV under control and live a normal lifespan.

The following discussion points are intended to inspire conversations about achieving the goal of viral suppression and living a healthy life with HIV.

GUY

Guy works as a HIV Medication Adherence Counselor. When he talks about his job, he says,

I know that in order for me to inspire my clients and my friends to take charge of their health, I have to be okay.

- Do you agree with that statement?
- Do you have people in your life who inspire you? Do you inspire others?
- How does taking charge of one’s health inspire others?

Guy mentions his favorite quote by Maya Angelou is,

Do the very best you can until you know better. Then when you know better, do better.

- What does this quote mean to you? What does knowing better mean? What does doing better mean?
- What quote(s) inspire(s) you? Why?
KEN

Ken talks about living healthy with HIV and says,

“Being adherent, it heals. Having a voice, that heals.

Do you agree with that statement? Why or why not?

What do you find healing? How do you incorporate this into your life?

What does ‘healing’ mean to you? What does it look like? Feel like?

Do you feel like you have a voice? Why or why not?

Now that he’s living a healthy life with HIV, Ken says,

“I’m feeling more in control with my life now. I get to choose my path now.

Do you (or your clients) feel in control of your life? What would help? What steps can you take to feel more in control?

How is the feeling of being in control related to staying healthy with HIV?

What do you think your “path” is? Did you choose it? Can you choose it?”
Patrick says,

"I need to continue to be healthy and have a suppressed viral load so I can continue the work of advocacy."

This is important to him because when he was diagnosed, he didn’t have anyone to look up to or who to go to for help.

- Who do you have that you can look up to or go for help? Are there people you know that have had similar challenges as you?
- What websites, blogs, or videos do you know of where you can listen to other people’s stories and experiences?

Since being diagnosed with HIV, Patrick has joined a tennis league and run several marathons. He says,

"There’s a light beyond struggling to be adherent to your medication. Reaching viral suppression really does improve your quality of life."

- If you are HIV-positive, what goals do you have as a result of adhering to your HIV medications?
- How do you think viral suppression can/will improve your quality of life? (Or your clients’ quality of life.)
PAUL

Paul is 65 years old and says,

"Being adherent has some positive effects. I look healthy and I feel healthy. And I feel like I've got a lot of years ahead of me."

- If you are HIV-positive, do you think you look healthy? Do you feel healthy? What can you do to look and feel healthier?
- Do you feel like you have a lot of years ahead of you? What do you hope to accomplish during this time?

Paul ends his video by saying,

"It's never too late."

- What do you think he means when he says it's "never too late"? Too late for what?
- Have you ever felt that it was too late? How did you deal with that?

URIAH

Uriah talks about the living healthy with HIV and says,

"Since my diagnosis, I've seen parts of the world that I never dreamed of."

- What places do you want to visit? What other dreams do you have?
- How does achieving the goal of viral suppression relate to individuals' abilities to achieve their dreams?
Because Uriah is living a healthy live with HIV, he says,

"I’m painfully excited as to what the future holds for me.

- What about your future excites you?