



PROMISE for High Impact Prevention



A Compendium Featuring Role Model Stories Supporting
the HIV Care Continuum



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- This PROMISE for HIP Role Model Story Compendium is intended to be useful to those implementing Community PROMISE using the care continuum with people living with HIV/AIDS (PLWHA) and their partners. The usefulness of this Compendium will be increased if the stories are adapted and pilot tested with your target population.
- We welcome any input that may be generated from this compendium. Please contact Dr. Jonny Andia, DHAP CDC, via e-mail at efn4@cdcl.gov with any comments, questions, suggestions, or concerns.



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My Painting, My Life

I am a painter and originally from Chicago. I've been living in Atlanta since last year. I ran from Chicago after I broke up with my lover after finding out that he was HIV positive.



Currently, I work on my paintings for very long hours every day so I don't have to think about the reason why he didn't mention he was HIV positive. I try to eat well and keep myself busy painting non-stop so I don't think about the idea that I might have HIV. Just the idea of possibly being HIV positive takes control of my mind and my soul. Last month, I started to feel unusually fatigued. I've had this flu for so long that it has been affecting my painting. So last week, in the supermarket I saw my dear friend Carol who is a nurse. She knows everything about me and what happened with my boyfriend in Chicago. She always wanted me to go to the doctor, but I don't want to think about doing that. Well, this



time she saw me in bad shape and asked me "did you go to the doctor for a check-up?" I responded, "I've been postponing that because I am afraid of any bad news and besides, I feel good now". She is a good friend and cares about me, and I could see she didn't like how I looked. So, after her usual talk about going to the doctor I asked her if she could come with me for support. She was happy to hear that and she agreed to come with me. She said, "Of course, I will go with you!" Thank God that I have her; she is my only support at this moment. She says that in case the HIV test comes back positive, I will have several options. "People are living with HIV for many years now. "Right now, HIV is considered a chronic disease like diabetes and with good care, you can live a full and happy life", she said. I am afraid about having HIV, but she is my support. I am going to see the doctor and I am ready for any news.

Characterization	African American, Male
Membership	Ex-partner is PLWHA-MSM
Risk Behavior	Non-HIV testing
Goal	HIV testing
Risk Determinant	SS; Pros & Cons; SI
Stage of Change	Contemplation to Preparation
Barrier to Change	Afraid to know status; knowledge; HIV meds side effects
Positive Outcome	Is now ready for any news
Original Source	Adapted from Mistercenter.org (23) (CDC grantee) 2012



Telling It Like It Is

I want to share some good news about how things have changed for me since I moved to the city last year. I was excited about all the opportunities I had to meet other guys. You could find me cruising in Central Park or partying in Chelsea almost every day. Fun times for this 24-year-old! And then I tested positive for HIV. After that I just kind of kept to myself. That worked for a while ... until I got lonely ... and horny. As luck would have it, I met someone who seemed really cool. We clicked right away. Before I knew it, we were having sex and spending a lot of time together. All along, I wanted to tell him I was living with HIV, but I was scared about how he would react. One day, he found my HIV meds and confronted me. We broke up that night.



After experiencing that heartbreak, I realized I wanted to find a way to be open about my HIV status with my sex partners. I wasn't sure how to do that, so I asked my case manager. She encouraged me to think about what I need to feel comfortable to tell guys I'm positive. We practiced having that conversation. At first it was kind of hard. But it got easier each time I did it with her.

I have decided to slow things down. From now on, I'm going to focus on being friends first—without any sex. That way, we can spend time getting to know each other and feeling more comfortable with each other. This plan makes me feel more confident that I will be able to tell someone my HIV status before having sex.

Characterization	24 y/o, Male
Membership	PLWHA-MSM
Risk Behavior	Non-disclosure
Goal	Disclosure with new partner
Risk Determinant	SE
Stage of Change	Contemplation to preparation
Barrier to Change	Fear of disclosure
Positive Outcome	Feels more confident to disclose status
Original Source	Adapted mistercenter.org (25) CDC grantee 2012.



It Didn't Scare Him Off



My name is Toya and I am a 34 year old single mother living with HIV. It's not easy being a single mother. Some guys see your kid and they run the other way. And, if a guy doesn't mind the

kid, I still have to worry about what they will do when I tell them my status. A few guys have been ok with it and others couldn't handle it. My mom always says that the guys that can't handle it aren't real men anyway. My mom's support helps give me the strength to speak out about having HIV. She is the first person I told I was positive. I am so glad I told her because it is so much better when someone has your back. She has been there for me in every way.

I have been with a good man now for a couple months. He is so freakin' fly! He has a nice hard body and his kiss just makes me melt. He even likes my

kid! I had been trying to tell him about my status for the longest time, but it was so hard. I didn't want him to get scared and stop seeing me, but I know how easy it is to get caught up in the moment. I knew I couldn't let that happen without telling him my status. I thought about what my mom said about being a real man, so I told him. I'm so proud of myself for that! I am proud of myself for being brave and telling him even though I worried it might scare him off. It didn't scare him off! He is still with me and our relationship is going strong. We haven't started having sex yet, but I know when we do we will play safe and use condoms. I don't know what will happen in the future, but I can always be proud of myself for being honest!

