# older and wiser: many faces of HIV



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#### ACRIA – Who we are, what we do

ACRIA, the AIDS Community Research Initiative of America, conducts a comprehensive HIV Health Literacy Program that offers a diverse roster of services for people with HIV. ACRIA is an independent, not-for-profit communitybased AIDS research and education organization committed to improving the length and quality of life for people living with HIV disease through medical research and HIV health literacy.

#### Disclaimers

The information in this Discussion Guide is presented for educational and informational purposes only and is not intended as medical advice. All decisions regarding a patient's personal treatment and therapy choices should be made in consultation with a physician.

The stories featured are factual or based on fact. The interviews combine actual subjects and dramatizations by professional actors. This is no indication of their sexual orientation or medical status.

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## **Table of Contents**

Preface	2
Introduction	4
A Snapshot of Older Adults Living with HIV	6
How to use this guide	10
Characters' profiles	12
Javier	14
Ed	16
Joe & José	18
Brenda Lee	20
Juanita	22
Donald	24
Eva	26
Ramón	28
Prevention challenges	30
Tips for talking to your doctor about sex	31
Resources	32

2

The Centers for Disease Control and Prevention (CDC) estimates that people over 50 will account for half of all those with HIV in the U.S. by 2015. Almost 45% of New York City residents with HIV are over 50, as are 31% of the over one million people with HIV in the U.S.

Studies have shown that at least 60% of people over 50 are sexually active, but safer sex messages are rarely targeted to this age group—which allows deadly myths like those above to linger and spread among our seniors. Older adults do not always know they may be at risk for HIV. Some came of age in the decades before AIDS and did not get the information about HIV prevention that younger generations did. Some were married or in long term relationships and didn't feel the need to learn about HIV or other sexually transmitted infections.

Sex education for older people dispels myths about sex and HIV and corrects negative and dangerous stereotypes. It promotes the understanding that full sexual expression extends throughout our lives, not just in our youth, and that emotionally, mentally, and physically healthy sexual relationships are both possible and important to create at any age.

Today we are faced with new challenges in HIV treatment and prevention. A study by the CDC and the National Institutes of Health found that older adults who cannot read and understand basic health information appear to have higher mortality rates over a five-year period than those with adequate health literacy.

This speaks to the urgency of providing adults over 50 with the HIV prevention education they need to stay healthy. We must correct the myths and realize HIV can strike anyone. So many times our elders are left to fend for themselves. We forget the contributions they have made and the respect they deserve. Society and the medical community must not forget our seniors—that much they deserve.

Myths about HIV commonly held by adults over 50:

Monogamous couples are not at risk of contracting HIV.

Older people don't have sex.

Women who have already gone through menopause cannot get infected with HIV.

"It cannot happen to me."

"I can protect myself from HIV because I can detect the signs of the illness."

HIV is a homosexual disease.

## Introduction

### Health Care Providers

## Understanding the Challenges of Behavior Change

As a facilitator, it is critical that you integrate current, proven behavior change theories into the discussion. This will help participants understand how and why culture, gender, attitudes toward sex, body image, and other social factors influence the sexual choices we all make.

To assist you with this, ACRIA strongly recommends you become familiar with the Stages of Change Model, or SCM. This model was originally developed in the late 1970's and early 1980's by James Prochaska and Carlo DiClemente at the University of Rhode Island, when they were studying how smokers were able to give up their habit, or addiction. The SCM has been applied to a broad range of behaviors, including weight loss, injury prevention, and overcoming alcohol and drug problems, among others.

The idea behind the SCM is that behavior change does not happen in one step. Rather, people tend to progress through



a series of stages on their way to successful change. Also, each of us progresses through the stages at our own rate.

#### The Stages of Change The stages of change can include:

- **Pre-contemplation** (not yet acknowledging that there is a problem or that behavior that needs to be changed)
- **Contemplation** (acknowledging that there is a problem but not yet ready or sure of the desire to change)
- Preparation/Determination (getting ready to change)

#### Health Care Consumers

#### Understanding the Challenges of HIV Prevention

Far too few Americans over 50 who are at risk for HIV use condoms or get tested for HIV. In one national survey, at-risk people over 50 were six times less likely to use condoms and five times less likely to have been tested for HIV than at-risk people in their 20s.

