



# PROJECT CAATCH

CONSUMER ACCESS AND ADHERENCE TO CARE FOR HIV

MEDICAL CARE COORDINATOR/PEER INTERVENTION MANUAL





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# Introduction

## About MassCARE and Project CAATCH

### MassCARE

MassCARE (Massachusetts Community AIDS Resource Enhancement) a program of the Massachusetts Department of Public Health (MA DPH), is a network of services and supports for women, infants, children and youth and their families, working with three Federally Qualified Health Centers located in Lowell, Brockton and Worcester. MassCARE has been a Ryan White HIV/AIDS Program (RWHAP) Part D grantee since 1991 and was one of the first Pediatric AIDS Demonstration Projects in the United States. The program provides medical case management with an HIV medical home approach, peer services (both one-to-one and group level) and other family-centered social services and supports. MassCARE also provides statewide and regional consumer programming for women and youth focused on health literacy, chronic disease self-management, and health care transition for youth.

### Project CAATCH

Project CAATCH (Consumer Access and Adherence to Care for HIV) uses evidence informed practices, including motivational interviewing, to address identified gaps in the continuum of care for client retention and viral load suppression measures. Through this initiative, which began through supplemental funding in 2015 and is now considered a best practice by HRSA, we deliver a curriculum of educational sessions to promote client engagement and retention, in order to increase overall rates of viral suppression for all MassCARE enrolled clients over 18 years of age at three MassCARE clinic locations in Massachusetts.





A care coordinator and peer team co-deliver a curriculum that includes six core CAATCH educational sessions on the following topics: 1) the HIV viral life cycle and medications at work, 2) communicating with health care providers, 3) understanding basic lab tests (CD4, viral load and others), 4) managing stigma and disclosure, 5) HIV and substance use disorders, and 6) HIV and wellbeing. In addition to the educational sessions, clients are contacted weekly for six months after completion of the sessions to assure they keep their health appointments, maintain their medication regime, and have supports to address barriers to care and continue improving their health and medical care engagement. Our experience to date has shown that with targeted and focused education as well as consistent contact and communication, clients have improved their engagement in HIV primary care and their health outcomes.

Project CAATCH replicates adapted versions of interventions and lessons learned from two past HRSA Minority AIDS Initiatives (MAI):

### **The PEER Center (2005–2011)**

The PEER Center funded to Boston University developed training and organizational resources and provided support to help agencies and communities launch a peer program, or strengthen one that was already in place, to engage and retain people living with HIV in care treatment. This was a collaboration with the Justice Resource Institute (JRI), and three national peer education, training, and capacity-building sites.

Source: <https://ciswh.org/project/peer-center/>

### **Client Retention and Re-Engagement Project (2011–2014)**

The MAI Retention and Re-Engagement in HIV Care Project funded to Boston University focused on providing better access to resources, housing, and proper care for racial/ethnic minority communities where the HIV/AIDS epidemic continues to grow and the need for mental health and outpatient substance abuse treatment services has increased. The project implemented and evaluated an innovative and replicable HIV service delivery model at three clinic locations (Brooklyn PATH Center in Brooklyn, NY, Care Resource in Miami, FL, and PRCONCRA in San Juan, PR) using peers with HIV to educate, assist and provide emotional support to clients of color who were newly diagnosed with HIV, were existing clients not fully engaged in HIV primary care, or were at-risk for dis-engaging from HIV primary care.

Source: <https://ciswh.org/project/minority-aids-initiative-retention-and-re-engagement-in-hiv-care-project/>



Project CAATCH is guided by the following principals:

- 1** *Health equity* guides the implementation of Project CAATCH. Clinics with lower rates of client retention in HIV care and lower rates of viral load suppression have been selected to implement this intervention. Eligible clients have complete access to Project CAATCH services and to the high quality HIV care and services provided at the clinic. Equitable distribution means investing more resources in areas where the need is greater. Project CAATCH activities provide a complete continuum of care and supportive services to eliminate barriers to care and factors contributing to ill health.
  
- 2** *Client centered and non-judgmental care* is key to client success. The Project CAATCH model is designed to truly meet the client where he/she is at. The Project CAATCH team (care coordinator and peer) conducts an assessment of clients upon entry to determine their needs and barriers to care. It is imperative to conduct this assessment and address these needs and barriers before and during the CAATCH intervention. In addition, clients are encouraged to be active partners in their own health care. Information and education is provided to clients, but they are ultimately responsible for making their own decisions about their care. Project CAATCH staff may not agree with a client's decision, however they do support them in making it.
  
- 3** *Integration of Project CAATCH staff into the clinical team* is necessary to facilitate open and consistent communication. The Project CAATCH team is integrated into the clinical care team. They attend weekly case conferencing team meetings, provide input on client care planning, and have both read and write access in the clinic's electronic health record (EHR) system.
  
- 4** *Teaching is an iterative process.* The Project CAATCH sessions are informational in nature but build the foundation for continued discussions and teaching about HIV and HIV related issues. In addition, the sessions can always be re-visited with clients as needed (when medication regimens change, new labs are conducted, etc.) to reinforce concepts.



## About This Guide

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This manual is designed to support the implementation of Project CAATCH by Ryan White HIV/AIDS Provider Clinics or other clinics working with people living with HIV. This intervention can be used with clients who are not fully engaged in HIV care; are not virally suppressed; or are new to HIV care (newly diagnosed, newly linked to care, or new to the clinic.)

Each section includes handouts to share with clients; videos to watch with clients; and optional handouts/materials to share with clients when appropriate.

## Key Components of CAATCH

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### Staff

Project CAATCH is designed to be implemented by a dyad consisting of a peer living with HIV and a care coordinator. The dyad model supports the following:

- ◆ Distribution of work – each member can play a specific role or swap roles depending on the needs of the clients.
- ◆ Supportive relationships – the client builds a relationship with two separate people to support his/her care at the clinic.
- ◆ Project coverage – working in a dyad allows for one person to be out of the office while the other is still there and available to the client.
- ◆ Team care – working in pairs provides built-in support. The peer and care coordinator share experiences and can support one another.
- ◆ Continual communication – the dyad works closely with both the client and the clinical care team. Clients build a strong relationship with their CAATCH team and share not only HIV related information but details about their lives that are important to them and can impact their ability to fully engage in HIV care. Pairing the clinical information collected by the medical providers with the life experiences and details shared with the CAATCH team builds a richer story for all staff to best meet the unique needs of the client.