Characterization	34 y/o, African American, Female
Membership	PLWHA-heterosexual
Risk Behavior	Non-disclosure
Goal	Disclosing HIV status
Risk Determinant	SS; Pros & Cons
Stage of Change	Preparation to Action
Barrier to Change	Worried that disclosing status will scare partner away
Positive Outcome	Proud for disclosing status with partner
Original Source	Act Against AIDS video database

Things Have Been Great

My name is Con and last year I found out that I have HIV. It wasn't easy learning that I have HIV. I used to fool around with boys and girls and in reality I don't know who gave me HIV. But since I learned about my status my life has changed a lot. One good change is that I am much closer to my family. I really needed their support when I found out because I was depressed for a while. It was difficult to tell my friends. When I told them some didn't want to hang out with me anymore. I found out who my true friends were too. They are the ones that stuck around and supported me through this difficult time. I have been going to the doctor and doing a lot of exercises. After I tested positive, I made a promise to myself that I would tell who ever I became involved with about my status. Well one of my friends that didn't know my status and I have been getting really close. I think we are falling in love. I had been planning to tell my friend about my status, but the timing was never right. I had so many plans of how to do it, but I was so afraid he wouldn't be interested in me if I told him. Finally, one day we were in the park and we got on the subject of sex and STDs. My friend asked if I

would ever date someone with an STD. I knew that was my moment to open up to my friend. I told my friend and it was such a relief. Things have been great since. I think it brought us closer for me to tell my friend something that showed I trusted in them.



Characterization	24 y/o, Asian, Male
Membership	PLWHA-Bisexual
Risk Behavior	Non-disclosure
Goal	Disclosing HIV status
Risk Determinant	Pros & Cons; SE; SS
Stage of Change	Preparation to Action
Barrier to Change	Fear of rejection
Positive Outcome	Feels closer to friend interest
Original Source	Multiple sources; Act Against AIDS video database; Condoms Count, Stories from the Bronx (Women's Center)



Switch It Up

My name is Tiffany and I am Transgender. I do hair in Newport News to pay the bills, but my man is the one who really takes care of me. We've been together a long time and used condoms in the beginning. But, when we got tested together, he saw that we were both clean so he hasn't used condoms since. When you're one of the girls like me, you want to keep your boyfriend so I did it raw. Well, a couple of months ago he started getting sick, with a terrible flu and some rash on his body. I thought it was just a simple health problem. Also, I noticed that he was behaving strange, like hanging up the phone when I came in the room or hanging out with feminine guys when I wasn't around. Well, last night I discovered he was taking some pills and I wanted to know about it. I confronted him and he told me that he just found out that he was HIV positive. I saw his face and he was crying. He said, "Sorry, sorry". Then I asked "why didn't you tell me?"

"You want to kill me", I told him. I started crying and crying. He told me that he was looking for the right time to tell me but it was very difficult for him. We cried and cried for two days. I wanted to leave him, but I



couldn't. I loved him. It was terrible. "Why didn't he say anything" I was asking myself. I missed work for a couple of days and then my salon friend, Olivia, called me. She was worried when I didn't show up for work without calling in. Well, I spoke with her over the phone and told her everything. Well, I knew that the first step was to get tested and then she explained to me that now a days HIV medications are very effective and if he takes them every day he can live for a long time and be healthy too. She gave me hope. However, I needed to go to the clinic to have an HIV test. Thank God my test was negative and I didn't leave my man because I love him. We are planning for the future and I want to take care of him I guess that was the reason I came out negative, to look after and support him. I want him to be healthy.

Characterization	African American, Female
Membership	Transgender; partner of PLWHA
Risk Behavior	Non-disclosure
Goal	Status Disclosure; help partner deal with HIV status and take meds
Risk Determinant	SE; SS
Stage of Change	Contemplation to Preparation
Barrier to Change	Partner didn't want to disclose status
Positive Outcome	Will help her partner deal with HIV condition
Original Source	Adapted current CDC grantee 2011.



My Friend with Pneumonia

I am David and I am a 29 year old African-American male. I received my HIV diagnosis last year at 28 years old when I finished college. Currently I live downtown with my roommate, Robert, who is also HIV positive. Robert seemed to feel healthy. I've been refusing treatment because I don't feel anything wrong and I don't want any discomfort of any drug in my body. I always say that I will go to the doctor when I feel sick, but for now I feel great. Last week I took Robert to the emergency room after a very debilitating case of pneumonia. After taking Robert to the hospital and witnessing his illness for several days, I spoke with the hospital's nurse. I discussed my HIV

condition with the nurse and she was very surprised that I was not taking my HIV meds. "How come you don't take your meds", she asked me. "Well I don't feel anything wrong yet and I don't



want to feel those horrible side effects... so I keep myself healthy, eating well and exercising", I said. "Well I understand, but you will need to be careful since you don't know how strong your immune system is. It will be wise for you to have an appointment with your doctor, and check that out", she said. I didn't want to have any opportunistic infections like my friend Robert so after speaking with the nurse I went home and decided to visit my doctor next week. I think she has a point. I don't want to keep wondering if my immune system is weak. I want to keep myself healthy and live longer; I will visit my doctor next week.