The number of older adults vulnerable to HIV suggests that older adults may not be aware of the risk factors for HIV or how to protect themselves. Often health professionals don't give older adults the information necessary to help them protect themselves against infection. This is due in part to the general perception that older adults are not at risk for HIV, and to society's reluctance to discuss sexual and drug-taking behaviors that increase HIV risk.

Doctors and nurses often do not consider HIV to be a risk for their older patients. A study of doctors in Texas found that most doctors "rarely" or "never" asked patients older than 50 about HIV or discussed how to avoid it. Doctors were much more likely to say they rarely or never asked patients over 50 about HIV risk factors (40%) than they were to say the same about patients under 30 (6.8%).

Another challenge is that many older adults live in assisted living communities, where there is still great stigma attached to HIV, often linking it to homosexuality or substance abuse. Management may resist providing HIV materials or presentations in their facilities

Older adults need support and education to ensure that their lives over 50 are as rewarding and safe as they were before 50. And that support will not only help our seniors stay healthy, but will empower them as leaders and teachers of younger generations.

- Action/Willpower (changing behavior)
- Maintenance (maintaining the behavior change)
- **Relapse** (returning to older behaviors and abandoning the new changes-relapse doesn't always happen

## For the Record

#### Over the Hill? Not Under the Sheets

#### A Snapshot of Older Adults Living with HIV

In 2005, 1,000 people volunteered for an unprecedented ACRIA study designed to shed light on the unique needs of people over 50 living with HIV. In the study—called Research in Older Adults with HIV, or ROAH—80% of the volunteers were people of color and 33% were women, mirroring older people living with HIV in New York City. ROAH found that their concerns focused on the illnesses of aging, increased feelings of isolation from social support networks, and the negative impact of HIV stigma, shame, or ageism, which is discrimination based on age.

- Volunteers had been living with HIV for an average of 13 years, and while half had AIDS diagnoses based on serious illness, only 13% had CD4 counts below 200. Nearly 85% were taking HIV meds.
- 67% self-identified as heterosexual, 9% as bisexual, and 24% as homosexual.
- 70% lived alone, which is double the number of all older New Yorkers.
- More than half of those who had used alcohol or drugs were in recovery. Over one-third continued to use recreational drugs or alcohol, and more than half smoked.
- 36% had used injection drugs at some time.

ROAH and other research have found that older adults with HIV often lack the family and community support that can provide the care they will need as they age. This type of care is critical; about 44 million Americans currently act as caregivers to family and friends who have various illnesses. If this informal care were replaced by paid caregivers, it would cost more than \$300 billion a year.

### A few more things

A recent landmark study of 3,000 people confirmed that interest in sex does not fall off later in life—and if it does, it is usually due to poor health or to having no partner.

- 73% of people aged 57 to 64 reported having sex in the previous year, as did 53% of those aged 64 to 75 and 26% of those aged 75 to 85.
- Over 53% of the men reported having sex exclusively with women, 38% exclusively with men, and almost 10% with both sexes.
- Among those who were sexually active, the majority reported having sex two to three times a month.
- If a person's health was very good, that person was twice as likely to be sexually active as those in poor health.

People aged 57-85 asked "How important a part of your life would you say that sex is?"

	Men	Women
Not at all important	<b>13.</b> %	35.2%
Somewhat important	<b>50.4</b> %	<b>47</b> %
Very important	<b>36.5</b> %	<b>18</b> %

In 2005, persons aged 50 and older accounted for:

- 15% of new HIV diagnoses.
- 24% of people with HIV (up from 17% in 2001).
- 19% of new AIDS diagnoses.
- 29% of people with AIDS.
- 35% of deaths from AIDS.

The rates of HIV among people over 50 were 12 times as high among blacks and five times as high among Latinos as they were among whites.