## Training

Original Project CAATCH staff attended a two-day training conducted by a content expert with years of experience training peers living with HIV to work in clinical settings. The two-day training was supplemented with an additional one-day training. Supplemental trainings such as motivational interviewing and trauma informed care practices were provided through web-based training communities.

## Location

Project CAATCH is currently being implemented at three health centers receiving RWHAP Part D funding through the Massachusetts Department of Public Health (MA DPH). Each clinic also receives RWHAP Part C funding to support the provision of HIV outpatient ambulatory health services. Project CAATCH staff are integrated into the clinical team and attend client case conferencing, have read and write access to the clinic electronic health record and communicate both formally and informally with all clinic staff daily.

## Educational Sessions

Six educational sessions are the cornerstone of Project CAATCH. Each session is about 45 minutes long and can be delivered in any order as determined by the client needs. Ideally the sessions are conducted weekly or bi-weekly with CAATCH clients. The sessions are spaced out so that by the end of the last session, the client will have attended at least one medical visit that includes a review of his/her most recent lab results. The six sessions are:

- ◆ HIV Life Cycle and Medications at Work
- ◆ Treatment Adherence and Communication with Your Provider
- ◆ Understanding Lab Values
- ◆ Managing HIV Stigma and Disclosure
- ◆ Substance Use Disorders and Harm Reduction
- ◆ HIV and Wellbeing

For each session listed, the manual includes the following: a session materials list; a suggested introduction and assessment script; teaching content and points; handouts; and a list of competencies to be addressed and evaluated. These sessions are meant to be flexible. The content of the curriculum can be adapted to suit the needs of each particular client. The care coordinator and peer work together to decide who will lead a session with a client. Sessions can be done together or separately, depending on the comfort of the staff and client. Clients are offered a \$50 gift card as a stipend upon completion of session two, session four, and session six.



### Follow-up Post Sessions

After the six sessions are completed, the CAATCH team maintains weekly contact with the client for six months. The content of the contact may vary depending on client needs and may be done in person when the client attends an appointment at the clinic or a meeting at a community agency. It can also be done over the phone to check in on or remind the client of an upcoming appointment; or by text or email (depending on the communications protocol of the clinic).

### Program Graduation

Once the client has completed all of the educational sessions, has consistently attended medical and case management appointments, and his/her barriers to care have been adequately addressed, the CAATCH team will meet with the client to discuss their readiness to transition to the clinic standard of care (usually case management services). Once all parties are in agreement, the next meeting of the CAATCH team and the client will include the clinic case manager. The CAATCH team conducts a warm client handoff to the case manager and celebrates their success in completing Project CAATCH with a mini-graduation ceremony and/or a completion certificate. See [Handout 27: Certificate of Completion](#).

### Identifying and Outreaching to Eligible Clients

This intervention can be used with clients who are new to care (newly diagnosed, newly linked to care or new to the clinic), and clients who are not fully engaged in HIV care or are not virally suppressed. Project CAATCH is offered to all newly enrolled MassCARE clients as well as to clients who are not fully engaged in care or have yet to reach viral suppression. For those clients not fully engaged in care or not virally suppressed, there are several methods a clinic can employ to identify clients for this intervention in the clinic and community.

- 1. Use clinic data systems** – Using clinic data systems, identify potential intervention clients by filtering client records to identify clients who are not virally suppressed based on the most recent lab values, have not attended an appointment in the past six months, and/or have canceled two or more appointments in the past year. Place the clients who meet these criteria on a list for review by the clinical care team and case managers to determine the status of the clients. These staff usually have some information on the location or status of the client, such as the client may have transferred to another clinic; moved out of state; or has an agreement with the provider about how often he/she needs to attend appointments. This information should be entered into the clinic electronic health record (EHR) to update the individual's client record.



2. **Utilize clinic huddles and case conferencing** – Many clinics hold weekly or sometimes daily huddles to discuss clients who are coming in to the clinic or who have challenges requiring a coordinated care effort. These meetings are also a venue in which clinicians and staff can identify clients they have not seen in a while and/or are concerned about who may be a good fit for this intervention.
3. **Strengthen referrals** – All clinics take client referrals from local health departments, community agencies, and other clinics. Include this intervention in the list of your clinic’s services available for referrals. Provide the eligibility criteria to your partner agencies as well as a contact person for the intervention, and any other specific referral details or protocols to increase the success of the referral process.

For clients who have fallen out of care or are loosely engaged, outreach is a key component of recruiting them into this intervention. If these clients were already solidly linked and engaged in care, this intervention would not be needed. In some cases it will be necessary to go out into the community to locate clients for this intervention.

1. Start by using the list created above in #1 and #2.
2. Once a list of clients who meet the intervention criteria is created, assign 10 – 12 clients per week to an outreach specialist or the CAATCH team to contact using an outreach protocol that includes **both phone and in-person** outreach (inquire about your agency’s outreach protocols and policies).
3. Once a client is located, tell her/him about the intervention and offer to set up an appointment time with the CAATCH team AND a clinical appointment.
4. Appointments: sometimes getting the client to come to the clinic can be difficult. For those times, the initial and second appointments can be held either in the community or in the client’s home. This flexibility allows clients who are reluctant to go to the clinic to meet where they feel most comfortable while engaging in CAATCH.
5. After thoroughly implementing the outreach protocol, if there are any clients on the list that were never located and no additional information about their status was identified, add the client to a “lost to care” list.

### Preparing for a Client Session

Whether the client is new or existing, it’s important to prepare for the client sessions. Communicating to the client in advance about what will happen in the session helps them: know what to expect; identify barriers to attending the session; and receive assistance to address those barriers. It also allows the CAATCH team to prepare and create a plan to guide the session.

### **For the first visit with a client:**

Once an appointment is made to meet with a new client, contact the client in advance of the appointment to:

- ✓ remind him/her of the upcoming appointment;
- ✓ ask where the client would like to meet (in or outside of the clinic);
- ✓ assess client needs or barriers to attending the session (offer assistance with transportation if this is an identified barrier); and
- ✓ ask if the client would like to have someone attend the session with him/her (This may need to be pre-empted with a discussion about the content of each of the sessions. Some sessions may be more appropriate for a “guest” than others.)

### **For the following visits with a client:**

Once an appointment is made to meet with a client, contact the client in advance of the appointment to:

- ✓ remind him/her of the upcoming appointment;
- ✓ confirm the agreed upon location (in or outside of the clinic);
- ✓ assess client needs or barriers to attending the session (offer assistance with transportation if this is an identified barrier);
- ✓ ask if the client would like to have someone attend the session with him/her (This may need to be pre-empted with a discussion about the content of each of the sessions. Some sessions may be more appropriate for a “guest” than others.);
- ✓ review your notes from previous sessions;
- ✓ check progress notes from other providers (if you have access to these);
- ✓ check for updated lab results;
- ✓ if possible and as needed, meet with team to discuss progress of the client to identify any barriers to care or client needs;
- ✓ check for upcoming client appointments in your clinic (medical, case management, mental health, etc.) to remind the client of;
- ✓ prepare handouts and other items included in the list of materials for the session; and
- ✓ obtain gift card stipend and receipt form for upcoming session.