Characterization	29 y/o, African American, Male
Membership	PLWHA
Risk Behavior	Non-Linkage to care
Goal	Linkage to care
Risk Determinant	Pros & Cons; K; SE; SI
Stage of Change	Contemplation to Preparation
Barrier to Change	HIV meds side effects; lack of knowledge
Positive Outcome	Keep self healthy
Original Source	Adapted from Mistercenter.org (22) (CDC grantee 2012)



Afraid to Tell



I've been in New York City less than a year now pursuing my nursing degree. Meeting people hasn't been so easy since my boyfriend and I split and I tested positive for HIV. Physically, I feel strong and healthy, but emotionally I feel alone and depressed. How can an intelligent nursing degree major be HIV positive? I am embarrassed and ashamed; I should know better. I am afraid to tell the world, especially my parents who live in Atlanta. They know about my sexual identity and they are supportive. Most importantly, they told me to take care of myself. I have let them down. See, this can't be happening to me. Yesterday, in class my teacher, whom I admire and respect, told us about new HIV treatments and the progress science is making with respect to treating HIV infection. "HIV doesn't have to be a death sentence anymore," he mentioned. After class, I thought about my life, my family and my situation. I am thinking I should get into care as soon as possible since my

professor says that early antiretroviral therapy can really fight the virus pretty well. I know that my life changed when I learned about testing positive, but I have been postponing this for the last 6 months or so. Also, I am afraid to tell my parents; they don't deserve this, but it is what it is....Tomorrow, I will go to the hospital to talk with the doctor about my options, and of course call my parents. That is what they would like me to do.



Characterization	African American, Male
Membership	PLWHA-MSM
Risk Behavior	Non-linkage to care
Goal	Linkage to care
Risk Determinant	SE; K; SS; S; SB; SN
Stage of Change	Contemplation to preparation
Barrier to Change	Afraid to disclose status to parents
Positive Outcome	Will do what his parents want him to do
Original Source	Adapted from Mistercenter.org (19)(CDC grantee) 2012



It Won't Control Me

Something just wasn't right with my body. "A 26 year old should not feel this way", I thought. I had no clue what was going on until I went to the doctor to get some blood work done. That is when I found out I had



HIV. I was so shocked. I was in what I thought was a committed relationship at the time. Apparently my boyfriend was cheating on me and we had not been using condoms. My world was turned upside down. There I was a college student in control of my own life and suddenly I felt I had lost complete control. My diagnosis was a couple of years ago now and I still haven't told my parents. We are very close and they visit me almost every week. My family is all I have and I don't want to disappoint them with this news. I haven't been to the doctor yet because I don't want my parents to find out. I don't want them to ask why I am going to the doctor or what kind of

medication I am taking if I end up getting on meds. I did some research online and found out that people with HIV are living normal lives, especially if they get into care. I also found out that the more support a person has the easier it is to deal with having HIV. I needed to figure out what to do. That day, I went to the church and prayed, and then I went to my parents' home and told them. They cried but after a while they kissed me and said they loved me no matter what. I felt relieved and proud that I did the right thing. I have their love and I am ready to get into care.

Characterization	26 y/o, Hispanic, Female
Membership	PLWHA-heterosexual
Risk Behavior	Non-linkage to care
Goal	Linkage to care
Risk Determinant	SN; PS
Stage of Change	Contemplation to preparation
Barrier to Change	Afraid to tell parents about HIV status
Positive Outcome	Relieved and proud
Original Source	Act Against AIDS video database; Lower East Side Health Project



Nuyorican

I am pretty lucky to live with my best friend; we're like two peas in a pod. I like being a home body, chilling and playing Nintendo 3. I'm a 26 year old Puerto Rican raised in New York City or Nuyorican, living in Atlanta as an HIV positive man. Six months ago it wasn't like that. I was in New York, living with my boyfriend and I discovered that he was cheating on me. I confronted him and we had a big fight. Well, it was sad because I loved him. Breaking up with him affected me and I stopped taking my HIV pills. I didn't care much about my life anymore. I was depressed and didn't want to talk to anyone. One day my favorite uncle called me and asked



me for help. I couldn't say no since he has been there for me so many times. So I said I would go to Atlanta to help him. So, I moved to Atlanta to help my uncle. In Atlanta, I realized that life goes on and I started going out with a couple of people. Well, I found a new friend who is a sweetheart because he knows about my condition and don't mind being with me as long as I continue in care. Since my arrival in Atlanta, I have not been feeling well so I asked him to go to the hospital with me to continue with my HIV care. I have a reason to take care of me now. My uncle is fine now and my friend is great. He will be here for me, like I want to be there for him. I am ready to see my doctor and control this disease.

Characterization	26 y/o, Male. Nuyorican
Membership	PLWHA-MSM
Risk Behavior	Non-retention in care
Goal	Retention in Care; get back on ART regimen
Risk Determinant	Pros & Cons; SE; SS
Stage of Change	Preparation to Action
Barrier to Change	Broke up with boyfriend; lack of social support; depression
Positive Outcome	Has a reason to take care of himself now
Original Source	Adapted from original RMS from MISTER PROJECT (21) (CDC grantee 2012)



Lynda: My Experience, My Life

My name is Lynda. I'm 32 years old and I've never touched drugs, I don't even drink or smoke. But that doesn't mean anything, not these days. You see, six months ago I started feeling really bad, like I was sick all the time. I thought at first it was just a cold or flu. It started with little lumps on my throat, then, a month later I started waking up in the middle of the night soaked in sweat. I went to the hospital and got a swab HIV test. I found out that I was HIV positive. That means that one night when I was out working, I must have slept with someone who gave me the virus.