## A few more things

#### HIV/AIDS Cases by Age

Of the estimated number of HIV cases diagnosed in the 40 states with confidential name-based HIV infection reporting, persons' ages at time of diagnosis were distributed as follows.

Age	Estimated Number of HIV Cases in 2009
Under 13	165
Ages 13-14	21
Ages 15-19	2,036
Ages 20-24	6,237
Ages 25-29	5,951
Ages 30-34	5,020
Ages 35-39	5,232
Ages 40-44	5,519
Ages 45-49	4,865
Ages 50-54	3,323
Ages 55-59	2,004
Ages 60-64	900
Ages 65 or older	736

These numbers do not represent reported case counts. Rather, these numbers are point estimates, which result from adjustments of reported case counts. The reported case counts have been adjusted for reporting delays and for redistribution of cases in persons initially reported without an identified risk factor, but not for incomplete reporting.





#### Why we made this DVD

The contents of this DVD are greatly informed by ACRIA's ROAH behavioral research study of people age 50 and older living with HIV/AIDS, conducted from March through December 2005 and released in June 2006. The study was the first systematic investigation that represents the current demographic profile of older people with HIV in New York City (86% of participants were people of color and 30% were women). Our researchers discovered some surprising information about the social networks of this growing segment of the HIV population.

We found that 71% of these older adults live alone. Many are not able to rely upon typical sources of support such as parents, children, brothers or sisters, and other family members for emotional help or assistance with daily living. Why? Most do not have family to rely upon. They told us they mainly rely on friends—friends who are also HIV positive. The support these people provide is massive. In fact, it would take \$254 billion to replace the care-giving provided by family members and friends each year in the U.S.

According to the CDC, some older adults have less knowledge about HIV and are therefore less likely to protect themselves than those who are younger. Many do not perceive themselves as at risk for HIV, do not use condoms, and do not get tested for HIV. In addition, older people of color and those from immigrant communities may face discrimination and stigma that can lead to delayed testing, diagnosis, and a reluctance to seek services.

This DVD is an attempt not only to make the general public aware of the prevention and treatment needs faced by older adults, but also to facilitate open, honest, and empowering dialogue between and among health care providers and consumers who are over 50 years of age.

## How to use this guide

This guide will:

- encourage long-term commitment to behavior change instead of short-term information retention.
- encourage facilitator participation as both guide and co-learner.
- encourage integration of prior knowledge, learning styles, strengths, and needs of participants.
- cultivate critical thought and leadership skills to deal with controversial topics.
- serve as a companion to the "Older and Wiser: Many Faces of HIV" DVD produced by ACRIA, assisting anyone responsible for facilitating, developing, and implementing discussion groups or trainings targeting adults 50 and older.
- present factual information where needed, along with talking points that can be relevant and helpful in promoting a focused and respectful exchange.

#### Suggested discussion format

It is best to show the DVD at least a week prior to the group discussion if possible. Encourage participants to take notes and bring them to the discussion. Allow at least 45 minutes for the discussion. It may be helpful to take notes on the best ideas raised for follow-up meetings or action steps.

We encourage facilitators to be creative in adapting the materials to fit each discussion, audience, and available time. But it may be helpful to simply follow the guide's sequence.

This guide can be used in a variety of formats to ensure a dynamic interaction, rather than a one-way transfer of information to passive learners.

Participants may follow the outlined sequence in the guide.

Participants could be divided into small discussion groups and each assigned one portion of the DVD. After 5 to 10 minutes, each group can report back to the entire group, and the facilitator can encourage questions and comments from other participants.

It's worthwhile to include sound principles of adult learning. For example, adults have accumulated a foundation of life experiences and knowledge that may include work-related activities, family responsibilities, and previous education. They need to connect new learning to this knowledge/experience base. To help them do so, draw out the experience and knowledge they have that is relevant to this topic.