## Introduction and Assessment

Depending on the client's comfort, this pre-session introduction and assessment can be conducted at an introductory meeting or over the phone. The intent of this assessment is to gain background information that may be helpful in working with this client as well as to outline the relationship between the client and the peer/care coordinator team. Ideally this session is conducted by the peer.

### Introduction and Assessment

#### *Intro conversation starter*

- 🗨 Hi, my name is \_\_\_\_\_ and I am living with HIV. I have learned to manage and control it with support from others.
- 🗨 I've been living with HIV since \_\_\_\_\_ and I've overcome many obstacles because I got the support I needed to take control of HIV.
- 🗨 One of the things that helped me the most was learning about the disease and how to control it. It also helped to hear how others coped with their diagnosis, and the things they did to overcome the stress, fear, and anxiety associated with living with HIV.
- 🗨 I work closely with \_\_\_ who is a care coordinator here. Our role is to give you health information and provide you with support along the way.
- 🗨 Tell me about yourself. When did you receive your diagnosis and how have you been coping with the disease (medically, home life)? Do you have family or any other support?

#### *For clients who are new to the clinic or have been out of care; not newly diagnosed*

- 🗨 How did you find out you have HIV? How long have you been living with HIV?
- 🗨 When were you last seen by a doctor/clinician for your HIV? Where were you receiving care in the last year? What makes it hard for you to come to the clinic?
- 🗨 Are you taking medications? If yes, how is it going?
- 🗨 Who is your medical provider? What do you like about the way your medical provider manages your care? Is there anything that you would like to talk about with your medical provider? Is there anything that you wanted to say to your provider but didn't dare to? Is there anything that you dislike in the way your medical provider manages your medical care?
- 🗨 Where are you living now/what is your living situation?
- 🗨 Do you have anyone in your life that provides social or emotional support? Who else knows you have HIV?
- 🗨 Have you attended any medical appointments? Other appointments? How can I help you get to your appointments?



***For clients that are newly diagnosed with HIV***

- 🔗 How did you find out you have HIV?
- 🔗 Where are you living now/what is your living situation?
- 🔗 Do you have social or emotional supports? Who else knows you have HIV?
- 🔗 Have you made any medical appointments? Other appointments? How can I help you get to your appointments?
- 🔗 How do you feel about your diagnosis? (Peer may want to share their feelings about first learning about their diagnosis, how long he/she has been living with HIV, and what the experience was like for them)
- 🔗 What do you know about HIV? Where did you get this information? (HIV stands for human immunodeficiency virus. It weakens a person's immune system by destroying important cells that fight disease and infection. No effective cure exists for HIV. But with proper medical care, HIV can be controlled).\*\* If the client needs HIV basics you can view this information together online: <https://www.cdc.gov/hiv/basics/index.html>
- 🔗 Participating in this project will allow us to work together on your learning about HIV transmission/viral life cycle, medications, and resistance etc. over the next several weeks.
- 🔗 These are some of the things we'll be going over in our sessions—how does this sound? Is there anything else you'd like to discuss?
- 🔗 What questions do you have about HIV?
- 🔗 Thanks for taking the time to meet/talk with me today. Let's plan to talk again on\_\_\_\_\_.



# Session 1: HIV Viral Life Cycle and Medications at Work

## Materials

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### Handouts

- ◆ [Handout 1: Stages of HIV Infection](#)
- ◆ [Handout 2: HIV Transmission Risk](#)
- ◆ [Handout 3: HIV Viral Life Cycle \(VLC\)—the Big Picture Handout](#)

### Videos

- ◆ HIV: What's Going on Inside Your Body  
<https://www.youtube.com/watch?v=tVE5APDqrpc> – English  
<https://www.youtube.com/watch?v=hB-B0zpEZ-c> – Spanish
- ◆ HIV: The Goal of Undetectable  
<https://www.youtube.com/watch?v=mZ1blphjxbw> – English  
<https://www.youtube.com/watch?v=dN8RGgjon08> – Spanish

How medications work:

- ◆ HIV: Avoiding Resistance  
<https://www.youtube.com/watch?v=H1zLcJZxeE> – English  
<https://www.youtube.com/watch?v=ZvUdL8ACAZ4> – Spanish
- ◆ HIV Treatment Works: Ryan's story  
[https://www.youtube.com/watch?v=BD\\_4Js08qxs](https://www.youtube.com/watch?v=BD_4Js08qxs)
- ◆ Understanding HIV Treatments  
<https://www.youtube.com/watch?v=8003tTj2XfE>
- ◆ Tips for Treatment  
<https://www.youtube.com/watch?v=pJ6NgWv98DE&feature=youtu.be>
- ◆ Personal Stories from People Living with HIV  
<https://www.youtube.com/watch?v=2y84PSXayyY>



## Optional Handouts

Some clients may need more specific information related to HIV transmission, sexuality, and healthy sexual behavior. Pregnant or nursing clients may need information about HIV prevention during pregnancy or breastfeeding. Parents may need information about how to talk to their children about sexuality and sexual health. Teenagers may need more basic information about sexual health in addition to information about HIV. The optional handouts can be shared with clients as needed.

- ◆ [Optional Handout 20: Preventing HIV During Pregnancy/Breastfeeding: Using PrEP &/or PEP – flyer](#)
- ◆ [Optional Handout 21: TeenSpeak About Sexual Health Handbook](#) *(Note: This handbook includes great information on sexual health for teens with NYC based referrals. Please seek similar MA based referrals you can refer teens to when you share this handbook.)*
- ◆ [Optional Handout 22: Hey, What do I say? A Parent to Parent Guide on How to Talk to Children About Sexuality](#)

## Competencies to be demonstrated

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### ***After this session, the client will be able to***

- ◆ Describe HIV, the routes of HIV transmission and the stages of infection
- ◆ Explain the HIV Viral Life Cycle—(AFRITAB) Steps that occur for HIV to replicate inside the body
- ◆ Explain how medications work in the body to
  - Stop HIV from entering cells
  - Prevent HIV from reproducing in cells
- ◆ Discuss how HIV medications help the body's immune system get stronger (increase CD4)
- ◆ Explain how medications can reduce the amount of HIV virus in the body (reduce viral load)

## Session 1 – HIV Transmission and The Viral Life Cycle

### **Conversation starter:**

- 🗨️ Today we'll discuss HIV, how HIV is transmitted and the different steps it goes through once it enters your body. We will also talk about the body fluids that transmit HIV and the ones that don't, the pathways that allow HIV to enter the body, and symptoms of HIV and AIDS.
- 🗨️ We'll also discuss the immune system, the stages of HIV infection, and how HIV invades CD4 cells to multiply and then destroy those cells. This is called the Viral Life Cycle.
- 🗨️ Knowing how the virus works gives you the power to control it.
- 🗨️ Next we'll learn where/how medications work to reduce replication of HIV which allows the viral load to be low and your immune system to be strong.