I was so angry and scared; I think I must have cried for a month. I don't even know who gave it to me. I was pretty popular with the paying customers when I was younger. I didn't even think about getting infected with the virus back then. The doctor and the social workers at the hospital helped me a lot. I'm taking medication for the disease, and I go and talk to a social worker whenever I need to. But, sometimes it is difficult to go to the doctor's appointments because of my status.



Like the other day that I fought with my boyfriend and he told me that I was nothing and he didn't care about me. I thought he understood my condition but now I know. I started to cry and cry and I stopped going to the doctor. I couldn't understand why he would say that. Well, after missing a couple of appointments, I realize that I need it to talk to someone so I went to see my counselor and she told me that I need good, positive people around me. So I decided to ask him to leave, for good. I need someone who will support me and not criticize me. The past is the past. It's much better to be with someone who cares and understanding than to be with someone who doesn't care.

Characterization	32 y/o, Caucasian, Female
Membership	PLWHA-commercial sex worker
Risk Behavior	Non-Retention
Goal	Retention in Care
Risk Determinant	SS; Pros & Cons; SE
Stage of Change	Preparation to Action
Barrier to Change	Being around negative people
Positive Outcome	Asked partner to leave; needs be around people with positive outlook
Original Source	Lower East Side Health Project Role Model Stories Library Lynda: It's Not Worth Killing For September 1991 – Vol 1, No 4 (A)



Not Me, Not My People

I'm 40 and I have lived clean most of my life. I have a good husband and three great kids. I've always been very close to my family. I try to go to church every week and I pray for my children, that they'll live a good life, and stay away from drugs. When I was young I tried dope once. I was with Tito, Maritza's father. He was my first novio. I loved him so much. I would have done anything he asked. He wanted to share everything with me. He wanted me to shoot with him. In the end, he was no good. He walked out when Maritza was born, and left me with nothing.



Yeah, I never thought it would happen to me, but now my sister, Adriana is HIV positive. She found out during a regular doctor checkup about six months ago. She was desperate and believes that her 'novio' who uses recreational drugs

may have infected her. Well she was so desperate and depressed that she damned him. It is not easy for her because she is a single mother and has to take care of her 6 year old daughter too. Last week I visited her and she was crying and I found out that she didn't go to her regular doctor visits because she was depressed. She was crying and crying so we talked. I promised her that I will accompany her to visit her doctor and will visit her more often. She loved that idea. She asked me not to leave her alone and to always be there for her.

Not me? Not my people? Not true.

Characterization	40 y/o, Hispanic, Female
Membership	Sister is PLWHA
Risk Behavior	Non-retention in care
Goal	Retention in care
Risk Determinant	K; PR; SS
Stage of Change	Contemplation to Preparation
Barrier to Change	Drug use; non-adherence to ART
Positive Outcome	She has helped and will continue to help her sister
Original Source	Lower East Side Health Project Role Model Stories Library July 1991 – Vol 1, No 2 (A)



Maria

My name is Maria and I am a 23-year-old Latina. I got my HIV diagnosis at 19 years old and after a couple of months I started my ART treatment by the recommendation of my doctor. I love my doctor because he is very caring and a great man. It has been very hard following my ART regimen because the medicines caused several side effects, but most importantly I was afraid to disclose my HIV status at my job. During the first months of taking my HIV meds, I had diarrhea, nausea and severe pain in my abdomen. I couldn't get used to it. Plus, since most people at my job didn't know about my HIV condition, it was difficult for me to hide side effects. I couldn't tell my co-workers about my HIV condition. I was afraid about the talk and the rumors and honestly, I was afraid to lose my job. So, I didn't tell everyone until last month. Sometimes I couldn't take my pills at the time I needed to take them because I was in an important meeting; so, I used to skip them. It was very difficult! So, a couple of months ago, I went to see my doctor and after a long talk, he recommended I be sincere at least with my very close co-workers. This way I could develop an understanding of their real perceptions about HIV. I went home and after much thought, I decided to tell Jasmin, my next door office co-worker. She is a married woman who always brings me cookies. It was difficult for me, but I knew it was the right thing to do. So, one Monday morning I told Jasmin about my condition. I was surprised by her



reaction. "Yes, my close college friend also is HIV positive and she looks fantastic" she mentioned. Jasmin knew a lot about HIV. So we went for lunch and we talked. Jasmin

offered me support to 'take my pills on time' because I told her about my problem with keeping up with my meds schedule. It feels good to know that there are people out there that care. Thanks to my doctor that helped me confront this situation and thanks to Jasmin for her support. I know I will be able to continue with my HIV pills regimen from now on.

Characterization	23 y/o, Latina
Membership	PLWHA
Risk Behavior	Non-adherence to ART
Goal	Adherence to ART
Risk Determinant	Pros & Cons; SE; SS
Stage of Change	Preparation to Action
Barrier to Change	Perceptions about HIV disclosure to coworkers; management of ART schedule
Positive Outcome	Knows she can do it now with help
Original Source	Adapted from Lower East Side Health Project 1999. NYC



For the Love of Tony

Getting clean was the hardest thing I'd ever done, but I just couldn't live the "Life" anymore. I was tired of chasing the drugs, and getting over to get high. I finally thought, "That's it, I've had enough." I kicked on methadone, and I remember walking out of the hospital thinking that I was finally free. That was last year.