## **Characters' Profiles**

Javier is a 65-year-old Latino with HIV. He has been described by neighbors and friends as "handsome, charming, helpful, and well liked by the ladies." Those who knew him were surprised when he began exhibiting signs of dementia that appeared rather quickly. His daughter disclosed that he had AIDS. This highlighted the fact that older adults are engaging in sex, some of it unprotected. None of the women he was involved with would have thought in their wildest dreams that they would have to confront the reality of HIV because of sexual activity at their age.

Ed Shaw, 67, is a single heterosexual African-American man who was diagnosed with HIV 20 years ago. He believes he may have contracted HIV due to recreational drug use. He also admits that he didn't think he was at risk for HIV since "I wasn't white, I wasn't gay, and I didn't live in Haiti."

Currently he is chair of the New York Association on HIV Over Fifty. As a long-term survivor, he rejects the notion that HIV is a death sentence "There's a need for educating not only seniors," he says, "but also the family in general, because we want a zero infection rate."

Joe is a 58-year-old married white man who is HIV negative. He frequents dating sites on the Internet. "My wife knows next to nothing about this," he says. He also states that he lets people know he is married and has no intention of leaving his wife. He describes his encounters as "sexually charged." For example, he had an affair with a woman in her late sixties whose husband was wheelchair-bound and dying. He says that despite flirting with danger, he's never had an STD – but acknowledges that all it takes is "one slip."

Brenda Lee is a 63-year-old black woman who believes she got HIV from a man she met when she was in her early 30s. She found him very "nice" and attractive and suggested they both relocate to Connecticut, where he was originally from, so they could "start over again." Both were using drugs at the time. She found out his HIV status after he came home from a hospital stay for pneumonia. He told her, "You know I have HIV…you may need to see my doctor."

#### Note: The stories on the DVD are real. Some are enacted by actors.

Juanita is a 48-year-old Latina. She thinks she got HIV from her husband, whom she once caught with a "syringe stuck in his veins." She was married for 17 years and found out her HIV status five years after her husband's death. She blames doctors who dismissed her concerns about possible infection because of the misperception that because she was in a long-term "monogamous" relationship and had full-time employment, she didn't have any risks. She says, "They tell you they're checking you, but they're not."

Donald is a 56-year-old white man who was married for 24 years, a relationship he entered into right out of college. He contracted the virus from an affair with a young man he met at a work-related conference. He says they used condoms, but when one "came off" the young man assured him he was HIV negative. Donald didn't think he had reason to doubt the man, given his healthy appearance. Once Donald received his HIV diagnosis, he disclosed to his wife that he was gay. They stayed together until "the kids were out of the house."

Ramón is a 50-year-old bisexual Latino who has been sexually active since 18. Finding out he had HIV brought up feelings of being punished. He also has had to cope with homophobia in Latino culture. He knows of many youth who ran away from home to escape their parents' rejection. Consequently, some found themselves engaging in high-risk sexual activities that left them infected with any number of STIs. He strongly encourages everyone to use protection and take care of themselves.

Eva is a 57-year-old Latina who is HIV negative. Her deceased husband told her he didn't want her to be alone after he died. This has allowed her to go on living without guilt or remorse. Along the way she's met several men with whom she's enjoyed platonic relationships and, in some cases, sex. However, for Eva these encounters are also about friendship, tenderness, and companionship. She finds it very liberating to have finally reached menopause and not to have to worry about pregnancy.

## Javier

At 65, Javier probably held the common belief that he wasn't at risk for contracting an STD, and certainly not HIV. The women in his life probably also shared this belief.

## Discussion

Did you find it surprising that at 65 Javier was sexually active?

Why do you think so many seniors don't consider HIV a personal threat?

How did you feel about Javier's developing symptoms of dementia?

What issues does Javier's life suggest are important for public health education efforts?



Key Concept: Stages of Change Model

In the video Javier appeared content and engaging, but based on what you know about him, where would you place him on the Stages of Change cycle?

Where on the Stages of Change cycle would you place yourself or other service providers who may still experience feelings of discomfort, embarrassment, or even repulsion when counseling adults over 50 around sex and HIV risk reduction?

## Ed

Ed at one point didn't think he could contract the virus because "I wasn't white, I wasn't gay, and I didn't live in Haiti."