## Instructions

### Review the following handouts with the client:

- ✓ **Stages of Infection** – this handout outlines the stages of HIV infection. Review and discuss these stages with the client.
- ✓ **HIV Transmission Risk** – this handout is designed to support a conversation about HIV transmission risk in relation to the listed activities. Ask the client to identify which of the activities is high risk, low risk or no risk—and why. These could also be turned into flashcards. These activities can all be distilled down to blood, sexual fluids, saliva, sweat, tears (bodily fluids) and breast milk.
- ✓ **HIV Viral Life Cycle: The big picture** – walk the client through the HIV VLC. This will be important information to refer back to as you move into a discussion about medications in the next section of this session on HIV medications at work.

### Watch and discuss the videos:

- ✓ HIV: What's Going on Inside Your Body  
<https://www.youtube.com/watch?v=HL02LjVDEIw>

## Session 1 – HIV Medications at Work

### **Conversation starter:**

- 🗨️ HIV medications are beneficial for you; people living with HIV take medications to stay well. Because of HIV medicines, people with HIV are living longer, fuller lives. Many of us wouldn't be alive today if it weren't for them. Many people with HIV are living longer—10, 20, 30 years and beyond—because of HIV medications. You can do it too!
- 🗨️ Taking medications is one of the most important things you can do to take control of HIV.
- 🗨️ Each individual responds differently to medications: some people have side effects, while others have mild or no side effects; some people have side effects in the first 30 days and then they disappear. Because of this, once medication is prescribed it is important to stick to the schedule your doctor/clinician discussed with you and also not to judge how your body will respond to medications by other people's experiences but from your own experience. Be sure to report or write down any side effects; discuss them at your next doctor's appointment or call your doctor/clinician if the side effect is severe.
- 🗨️ Remember the benefits of taking medications outweigh any difficulty taking them. Remember, too, that if they don't work for you, your doctor/clinician can put you on different medications until you find the ones that are just right for you.
- 🗨️ We're fortunate today there are many medications to choose from, and newer medications have fewer side effects than the older ones.
- 🗨️ Taking medications can be complicated at first, but once you develop a daily routine, it gets easier.
- 🗨️ We can talk about ideas about how to remember to take medications on time and how to take them correctly. I will be here for you whenever you need support in taking your medications.
- 🗨️ It's a big commitment, but one that eventually becomes second nature for most, and one that could bring you good, stable health and longevity; people with HIV can be on medication for upwards of fifty years depending on their age of diagnosis.
- 🗨️ Together we—you, me, the doctor/clinician, care coordinator and everyone else involved in your care—can minimize any negative experiences you may (or may not) develop.
- 🗨️ Now, let's take a look at the goals of HIV medications and how they work to stop HIV from multiplying in order to give your immune system a fighting chance.
- 🗨️ Let's look at the different combination of medications that are available and where they work in the viral life cycle to reduce the virus. (Handouts)
- 🗨️ Thanks for taking the time to meet/talk with me today. Let's plan to talk again on\_\_\_\_\_.

## Instructions

### Watch and discuss the videos:

- ✓ HIV: The Goal of Undetectable  
<https://www.youtube.com/watch?v=mZ1blphjxbw> – English  
<https://www.youtube.com/watch?v=dN8RGgjon08> – Spanish
- ✓ HIV: Avoiding Resistance  
<https://www.youtube.com/watch?v=H1zLcJZxeE> – English  
<https://www.youtube.com/watch?v=ZvUdL8ACAZ4> – Spanish
- ✓ HIV Treatment Works: Ryan's story  
[https://www.youtube.com/watch?v=BD\\_4Js08qxs](https://www.youtube.com/watch?v=BD_4Js08qxs)
- ✓ Understanding HIV treatments:  
<https://www.youtube.com/watch?v=8003tTj2XfE>
- ✓ Tips for Treatment  
<https://www.youtube.com/watch?v=pJ6NgWv98DE&feature=youtu.be> – English  
<https://youtu.be/9zgho9dSeAg> – Spanish

### Competency Check:

At the end of the session, check in with the client about the information discussed today. Is the client able to describe the following?

- ✓ HIV and the stages of infection
- ✓ Routes of HIV transmission
- ✓ HIV viral life cycle
- ✓ How medications work in body
  - Stop HIV from entering cells
  - Prevent HIV from reproducing in cells
- ✓ HIV medications help the body's immune system get stronger (increase CD4)
- ✓ Medications can reduce the amount of HIV in the body (reduce viral load)

End the session by thanking the client for his/her time and schedule the next session.



## Session 2: Treatment Adherence and Communication with Your Provider

### Materials

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#### Handouts

- ◆ [Handout 4: How to Prepare for a Visit with your Doctor](#)
- ◆ [Handout 5: Symptoms Log](#)
- ◆ [Handout 6: Assessing Adherence](#)
- ◆ [Handout 7: Tips for Remembering to Take Medications](#)
- ◆ [Handout 8: Managing Side Effects Through Diet](#)
- ◆ [Handout 9: Managing Drug Side Effects](#)
- ◆ HIV Drug Chart (online only): [https://www.poz.com/drug\\_charts/hiv-drug-chart](https://www.poz.com/drug_charts/hiv-drug-chart)

#### Videos

- ◆ Speak Up: Tips for Talking to your Doctor  
<https://www.youtube.com/watch?v=rEt8xfQ9z1U>
- ◆ Empowered: Jen  
[https://www.youtube.com/watch?v=uYuV10\\_vR10](https://www.youtube.com/watch?v=uYuV10_vR10)
- ◆ Being Open with Your Healthcare Provider  
<https://youtu.be/8vJ68G2fIW4>
- ◆ Clear Communication with Your Provider  
<https://youtu.be/YBNOtvADAPY> – English  
<https://youtu.be/EK-xPFkgHG8> – Spanish
- ◆ HIV: Treat to Prevent  
<https://www.youtube.com/watch?v=65KKqTMhf2s>