Meeting Tony has been a great second opportunity in my life. My past drug use was difficult for me but Tony has been a great support for me. He once said that he loves me for who I am now, not for who I was when I was using. Last year, I started getting sick for no good reason and feeling tired every day. Over the counter medication was not working. So, I decided to go to the

doctor. The first thing he asked me was if I did drugs. I told him I stopped last year and my partner doesn't. So the doctor asked me to have an HIV test. I got scared and started to think, "Could I have been infected after all those years on drugs?"



I got tested and found out that I was positive for the HIV virus. Tony went for the test about a week

after I found out; thank God he was negative. That same night, Tony and I sat down and really talked. Because my past experience with medications and my current methadone use, I was worried about taking too many medications. And it has been tough. When I have side effects from my medicines or when I forget to take them at the right time, Tony has been there to remind me about the importance of following my treatment. At the beginning it was difficult since my methadone was interacting with my HIV meds. Tony helps me every day and calls the doctor for me when I don't feel well. He calls me from his job to remind me about taking my meds. Thank God my virus load is undetectable and sometimes we think about not using a condom, just once to see if it feels different, but then we talk about what might happen, and it just doesn't seem worth it. The real trick is that we have our lives together and I am glad for that.

Characterization	Caucasian, Female
Membership	PLWHA-In methadone treatment
Risk Behavior	Non-Adherence to ART
Goal	Adherence to Art
Risk Determinant	SS; K
Stage of Change	Action to maintenance
Barrier to Change	Side effects of ART
Positive Outcome	Viral load is undetectable and she is glad she has her life together partner
Original Source	Lower East Side Health Project Role Model Stories Library August 1991 – Vol 1, No 3 (A)



I'm a Tough Guy

Hello! My name is Dustin, but my fellow Native American friends call me Bearclaw. I am a 41 year old guy living with HIV. I had a pretty wild past when I was young. I was screwing every girl in sight, or at least every girl that wanted to have a little fun. Those times were fun, but now I am paying for not wearing condoms. I have calmed down a lot and now I work in construction.

For a while I thought that I didn't need medication for my HIV. "I'm a tough guy...I don't need no pill to make it", is what I used to say. My friend Randy who also has HIV had never taken his HIV meds; I figured I didn't need to either.

Besides, Randy was a really tough guy and I didn't want to seem weak. Well, I just got out of the hospital a week ago. I guess trying to be a "tough guy" and not



taking my HIV meds caught up with me. I ended up with pneumonia because my immune system got so weak from a high viral load. The Doc told me that if I took my HIV meds like he told me to, I wouldn't have been in such bad shape. I don't want to pay for not keeping myself safe again. I got HIV because I didn't use condoms. I ended up in the hospital because I didn't take my HIV meds. I don't want to get sick again! I am going back to the doc tomorrow to talk about getting on a good HIV meds plan to stay healthy and protect my body.

Characterization	41 y/o, Native American, Male
Membership	PLWHA-Heterosexual
Risk Behavior	Non-Adherence to ART
Goal	Adherence to ART
Risk Determinant	K; SI
Stage of Change	Contemplation to preparation
Barrier to Change	Wants to be a tough guy and take care of himself without meds
Positive Outcome	Will stay healthy and not get sick
Original Source	Indigenous Peoples Task Force role model story samples; Program Communication Branch (CDC) Together Participants list



My Viral Load is Lower and I Feel Much Better

My name is Brenda and I have had HIV for 17 years now. I have learned a lot about living with HIV over the years. The best lesson I learned was how to take your HIV meds like you are supposed to. You see, I didn't know that the virus could become resistant to the meds if you didn't take them the way you are supposed to. I would take my HIV meds sometimes and then I would take a break. At one of my Doctor visits I had a high viral load. The Doc told me it was from not staying on my meds all the time. He told me that the virus had become resistant to one of the meds I was on. I had to start out on a different medication all over again. Since my parents went with me on that visit they stayed on me to take my meds every day. They call every day and make sure I take my meds. Thank God for them because I have been on a good regimen for 7 months. I don't think I could have done it without

their support. My viral load is lower and I feel much better!



Characterization	African American, Female
Membership	PLWHA-heterosexual
Risk Behavior	Non-Adherence to ART
Goal	Adherence to ART
Risk Determinant	K; SI; SS
Stage of Change	Action to Maintenance
Barrier to Change	Lack of knowledge
Positive Outcome	Viral load is lower and she feels better
Original Source	Act Against AIDS; Program Communication Branch (CDC) Together Participants list



My Jail Experience

My name is Rose and I was diagnosed with HIV when I went to jail for selling ten bags of crack in the streets. I have been using crack the last 3 years after I lost Matt, my recent husband during the Iraq war. I loved Matt so much that I couldn't take it anymore. When he was killed in combat, life no longer had a meaning for me. I was very sad because he meant everything to me. Crack was the only thing that helped take my mind off of Matt, but getting crack almost every day was not easy. I had people who gave me crack for some sexual favors. I didn't care. I wanted more and more crack. To make matters worse, when I got busted, I found out that I was HIV positive and three months pregnant by Ricky, a friend who always



counseled me and comforted me during these difficult times.