### Discussion

How did this belief ultimately affect Ed?

What life-changing event led him to reconsider his position?

Is it surprising that Ed has lived with the virus for well over 20 years? Why? Why not?

Have you ever felt like you could never get infected with HIV?

Do you still hold that belief?

### Further Discussion

<i>Ed commented:</i> <i>"Living with the virus today, anyone can do."</i>	Do you agree or disagree with that statement?
"Stigma and discrimination can be combated if we talk about it [HIV] more."	Do you agree or disagree with that statement?
"There's a need for educat- ing not just the seniors, but also the family in general, because we want a zero infection rate."	Do you agree or disagree with that statement?



Key Concept: Stages of Change Model

As you listened to Ed's story, can you identify challenges he may have encountered in his journey from the "pre-contemplation" to "maintenance" stage?

In your experience as a service provider, have you ever encountered someone like Ed who is very literate in HIV prevention but who may have "relapsed" back into old risk-taking behaviors? What counseling issues could you focus on to help such a client regain control of his or her life?

## Joe & José

Although married, both Joe and José turn to internet dating sites for sexual and romantic adventures. While they are up-front about their marital status and intent to remain in that relationship, their risk-taking attitudes give them a certain security that they will not get caught. They both also believe that their respective spouses have no idea of these clandestine encounters.

### Discussion

How, if at all, do these men justify their forays into the internet dating sites?

Do you think the fact that Joe describes some of these encounters as "sexually charged" adds to his habitual visits to these internet sites?

Joe is a self-described risk taker. It there a reason he hasn't contracted any STD? Is this confidence or recklessness?

What new insights did you gain from both these men's behavior?

### Further Discussion

#### Joe and José commented:

"My wife knows next to nothing about this (frequenting internet dating sites)."

"In terms of sex, I take whatever safeguards I can...so as you get older you check 'em out and make sure they have no obvious signs of HIV or...so forth."

"I've not had even a single case of an STD....so it seems to...it only takes one slip, I know" Are they protecting their wives or are they perhaps rationalizing their infidelity?

What concerns, if any, does Joe and José's risk assessment raise for you?

Despite their risk assessment, both these men seem bent on engaging in high-risk behaviors with total strangers. What could be fueling this behavior?



#### Key Concept: Stages of Change Model

Both Joe and José, while not openly bragging about it, seem confident in their ability to have sex with women they meet on the internet with little if any risk of exposure or infection. As a service provider, where would you focus your counseling intervention with Joe and José, assuming they voluntarily came to see you? How would you assess their placement on the Stages of Change cycle? How would you translate that assessment so it makes sense to them?

While Joe and José give the impression that their sexual indiscretions are unknown to their respective spouses, what conversation can a service provider have to move them to keeping their spouses safe from HIV or any STI?

## Brenda Lee

Brenda Lee ended her relationship with her boyfriend when he disclosed that not only was he HIV positive but also gay.

### Discussion

What thoughts or emotions came up when you found out Brenda Lee's boyfriend disclosed he was gay?

What thoughts or emotions came up when you found out her boyfriend disclosed his HIV status over the phone?

Did you personally identify with any part of Brenda Lee's story?

What new insights did you gain about the role of trust in any relationship?

### Further Discussion

Brenda Lee commented: "I don't know if I got it because he was a homosexual or because we were using drugs [together]."	Ultimately does it matter how she became infected? What is the take-away lesson in this statement?
<i>"…he told me in the same breath that he was gay.</i> "	What do you think prevented him from disclosing his sexual orientation before now? Is there a good or a more appropriate time to do this?
<i>"I was too devastated immediately I thought I was going to die."</i>	How would you engage Brenda Lee to bring her through that crisis?



Key Concept: Stages of Change Model

Early on in her relationship with her then boyfriend, Brenda suggested they both relocate to Connecticut, where he was originally from, so they could "start over again." This theme—starting over—appears at least twice in her life, maybe allowing her to reframe and redirect her goals. Where on the Stages of Change cycle does this place her?