## Competencies to be demonstrated

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### ***After this session, the client will be able to***

- ◆ Explain how missing a few doses of HIV medications can increase the amount of HIV virus in the body
- ◆ Define “medication adherence” as sticking firmly to an HIV regimen- taking HIV medications every day and exactly as prescribed
- ◆ Describe ways to talk with a provider about side effects
- ◆ List ways to cope with side effects

## Session 2: Treatment Adherence: Communicating with your Health Care Provider

### **Conversation starter:**

- 🗨️ Today we will talk about HIV medication and the importance of adherence. We'll also discuss how communicating effectively with your care team impacts your health, as well as the importance of advocating for yourself.
- 🗨️ Adherence means “sticking to your medication schedule” by taking your medications correctly and on time every day. It also means managing side effects so that you're not discouraged from continuing to take your medications.
- 🗨️ Most people who stop taking HIV medications do so because of side effects. Perhaps they didn't have information about how to manage side effects, or no one helped them learn how to manage them. But you have a team of people including me to support you in sticking to your medications and to identify possible barriers to adherence. In addition, there are many methods and tools (e.g., apps, pillboxes, calendars, alarm watches, etc.) available to help you stay on schedule with your medication.
- 🗨️ We'll also talk about medication resistance; there are different types, and some are the direct result of not adhering to your medication.
- 🗨️ Resistance means the medications no longer work in blocking HIV from multiplying. HIV usually becomes resistant when it is not being controlled consistently by medications.
- 🗨️ When you take medications correctly your viral load goes down because the treatment stops the virus from growing in your body.
- 🗨️ If you miss one or two doses of your medication the virus can start to become “resistant” to treatment and start growing in your body.
- 🗨️ Eventually if you keep missing doses or stop taking medications as directed by your doctor/clinician, the treatment will not work to stop the virus. The virus will become resistant until your doctor/clinician can find a new treatment that you stick to.
- 🗨️ It is important to have drug resistance testing—before medication therapy begins and following treatment failure.
- 🗨️ Having a partnership with your provider is important because you have a right to equal ownership of your health decisions. Usually as a client we follow whatever the doctor/clinician tells us to do. But research shows that clients who ask questions increase their knowledge of their health and disease and have better health outcomes when they're fully involved in making their own health decisions. It is also important to be honest with your providers so they can best help and treat you.

- 🔗 To get the most out of your provider visit, be prepared and bring a list of questions for your clinician. I can help you prepare the list before your appointment. Writing down any symptoms you experience between medical appointments is helpful—it’s called a “symptom log.”
- 🔗 It is important to let your provider, care coordinator and/or your peer know if you have missed appointments. It is ok to honestly tell your doctor/clinician when you are uncomfortable with changes they are recommending. Being truthful with your providers is the best way to communicate and advocate for yourself.
- 🔗 What else should you communicate to other members of your care team?
  - Difficulties you experience with taking your medication as directed
  - Barriers to taking medication or following *any* doctor/clinician recommendations
  - Fears or concerns about taking medication
  - Physical barriers to care such as lack of transportation, being homeless, no food, etc.
  - Any emotional issues or support needs
  - Medical symptoms or the need for a medical appointment to be scheduled/rescheduled
  - Issues regarding HIV disclosure or the need for healthy sex materials (i.e. condoms, lube, etc.)
  - Use of substances like alcohol, recreational drugs, opioids, etc.
- 🔗 Sometimes it takes a while to create a trusting relationship. Your peer or care coordinator can attend your appointments with you, or you can ask a supportive person in your life to go with you. \*Offer to share with the client your clinic’s “client bill of rights”\*

## Instructions

### Review the following handouts with the client:

- ✓ **Preparing for a Visit with your Doctor Checklist** – this handout is designed to support a conversation about writing down questions to take to a clinic visit.
- ✓ **Symptoms Log** – use this handout to help a client record symptoms before a provider visit.
- ✓ Review your clinic’s **“Client Bill of Rights”**

### Watch and discuss the videos:

- ✓ Speak Up: Tips for Talking to your Doctor  
<https://www.youtube.com/watch?v=rEt8xfQ9z1U>
- ✓ Five Reasons to Adhere to HIV Treatment  
<https://www.youtube.com/watch?v=tIPjEsJVxXk>
- ✓ Empowered: Jen  
[https://www.youtube.com/watch?v=uYuV10\\_vR10](https://www.youtube.com/watch?v=uYuV10_vR10)
- ✓ Clear Communication with Your Provider  
<https://youtu.be/YBN0tvADAPY> – English  
<https://youtu.be/EK-xPFkqHG8> – Spanish

## Session 2 – Understanding and Managing Side Effects

### ***Conversation starter: Managing side effects:***

- 🗨 Many side effects to HIV medication happen in your digestive system, like nausea, diarrhea, bloating, gas, etc. People manage these with other medications or by eating certain foods which you can discuss with your doctor/clinician. Try a BRAT diet (bananas, rice, applesauce and toast) detailed in the handout.
- 🗨 It's always important to contact your provider immediately to let them know if you're experiencing side effects.
- 🗨 Even if you have side effects, don't stop taking your medications. Get guidance from your providers.
- 🗨 Thanks for taking the time to meet/talk with me today. Let's plan to talk again on\_\_\_\_\_.

## Instructions

### Review the following handouts with the client:

- ✓ **Assessing Adherence** – this handout is designed to initiate and support a conversation with the client about adherence. This website is a current (2019) listing of all the HIV medications and their dosing:  
[https://www.poz.com/drug\\_charts/hiv-drug-chart](https://www.poz.com/drug_charts/hiv-drug-chart)
- ✓ **Tips for Remembering to Take your Medications** – use this handout to discuss some ideas for remembering to take medications.
- ✓ **Managing Drug Side Effects** – this handout has helpful tips on how to effectively manage side effects of HIV medications

### Watch and discuss the videos:

- ✓ Five Reasons to Adhere to HIV Treatment  
<https://www.youtube.com/watch?v=tIPjEsJVxXk>

### Competency Check:

At the end of the session, check in with the client about the information discussed today. Is the client able to describe the following?

- ✓ Missing a few doses of HIV pills can increase the amount of HIV virus in the body.
- ✓ Medication adherence means sticking firmly to an [HIV regimen](#) – taking HIV medications every day and exactly as prescribed
- ✓ How to talk with your provider about side effects
- ✓ Ways to cope with side effects

End the session by thanking the client for his/her time and scheduling the next session.