The first thing they did in jail was to send me to detox for several days. It was horrible, because I suffered from withdrawals. I really felt sick and desperate. Then, after my detox, they started

me on HIV meds. They said the sooner I took the HIV meds the better the chances my

baby would be born HIV negative. So last month I started taking my HIV meds regularly. I want my baby to be HIV negative and I will do anything the doctor says to have a healthy baby. But I am worried about my life, a place to go after jail, my HIV condition and most importantly the future of my child. Ricky has promised me that I will be able to leave jail in 6 to 8 months. He is working with an organization that takes care of people like me, wives of veterans so he can find a good attorney. I want to be free and take care of my baby and take care of my HIV condition. I know that I have Ricky's support and the help from my late husband's memory to keep going in life.



Characterization	21 y/o, Pregnant Female
Membership	PLWHA-incarcerated
Risk Behavior	Non-adherence to ART
Goal	Adherence to ART
Risk Determinant	Pros & Cons; SS
Stage of Change	Preparation to Action
Barrier to Change	Depression
Positive Outcome	Knows she has Ricky's support and her late husband's memory to help her
Original Source	Personal Communication



My Second Trimester of Pregnancy

I am in my second trimester of pregnancy. I am 18 years old and found out that I have HIV when I went to my first OBGYN appointment at the clinic. I have been very independent and most of the time I have done things my way, including with my boyfriends. The father of my baby was a ladies man. He loved to be at parties and hang out with lots of girls. One day I found him with another woman in his car and I left him.

My current boyfriend, Frank, is a good person, so when I went home after my OBGYN visit and told him that I was HIV positive, I was in tears. I didn't want to do anything wrong with him. I was sad and scared. He was surprised and scared too. After a big silence, he left home. He was frustrated with me. After a couple of days, he returned and



immediately he went to get the HIV test. His test came back negative and I thank God for it. I am worried about being positive and he is too because of our child. I guess he is still with me because of our son.

My doctor told me about following my HIV meds every day. He told us that it is very likely if I follow my HIV regimen my baby will come out HIV negative. It is not easy to be pregnant and HIV positive. Some days, I feel nauseous, depressed and have headaches. I don't know if the symptoms are from my pregnancy or from the HIV meds. I don't know how many times I have been in the doctor's office. But, thanks to the support of my boyfriend and my love for my child, I will keep taking my HIV meds and hopefully, help my child be HIV negative.

Characterization	18 y/o, Pregnant Female
Membership	PLWHA
Risk Behavior	Non-adherence to ART
Goal	Adherence to ART
Risk Determinant	SE; SS
Stage of Change	Action to maintenance
Barrier to Change	Depression; drug use
Positive Outcome	Hopes that child will be HIV negative
Original Source	Personal Communication



My Life and My Faith

I am HIV positive and used to sell dope in the South Bronx. One day, I got busted for selling and went to prison for 5 years. In prison I went to rehab and got clean. Last year when I got out, my mistake was getting together with my old dope buddies and I used it again. I guess, I wanted to feel the good old times and ignore my HIV condition...but for some strange reason I just couldn't stop. It created big problems for me since I wanted more dope and I was not taking my HIV meds for around four months and not taking care of my health...it was terrible, until I got a horrible pneumonia and my neighbor took me to the hospital.



Thanks to him, I call him my angel, I am alive now. I met a counselor in the hospital that was very spiritual and we talked about the meaning of life, angels (like my neighbor who took me to the hospital) and responsibility. I started to see things

clearly and only then did I realize that the only person who could really burst that bubble was me. Nobody else had that power. I got into recovery, and thanks to my faith, things started to fall into place. I've been a hustler and a scammer all my life; the trick is I'm learning to play the game by the rules, and sticking to my guns. When I am frustrated, I meditate and that helps me make the game work for me, and now, for the first time I really feel like I've got the power... to continue with my HIV medications and get well again. I know it is a struggle but it's worth it to try.

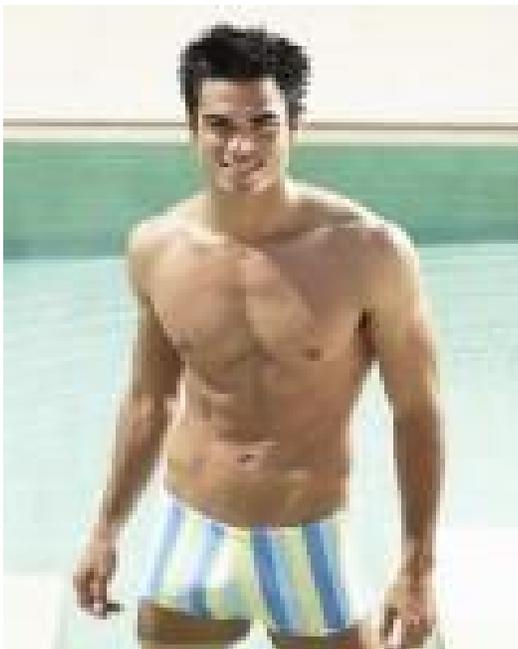


Characterization	Male
Membership	PLWHA-incarcerated; IDU
Risk Behavior	Non-adherence to ART
Goal	Adherence to ART
Risk Determinant	Pros & Cons; spiritual faith; SS; SE
Stage of Change	Preparation to Action
Barrier to Change	Drug use; lack of self-efficacy
Positive Outcome	feels in control
Original Source	RHISC Research Fellow paper: "Strategies to maintain wellness among HIV+ former opioid users." Dr. Nelson Tiburcio.