On the other hand, starting over can be stressful. How do you support someone like Brenda in managing her circumstances so that whatever crisis she faces doesn't force her to start from scratch?

### 22 Character's Challenges

## Juanita

The revelation that something was wrong came the day "I saw him with the syringe stuck in his arms. That's when I knew he was using." She found out that she had HIV five years after her husband died.

### Discussion

How did you feel as you heard Juanita's story, as she sat in the shadows?

Could you personally identify with her story?

What thoughts or emotions came up when you found out that Juanita learned her HIV status five years after her husband's death?

What new insights did you gain from listening to Juanita's story?

### Further Discussion

#### Juanita commented:

"Doctors don't check you for HIV....They tell you they're checking you, but they're not....They won't check you for HIV."

symptom of their own ignorance about who can or cannot become infected with HIV?

Are doctors acting irresponsibly or is this a

*"I saw him with the syringe stuck in his veins. That's when I found out he was using."* 

Since she was past childbearing age, she thought "What am I going to get protected for?!" Is it possible to live with someone for a long time and not know that he or she is an active IV drug abuser? How is that possible?

Do you think that "protection" is not needed when someone is past child-bearing age?



Key Concept: Stages of Change Model

It's not unusual for spouses of IV drug users/substance abusers to be in denial about this behavior. Discovering her husband with a needle in his arm forced Juanita to confront the fact he was an IV drug user. Do you believe she had prior suspicions? If so, what barriers could have prevented her from confirming her suspicions? How can some providers' assumptions about who is and who is not at risk for HIV inadvertently reinforce common myths about how the virus is transmitted?

Juanita complained that some providers would not test her for HIV because they assumed that her status as a married, employed woman protected her from HIV or other STIs. What personal and professional barriers could prevent some providers from improving on their HIV health literacy? What concerns does this raise for effective risk reduction in certain communities?

## Donald

Donald came to terms with his sexual orientation while still married with children. His brief encounter with another man at a jobrelated conference not only gave him the impetus to disclose his sexual orientation to his wife, but also led to his HIV infection.

### Discussion

As you watched Donald tell his story, what emotions came up for you?

Did you personally identify with any part of his story?

Were you surprised by his "coming out" at such a late stage in his marriage?

What new insights did you gain from listening to Donald's story?

### Further Discussion

#### Donald commented:

Talking about his encounter at the conference, Donald said, "I thought we were safe....We used condoms.... One time a condom came off.....He assured me that everything would be fine... that he was negative...I had no reason not to believe him...seemed like a fine, healthy young man...no reason to doubt his word."

Donald seems aware of using protection, but can you identify some myths about HIV infection Donald believed?

Why do you think he chose to have this sexual encounter after 24 years of marriage?



Key Concept: Stages of Change Model

After 24 years of marriage and in his mid-fifties, Donald finally found the courage to claim his sexual identity openly (i.e., "coming out"). Where would you place him in the Stages of Change cycle before this pivotal chapter in his life? What do you imagine propelled him to move from the safety of a heterosexual marriage to a life that had potential for social disapproval?

It is to be expected that at this point in his life Donald would want to experiment and celebrate his true sexual feelings. He was, however, entering a relatively new subculture with some naiveté. As a provider how do you support Donald?

His first sexual encounter and consequent infection with HIV required him to examine beliefs and assumptions about his sexuality and that of others (the broken condom coupled with the young man's assurance that everything was okay gave him comfort—temporarily, at least—that he wasn't at risk for HIV or other STIs. What can you do to prevent Donald from regressing into fear-based abstinence and developing instead a healthy form of practicing safer sex?

### 26 Character's Challenges

## Eva

Eva, thanks to her now deceased husband's encouragement, has built a social network with men for companionship, friendship, and, occasionally, sex.

#### Discussion

As you watched and listened to Eva, did she seem unconcerned or simply uninformed around her risk of exposure to HIV or other STIs?

Did you personally identify with anything in her story?

What new insights did you gain from listening to Eva's story?