## Session 3: Understanding Lab Values

### Materials

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#### Online Resources

- ◆ Laboratory Tests and HIV: Entire Lesson (<https://www.hiv.va.gov/client/diagnosis/labtests-single-page.asp>)
- ◆ Lab Monitoring Test Handout [www.thebody.com/content/art2599.html](http://www.thebody.com/content/art2599.html)
- ◆ Lab Tests and Results <https://www.hiv.gov/hiv-basics/staying-in-hiv-care/provider-visits-and-lab-test/lab-tests-and-results>
- ◆ Normal Laboratory Value Handout [www.aidsinfonet.org](http://www.aidsinfonet.org) Fact Sheet 120A

#### Handouts

- ◆ [Handout 10: Lab Tests Tracking Form](#)
- ◆ [Handout 11: What Do My Lab Results Mean?](#)
- ◆ Client labs – print out the client’s most recent labs or the past year of labs to show any changes

#### Videos

- ◆ HIV Lab Tests  
<https://youtu.be/zKSw8B6yy30> – English  
<https://youtu.be/OCr8riEbJxc> – Spanish
- ◆ HIV: Fighting Inflammation  
<https://www.youtube.com/watch?v=FGDHVGRQFCo>
- ◆ HIV: The Goal of Undetectable  
<https://www.youtube.com/watch?v=mZ1blphjxbw>
- ◆ Living with HIV: Dante: I’m HIV Undetectable  
<https://www.youtube.com/watch?v=SIODn9q50cE>



## Competencies to be demonstrated

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***After this session, the client will be able to***

- ◆ Describe why a higher CD4 count means a stronger immune system
- ◆ Describe why the goal is to have a viral load that is undetectable
- ◆ Explain why it is important to have regular lab tests

## Instructions

### Review the following website with the client:

- ✓ <https://www.hiv.va.gov/client/diagnosis/labtests-single-page.asp>
- ✓ **Lab monitoring spreadsheet** – using the client’s past and/or current labs complete this spreadsheet with the client. Make sure to insert the normal ranges for each lab and discuss where the client’s value falls in or out of that range.
- ✓ **What do my lab results mean?** This graphic shows the CD4 and VLC count in relation to one another. Use this handout to discuss this relationship and why other lab tests are important.
- ✓ \*For clients co-infected with HIV and HEP C you may consider bringing in a nurse to describe the impact of ART on the liver and kidneys\*
- ✓ Review the HIV Health Impacts

### Watch the following video:

- ✓ HIV Lab Tests  
<https://youtu.be/zKS8B6yy30> – English  
<https://youtu.be/0Cr8riEbJxc> – Spanish



## Session 3 – Understanding Lab Values

### **Conversation starter:**

- 🗨️ Your doctor/clinician will order blood tests on a regular basis to figure out how to treat your HIV with the correct medications and to regularly check if the treatment is working. Doctors/clinicians also want to identify side effects related to your taking HIV medication, or find out if there are other infections or problems present as a result of HIV. That's why it's so important to come in to get your blood drawn on a regular basis. Your doctor/clinician will schedule labs based on your progress; some labs are done every 3-4 months while others are scheduled twice a year. When clients do not stay in care it is very hard to control HIV and understand how medications impact the virus.
- 🗨️ We're not going to cover every single blood test in this session, just the most common ones including: CD4 count, CD4 percent, viral load count, complete blood-cell count, liver function, kidney function, lipid profile, blood pressure, glucose levels, and cholesterol. These tests tell a story about your health and what needs to be done to keep you healthy.
- 🗨️ We'll also discuss the health effects of HIV disease.
- 🗨️ Another reason to get your labs done regularly and understand what the numbers mean is that you and your doctor/clinician can do things to change the lab values whenever they're not normal. For example, if your cholesterol is too high, you and your doctor/clinician can make changes to your diet and medication to lower it. If your CD4 is too low, you and your doctor/clinician can make changes to your medications to increase it.
- 🗨️ It's kind of like checking the oil in your car engine or taking your car in for a tune-up. If you don't do these things, what will eventually happen to your car? [Responses: Your car will need costly repairs or you may need a new car.]
- 🗨️ Routine screenings for preventive care are very important such as: eye exams, oral health care, mammograms, PAPS, prostate, STD screenings. Preventive care vaccines like flu, pneumonia and hepatitis are also essential to maintaining good health. These services may be covered through Medicaid or Ryan White. If you are getting these services elsewhere it would be good to let your clinician here know about them and the results. The easiest way to do that is to fill out a release of information so this information can be shared between your healthcare providers. I can help you with this.
- 🗨️ Have you had labs done, and what were the results?
- 🗨️ Let's review them to make sure you understand the different lab values monitored. We can also track your results on a spreadsheet. That way you can keep track yourself and increase your understanding of labs and your health. Always ask for a copy of your labs and keep them in one place so that if you move or change physicians, your new physician has a history of your care and treatment.
- 🗨️ Thanks for taking the time to meet/talk with me today. Let's plan to talk again on \_\_\_\_\_.

### Competency Check:

At the end of the session, check in with the client about the information discussed today. Is the client able to describe the following?

- ✓ Why a higher CD4 count means a stronger immune system
- ✓ The goal is to have a viral load that is undetectable
- ✓ The importance of having lab work done regularly

End the session by thanking the client for his/her time and scheduling the next session.

## Session 3 – HIV Health Impacts

### Conversation starter:

- 🗨️ It's common for people with HIV to have other health issues. Some of these issues may be directly related to HIV or its treatment. Others may be completely unrelated. These health conditions can mean more doctors' visits, lab tests, and medications to keep up with. It's important to be aware of these and to do all you can to maintain your health.
- 🗨️ Coinfection is when a person has two or more infections at the same time. There are some common co-infections that affect people living with HIV. For example:
  - **Hepatitis B (HBV) and Hepatitis C (HCV)** are contagious liver diseases. Like HIV, they can be transmitted sexually or by injection drug use. About one-third of people living with HIV in the United States are co-infected with either HBV or HCV. If left untreated, HBV and HCV can lead to liver disease, liver cancer, and liver failure.
  - **Tuberculosis (TB)** is a disease caused by germs spread through the air from a person with untreated TB disease. TB usually affects the lungs, but it can affect other parts of the body. It can cause serious health problems if left untreated.
  - **Opportunistic infections (OIs)** are infections that occur more frequently or are more severe in people with weakened immune systems, such as people with HIV. People are at greatest risk for OIs when their CD4 count falls below 200. A weakened immune system makes it harder for the body to fight off HIV-related OIs like pneumonia, salmonella infection, candidiasis (thrush), toxoplasmosis, and tuberculosis (TB).
- 🗨️ Because of the inflammation caused by HIV, people living with HIV are also at greater risk for health conditions like cardiovascular disease, kidney disease, diabetes, bone disease, liver disease, cognitive disorders, and some types of cancer.
- 🗨️ HIV can also cause some health problems that are unique to women, like gynecological health issues; increased risk of cervical cancer; increased risk of heart disease; HIV medicine side effects and drug interactions; and aging-related issues.
- 🗨️ The best way to take care of yourself and prevent other health problems is to take your HIV medication daily as prescribed, and stay in regular medical care. Talk to your provider about any symptoms you are having. Eat healthy, exercise, don't smoke, and avoid alcohol and drug use to help you stay healthy as possible.
- 🗨️ Thanks for taking the time to meet/talk with me today. Let's plan to talk again on \_\_\_\_\_.