Jose

What's up! My name's Jose. I'm 23 years old and HIV positive. Since the last year I've been dating Duane who is HIV negative. We love each very much and sometimes we discuss having unprotected sex. I am afraid for him to get infected. So four months ago we made a plan to get him on Pre-Exposure Prophylaxis (PreEP), which is another way to keep from getting HIV. The doc asked us to keep using condoms but for Duane to take a pill every day, I guess sometimes condoms are not 100% secure so if something happens, he can be protected.



It has been three months since he started taking PreEP. Last week, the doctor tested him to make sure he is still HIV negative and he was. At first he hated to remember to take a pill every day and sometimes he forgot to take them but hell, if it keeps him safer, why not? He takes it with his muscle milk every morning before he hits the gym, so it's not hard to remember and I remind him to take his pills. We plan to keep it up! We still use condoms, but I feel better knowing he is on Pre-Exposure Prophylaxis when we do end up having sex.

Characterization	23 y/o, Hispanic, Male
Membership	MSM
Risk Behavior	Non-Pre-Exposure Prophylaxis (PrEP)
Goal	Pre-Exposure Prophylaxis
Risk Determinant	Pros & Cons; K; SE; PS
Stage of Change	Preparation to Action
Barrier to Change	Remembering to take pill daily
Positive Outcome	Partner feels better and safer
Original Source	Act Against AIDS video database; Personal Communication



Katrina

My name is Katrina and I've been dating my man, Jaden for 8 months now. He has HIV, but I don't. I won't lie; we have done it without condoms a few times, especially when things heat up so quick and we want to feel each other. A while back Jaden thought I should see his doctor and get checked. Jaden's doctor told me about some medicine called PrEP (Pre-Exposure Prophylaxis). The doctor said it was a pill I could take every day to lower the chance of getting HIV from Jaden. It is for people at higher risk of getting HIV, like me being in a relationship with Jaden who is HIV positive. He said it was similar to the pill Jaden takes to keep a low viral load. My girlfriend thought it was a good idea. I told her about Jaden having HIV, with Jaden's permission of course. She's always worried I'm gonna get HIV. So I made a plan to get on PrEP.

I took the docs advice and went on PrEP. I used to skip taking my pills a lot at first because I would forget. Now, me and Jaden take our pills together and I bought one of those weekly pill organizers just like his! Jaden keeps me on track with my pills because he doesn't want me to get HIV. He says he couldn't live with himself if I ended up with HIV. It has been four months now and I have been on a good schedule for taking my PrEP and I am still HIV-negative. I am proud of myself for that!



Characterization	Female, African American
Membership	Partner of PLWHA
Risk Behavior	Non-Pre-Exposure Prophylaxis (PrEP)
Goal	Pre-Exposure Prophylaxis
Risk Determinant	SS, SE
Stage of Change	Preparation to action
Barrier to Change	Remembering to take pill daily
Positive Outcome	HIV negative and proud of herself
Original Source	Personal Communication: Kathleen Green, Charles Collins, David Massey



- This PROMISE for High Impact Prevention (HIP) Role Model Stories Compendium is intended for use with persons who are HIV positive and their partners who are at high risk for acquiring or transmitting HIV.
- The stories in this intervention compendium are not intended for general audiences. This compendium is part of the Community PROMISE intervention package that includes implementation manuals, training and technical assistance materials, and other items used in intervention delivery. Also included in the package are: (1) the Centers for Disease Control and Prevention (CDC) fact sheet on male latex condoms, (2) the CDC Statement on Study Results of Products Containing Nonoxynol-9, (3) the Morbidity and Mortality Weekly Report (MMWR) article Nonoxynol-9, Spermicide Contraception Use—United States, 1999, (4) the ABC's of Smart Behavior, and (5) the CDC guidelines on the content of HIV educational materials prepared or purchased by CDC grantees (Content of AIDS-Related Written Materials, Pictorials, Audiovisuals, Questionnaires, Survey Instruments, and Educational Sessions in CDC Assistance Programs).
- Before conducting this intervention in your community, all role model stories must be approved by your community HIV review panel for acceptability in your project area. Once approved, the intervention package materials are to be used by trained facilitators when implementing the intervention.



WHOM IS THIS COMPENDIUM FOR?

- This Compendium uses evidence-based social science technologies to develop highly effective role model stories to support the HIV care continuum and to help meet the Division of HIV/AIDS Program's strategic plans. These technologies can be applied by agencies that are implementing Community PROMISE, plan to implement Community PROMISE, or need information to make a decision about implementation of Community PROMISE or other HIV evidence-based programs that work with PLWHA. Agencies that select and manage community peer-related models will benefit from the role model story samples using the HIV continuum of care topics.

WHAT IS THIS COMPENDIUM FOR?