### Further Discussion

#### Eva commented:

"Yes, I have male friends and I'm not ashamed to say it....They're good men and it's not all about sex....."

Eva seems fulfilled and satisfied with her life; however what popular and risky myth does this statement imply?



#### Key Concept: Stages of Change Model

Health care providers are often reluctant to recognize the sexual needs and challenges faced by women who are over 50, and single, widowed, or divorced. Despite research and public health information, many still hold the belief that adults over 50 are sexually inactive. Given these factors, what special counseling issues do women like Eva present?

The physical and emotional symptoms of menopause can disrupt sleep, sap one's energy, and, at least indirectly, trigger feelings of sadness and loss. For Eva this is all behind her, and with her now deceased husband's blessing she is free to date and experience her sexuality in new ways. What can you as a health care provider do to help Eva incorporate principles of risk reduction into her social network?

What specific information does she need to help her make the transition from pre-contemplation to, at a minimum, action?

## Ramón

28

Ramón, like so many youth, experimented with high-risk sexual behaviors. He eventually got HIV and for a time experienced deep feelings of guilt and remorse. "Why, why me?!" was his reaction once he found out he had HIV.

### Discussion

As you watched Ramón tell his story, what emotions came up for you?

Did you personally identify with anything in his story?

Do you agree or disagree with his depiction of the Latino community as being very homophobic?

What new insights did you gain from listening to Ramón's story?

### Further Discussion

#### Ramón commented:

Speaking of Latino parents' attitudes toward their gay children "...many of their children run away from home because their parents don't understand them...so they go out and engage in risky sexual activities."

Without resorting to blame, how can a lack of community and parental support encourage risky sexual behaviors? How can we as a society help youth to go from risk to taking better care of themselves?



Key Concept: Stages of Change Model

Ramón ends his story by encouraging viewers to "please take care of yourself....Always use protection." How can this message be effectively implemented to reach youth stuck in the "pre-contemplation" or even "contemplation" stages?

How can this message be effectively implemented to reach adults over 50 who may also be stuck in "pre-contemplation" or "contemplation" stages?

#### **Prevention Challenges**

- People over 50 may have the same risk factors for HIV that younger people have.
- Many older people are sexually active but may not be practicing safer sex. Older women may be especially at risk because age-related vaginal thinning and dryness can cause tears in the vagina.
- Some older people inject drugs or smoke crack cocaine, which can put them at risk for HIV. HIV transmission through injection drug use accounts for more than 16% of AIDS cases among people over 50.
- Some older people may be less knowledgeable about HIV than younger people and therefore less likely to protect themselves. Many do not perceive themselves as at risk for HIV, do not use condoms, and do not get tested for HIV.
- The stigma of HIV may be severe among older people, leading them to hide their diagnosis from family and friends. Failure to disclose one's HIV status limits emotional and practical support.
- Older people of color and immigrants may find it difficult to overcome discrimination and stigma. They can be more vulnerable to rejection from the broader communities they depend upon for support, and thus are at risk for later testing, diagnosis, and reluctance to seek services.
- Health care professionals may underestimate their older patients' risk for HIV and so may miss opportunities to deliver prevention messages, offer HIV testing, or make an early diagnosis that could help their patients get early care.
- Physicians may miss an HIV diagnosis because some symptoms can mimic those of normal aging, such as fatigue, weight loss, and mental confusion. Early diagnosis can improve a person's chances of living a longer and healthier life.

#### Get tested

- If you are sexually active, you should get tested for HIV and all other STDs regularly– at least once a year. You owe it to yourself and your partners.
- It's particularly important to get tested if you have ever engaged in high-risk sexual behavior or drug use (shared needles, etc.). Also be sure to talk to your health care provider about your sexual and drug-using practices when you get tested.
- If you or your partner had a blood transfusion between 1978 and 1985, or an operation or blood transfusion in a developing country at any time, you should get an HIV test.
- If you have a partner, both of you should be tested for HIV and other STDs.