Source: <https://www.hiv.gov/hiv-basics/staying-in-hiv-care/other-related-health-issues/other-health-issues-of-special-concern-for-people-living-with-hiv>



## Session 4: Managing Stigma & Disclosure

### Materials

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#### Handouts

- ◆ [Handout 14: Internalized HIV-Related Stigma Infographic](#)

#### Videos

- ◆ HIV Disclosure: The Right Time is in Your Time  
<https://www.youtube.com/watch?v=cjggnBYk2YY>
- ◆ HIV and Disclosure  
[https://www.youtube.com/watch?v=sbZA\\_IAl6zM](https://www.youtube.com/watch?v=sbZA_IAl6zM)
- ◆ Tips for Disclosing Your Diagnosis  
[https://www.youtube.com/watch?v=3YwSzzJ7\\_YA&feature=youtu.be](https://www.youtube.com/watch?v=3YwSzzJ7_YA&feature=youtu.be) – English  
[https://youtu.be/zyM\\_JUd\\_lhQ](https://youtu.be/zyM_JUd_lhQ) – Spanish
- ◆ The Stigma Around HIV  
<https://www.youtube.com/watch?v=i8ZOxdSNYb4>

### Optional Materials

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#### *For Youth:*

#### Handout

- ◆ [Optional Handout 21: TeenSpeak Sexual Health](#)

#### Video

- ◆ Amaze.org's educational videos on youth sex education  
<https://amaze.org/>
- ◆ Transgender Youth 101:  
<https://youtu.be/fuZ7AlsTczl>



## ***For Transgender Clients:***

### **Handout**

- ◆ [Optional Handout 24: Ten Tips for Working with Transgender Clients](#)
- ◆ [Optional Handout 25: Transgender Non-Conforming Card](#) – a resource for transgender individuals to fill out and use during healthcare visits
- ◆ [Optional Handout 23: Coming Out Transgender](#)

### **Videos**

- ◆ Empowered Trans: Phoebe  
<https://youtu.be/6hTDmfOCDhM>
- ◆ Empowered Trans: Victory  
[https://youtu.be/4x8ul\\_fQjOU](https://youtu.be/4x8ul_fQjOU)
- ◆ CDC’s HIV Treatment Works: Whitney’s Story  
<https://youtu.be/8qWKY5-UpBs>
- ◆ CDC’s HIV Treatment Works: Jada’s Story  
<https://youtu.be/kpRXMEGdvec>

## **Working with Transgender Clients**

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The stigma transgender people face can be raw, painful, and literally life threatening. When people face threats on multiple fronts as a constant part of their daily lives, it can wear them down.

Trans individuals are often mis-gendered by others. They may have their identity challenged. They may be called by the wrong pronouns and/or the wrong name. They may also be given a backhanded compliment like “I never would have known you used to be a man.”

Trans stigma can be a barrier to care. When a transgender client experiences stigma in a healthcare environment, it can be hard to get the care and treatment they need, because the providers may not be addressing their specific transgender health needs. Providers may base their treatment on assumptions about a person’s gender, body, or what/who they think a person should be, not on who they are currently.



As a healthcare provider, how you talk to and treat transgender clients impacts their healthcare. To prepare for working with transgender clients, providers should read [Optional Handout 23: Ten Tips for Working with Transgender Clients](#).

Source:

<https://prevention.ucsf.edu/sites/prevention.ucsf.edu/files/trans101/index.html#/id/co-25>

## Competencies to be demonstrated

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***After this session, the client will be able to***

- ◆ Identify at least one person who knows about the client's status that the client can turn to for support (family member, friend, HIV team member)
- ◆ Explain stigma and its effects on a person living with HIV

## Instructions

### Review the following handout when working with transgender clients:

- ✓ **10 Tips for Working with Transgender Patients** – This pamphlet provides tips and information to help Providers improve quality of care and health outcomes for transgender clients.

### Review and discuss the following handouts with clients:

- ✓ **Internalized HIV-related Stigma** – This infographic provides information on how people with HIV may experience internalized stigma about having HIV.
- ✓ **Some Considerations Before You Disclose** – A list of things to consider before disclosing HIV status to others.
- ✓ **How Stigma Leads to Sickness** – Provides information on how HIV stigma impacts a client's health and care.

### Watch and discuss the videos:

- ✓ HIV Disclosure: The Right Time is in Your Time  
<https://www.youtube.com/watch?v=cjggnBYk2YY>
- ✓ Tips for Disclosing Your Diagnosis  
[https://www.youtube.com/watch?v=3YwSzzJ7\\_YA&feature=youtu.be](https://www.youtube.com/watch?v=3YwSzzJ7_YA&feature=youtu.be) – English  
[https://youtu.be/zyM\\_JUd\\_lhQ](https://youtu.be/zyM_JUd_lhQ) – Spanish

## Session 4 – HIV Disclosure and Stigma

### Conversation starter: Disclosure and Stigma

- 🗨️ To tell or not to tell. Whom should I tell: everyone or a few people? Whether you've been living with HIV for a while or you're newly diagnosed, disclosing your status is different for each person and can be complicated. There is no exact way of knowing when the right time is or the right way to share this information.
- 🗨️ Is there anyone you feel that you *must* tell, like a spouse, a partner, or perhaps someone with whom you've been sexually involved? It takes time to adjust to a diagnosis of HIV, but keep in mind that there are HIV laws and statues in each state that are different. In some states, it is unlawful for a person living with HIV to engage in sexual activity with another person, donate organs or blood, or share needles. Condoms are not always a defense, despite the fact that condoms have been proven to reduce the risk of HIV infection, so know the laws in your state. With that in mind, it's a good idea not to rush into disclosing your status without first giving it some thought. There are some general tips:

Consider the five “W's”-who, what, when, where and why.