- The role model stories provided in this Compendium provide effective modeling stories from people who are in all steps of the HIV continuum of care cascade. Agencies should pilot test the role model stories with their target population and adapt them to their particular circumstance. It is appropriate to collaborate with their community board to assess the appropriateness of the stories before releasing them in the field.





- Community PROMISE (Peers Reaching Out and Modeling Intervention Strategies) is a science-based community level intervention that uses community peers and small media in the form of Role Model Stories to change community norms, attitudes, and behaviors. Role Model Stories distributed by peers can engage persons living with HIV to seek medical care, keep them adherent to medications, and retain and/or re-engage them in care.
- Each role model story featured in this compendium is accompanied by a table of 8 components that help summarize the story. Characterization is a short description about the role model and the circumstances of his or her life; membership is a description of the role model's membership in the population, such as PLWHA, MSM, incarcerated, IDU; risk behavior: many individuals have more than one risk behavior, but for the purpose of a role model story it is important to identify only one risk behavior; goal: each role model story should contain only one goal. This may be getting tested for HIV or adhering to ART; risk determinant: this includes factors that influence behavior change such as social norms or social support; stage of change: role model stories should illustrate movement from one stage of behavior change to another; barrier to change: these include any barriers that prevent the role model from taking part in the goal behavior. (i.e., fear of disclosing HIV status, side effects of ART); positive outcome: this component refers to the positive outcome that reinforces intention to adopt the desired behavior. Original source refers to the source that the role model story was adapted from.
- PROMISE for Positives has a goal of improving the quality of life for HIV positive individuals by using Role Model Stories to encourage and support persons living with HIV/AIDS to fully participate in the care continuum.





A role model story represents a social/cultural and behavioral approach to model and diffuse a new behavior within a community. Practice has demonstrated that there are multiple strategies to develop role model stories (Good, Better and Best ways to develop role model stories-see PROMISE manual-Module 3). The role model stories in this compendium were produced using secondary sources of data (old role model stories, newspaper and magazine articles, research journals, online vignettes, prior interview scripts, personal communication with experts in the field) and a solid pilot testing/validation mechanism (principally with the target population and experts in the field) to assess the validity of the role model story for the target population.

Steps to develop role model stories using secondary sources:

1. Identify the target population: People Living with HIV/AIDS (PLWHA)
2. Identify the risk behavior: We conceptualized multiple areas of risk behaviors for these new role model stories looking at the continuum of HIV care:
 - a. Non-HIV testing
 - b. Non-linked to care;
 - c. Non-retained to care;
 - d. Non-use of or poor adherence to anti-retroviral therapy;
 - e. Non-disclosure of HIV status;
 - f. Non-use of Pre-Exposure Prophylaxis (PrEP)
3. Select one risk behavior (see above) and identify your secondary source. Secondary sources are numerous; it can be a prior role model story that you want to ‘recycle’ and adapt with this new risk behavior or an existing story in popular media/specialized HIV/AIDS source magazines and articles. Remember, if your target population is PLWHA then you need to identify stories and anecdotes from PLWHA for your story. You will be surprised how many good ‘stories’ you will find.
4. If you use a prior role model story used by another agency, adapt it using the guidelines provided by the PROMISE manual. Always add the ‘local’ flavor to recycle the story, so people will identify with your story.
5. Once you have put together the story using the 8 characteristics, consult with your in-house and external experts. These generally are your key stakeholders who have extensive experience with your target population. Consultation is a very valid method to improve your story. Remember to add graphics into the story.

PILOT TEST the story with your target population. The main questions you will try to answer here are: how real is this story? How does the language sound? Does the story generate conversation? Remember that this is the most important step; the pilot test will provide VALIDATION to the story within the target population.



- **Community PROMISE (Peers Reaching Out and Modeling Intervention Strategies):**
 - An effective community-level STD/HIV prevention intervention that relies on role model stories and peers from the target population of your community.
- **Role Model Story:**
 - a brief publication that depicts the actual or planned behavior change of a specific target population member or “role model”
- **High Impact Prevention (HIP):**
 - interventions that are scientifically proven, cost-effective, scalable, and targeted
- **HIV Testing:**
 - learning HIV status by undergoing an HIV test
- **Status Disclosure:**
 - the act of an HIV positive individual disclosing their HIV status to a sexual partner
- **Linkage to Care:**
 - seeking or finding HIV care or treatment if an individual tests positive for HIV
- **Retention in Care:**
 - remaining in HIV care or treatment if an individual is HIV positive
- **Adherence to Anti-Retroviral Treatment (ART):**
 - maintaining a constant ART/HIV medication regimen
- **Pre-Exposure Prophylaxis (PrEP):**
 - taking daily medication to lower the risk of acquiring HIV in high risk situations
- **Person(s) Living with HIV/AIDS (PLWHA):**
 - an individual(s) who is living with HIV/AIDS who may or may not be in treatment or aware of their status
- **Continuum of Care for PLWHA**
 - includes diagnosis (HIV testing), linkage to and retention in continuous medical care for HIV, prevention counseling and other services that reduce transmission, and appropriately timed and consistent antiretroviral therapy (ART) for viral suppression.

Key Abbreviations:	SS: Social Support	SI: Social Influence	SE: Self Efficacy
	K: Lack of Knowledge	SB: Self Blame	S: Stigma
	SN: Social Norms	PR: Perceived Risk	PS: Perceived Susceptibility