## Tips for talking to Your Doctor about Sex

You can take an active role when it comes to your health. Doctors can be one of your best sources of support and information, so here are some tips for talking to them:

Before your appointment, take some time to think about what you want to discuss. Having a clear agenda will help you and your doctor make the most of your visit. This can include questions about your sexual practices.

Write down your questions before you go. A trip to the doctor may make you feel anxious or nervous, and you might forget your questions. Having them in writing can help you remember.

If you want to talk about sexual concerns, set the agenda for that visit right at the start. You might say, "I have some concerns about my sex life. Could we take some time today to discuss them?" Your initiative can guide your doctor to prioritize your sexual concerns.

Share your life's realities with your doctor. This may mean opening up to your doctor about the people around you who make it tough to stay safe. Naming your obstacles will help your doctor better support you in staying healthy.

Your doctor may overlook your successes. If you've cut back on your drinking, drug use, or the number of your sexual partners, share that. Knowing you are making a change will help your doctor think of ways to support you further.

If you hear your doctor repeat the same advice time after time, consider it proof that she or he cares about you. Such words of concern can make a big difference.

Do your own research on the Internet or in the library to learn more about what sexual practices are considered safe and unsafe, and what you can do to protect yourself and others. After the research, you may have more questions for your doctor.

Keep the door open for further discussions. Ask your doctor if she or he is willing to take more time to discuss safer sex with you at your next appointment or whether there is another member of the health care team who can help you develop a safer sex plan.

If your doctor dances around the topic of sex, you can steer the conversation so that it meets your needs. You can say, "How can I stay healthy and have sex?"

If you have HIV, let your doctor know that you do not want to pass it on to others. You can ask for suggestions on how to disclose your HIV status and how to negotiate safer sex. Ask about the risk of re-infection with a different strain of HIV, and the risk of getting other sexually transmitted infections.

If you find that your doctor is not receptive to talking about sex and drug use, it might be time to think about changing doctors.

#### Resources

AIDS Community Research Initiative of America (ACRIA), Center of HIV and Aging acria.org 212-924-3934

Administration on Aging aoa.gov (search for "HIV")

American Association of Retired Persons aarp.org

American Society on Aging asaging.org (search for "HIV")

The Body: An AIDS and HIV Information Resource thebody.com

Centers for Disease Control and Prevention cdc.gov

Council of Senior Centers and Services of New York City cscs-ny.org 212-398-6565

Gay Men's Health Crisis (GMHC) gmhc.org 212-367-1000

The Graying of AIDS grayingofaids.org

HelpAge International helpage.org

NIH National Institute on Aging nia.nih.gov

New York Association on HIV Over 50 (NYAHOF) nyahof.org 212-367-1009

Services and Advocacy for Gay, Lesbian, Bisexual, Transgender Elders (SAGE)

sageusa.org 212-741-2247

Sexuality Information and Education Council of the U.S.

siecus.org

Terrence Higgins Trust tht.org.uk

DVD missing? Call 212-924-3934 x134 for a free copy.



ACRIA is an independent, not-for-profit community-based AIDS research and education organization committed to improving the length and quality of life for people with HIV through medical research and health literacy.

ACRIA conducts an HIV Health Literacy Program to offer people with HIV and their care providers the tools and information they need to make informed treatment decisions. Health Literacy Program services include: workshops conducted at community-based groups throughout the New York City area in English and Spanish; technical assistance trainings for staff of AIDS service organizations; individual treatment counseling; and publications, including a guarterly treatment periodical and booklets in English and Spanish on treatment-related topics. TrialSearch is our online, searchable database of HIV clinical trials enrolling throughout the United States. ACRIA's National Training and Technical Assistance Program offers training and ongoing support to help non-medical service providers and community members in various parts of the country acquire the skills and information needed to provide HIV treatment education in their communities. The Older Adults Training and Technical Assistance Program offers similar services locally and nationally with a focus on the needs of middle-aged and older adults.

To learn more about ACRIA's research studies or the HIV Health Literacy Program, please call or email us at treatmented@acria.org. Information about our programs and copies of all of our publications are also available on our website.

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