- Who do you need to tell?
- What do you want to tell them about your HIV infection, and what are you expecting from the person you are disclosing your status to?
- When should you tell them?
- Where is the best place to have this conversation?
- Why are you telling them?
- 🗨️ Test the waters with someone you may want to disclose to by having a casual discussion using a celebrity example (Charlie Sheen, Magic Johnson, etc.)
- 🗨️ Who needs to know? Medical staff? Employers? Intimate partner? (it is important to know the HIV reporting laws in your state) *Keep it simple. You don't have to tell your life story.*
- 🗨️ Your clinical team knows your HIV status, but is it important to know
  - All employees of this and other clinics are required by law to keep all client information confidential. This ranges from whether or not you are a client at the clinic to all of your specific medical details. This information CANNOT be shared without your consent and approval.
  - Employees not involved directly in your medical care are not allowed to view your records.
  - I'd like to share the clinic's client bill of rights and the clinic's confidentiality policies.

### ***HIV Stigma – What is it?***

- 🔗 HIV stigma is negative attitudes and beliefs about people with HIV. It is the prejudice that comes with labeling an individual as part of a group believed to be socially unacceptable. Stigma is rooted in fear and lack of knowledge.
- 🔗 Stigma can cause people living with HIV to be afraid of accessing medical care and other services.
- 🔗 For a person who is living with HIV, stigma can be internal. They may experience feelings of shame, guilt, fear, and negative self-worth related to living with HIV.
- 🔗 Project CAATCH and this clinic work hard to make sure our clients have no reason to be afraid here and can access services free of stigma. If you ever have concerns or worries about accessing care here, please let us know.
- 🔗 Thanks for taking the time to meet/talk with me today. Let's plan to talk again on \_\_\_\_\_.

### Competency Check:

At the end of the session, check in with the client about the information discussed today. Is the client able to describe the following?

- ✓ Identify at least one person who knows about the client's status that he/she can turn to for support (family member, friend, HIV team member, peer)
- ✓ Explain stigma and its effects on a person living with HIV

End the session by thanking the client for his/her time and scheduling the next session.



## Session 5: Substance Use Disorders and Harm Reduction

### Materials

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#### Handouts

- ◆ [Handout 15: HIV and Substance use: Drug interactions](#)
- ◆ [Handout 16: Harm Reduction: Steps for Safer Injection](#)

#### Videos

- ◆ The Harm Reduction Approach to Substance Use  
<https://www.youtube.com/watch?v=25UK-luJo-0&feature=youtu.be> – English  
<https://youtu.be/eAWCkwLfxCM> – Spanish

### Competencies to be demonstrated

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#### *After this session, the client will be able to describe*

- ◆ How recreational drugs (e.g., alcohol, heroin, etc.) can affect the effectiveness of HIV medications
- ◆ Harm reduction strategies

### Instructions

Research clinic and city resources for needle exchange; Narcan distribution sites; and inpatient and outpatient substance use treatment programs to share with your client.

### Review and discuss the two handouts:

- ✓ **HIV and Substance use: Drug interactions** – Provides a list of commonly used recreational drugs and alcohol and their interactions with HIV medications.
- ✓ **Harm Reduction: Steps for Safer Injection** – Provides information for heroin users on how to reduce harm in heroin use practices.

### Watch the video:

- ✓ The Harm Reduction Approach to Substance Use  
<https://www.youtube.com/watch?v=25UK-luJo-0&feature=youtu.be> – English  
<https://youtu.be/eAWCkwLFXCM> – Spanish

## Session 5- Harm and Risk Reduction

### **Conversation starters/prevention messages: drug use (for clients who use alcohol and/or drugs)**

- 🔗 Alcohol and other drugs can suppress your immune system. Using drugs and alcohol can also cause you to take risks you wouldn't normally take. Using drugs and alcohol with your HIV treatment can seriously affect your health. Does your substance use interfere with taking your medication? Does your drug use interfere with your life functions?
- 🔗 It is important to talk with your provider about your drug and alcohol use.
- 🔗 The first four weeks of taking a new HIV treatment, when your body is getting used to the new drugs, are likely to be the riskiest time for drug and alcohol interactions.
- 🔗 A frank discussion with your HIV doctor/clinician or pharmacist can give you a better understanding of the risks, based on your own situation.
- 🔗 Drug use can interfere with sleeping patterns and routines, making missed doses of your HIV treatment more likely.
- 🔗 Because all drugs are processed through your liver, it is important to know that too many drugs being processed at the same time can impact liver function and make you feel sick; it can cause liver failure, permanent liver damage, or overdose.
- 🔗 When HIV medications and other substances are taken at the same time, there can be different effects. Drugs can act as inhibitors or inducers (or both), which determine the kind of drug interactions that occur. Some recreational drugs do interact with ARV. When both recreational drugs and ARV are "in line" for processing in the liver, this can lead to overdose of either the medication or the recreational drug.
- 🔗 If you inject drugs, make sure you use a new needle every time to avoid infections that may cause abscesses.
- 🔗 Do not share needles with anyone else, as this is the easiest way to transmit HIV. And do not use a needle that someone else has used. This is the easiest way to acquire hepatitis B or C or other blood-borne infections.
- 🔗 If you do share needles and works, make sure you clean your needle and works with bleach and water (see [Handout: 5 Harm Reduction Tips for Heroin Users](#)).
- 🔗 **Tip for Interventionist:** Praise client successes but honestly discuss current issues (Example: Praise a client for taking buprenorphine to address opioid addiction. If the client's urine analysis is positive for another substance, discuss this substance use directly with the client.)

### Competency Check:

At the end of the session, check in with the client about the information discussed today. Is the client able to describe the following?

- ✓ How recreational drugs (e.g., alcohol, heroin, etc.) can affect the effectiveness of HIV medications
- ✓ Describe harm/risk reduction strategies

End the session by thanking the client for his/her time and scheduling the next session.



## Session 6: HIV and Wellbeing

### Materials

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#### Handouts

- ◆ [Handout 17: Symptoms of Clinical Depression and Anxiety Disorders](#)
- ◆ [Handout 18: Tips for Dealing With Stress, Anxiety, or Depression \(mild\)](#)

#### Videos

- ◆ Empowered: Gina (domestic violence)  
[https://www.youtube.com/watch?v=ozOGgUY\\_vLU](https://www.youtube.com/watch?v=ozOGgUY_vLU)
- ◆ Managing Your Mental Health & HIV  
<https://www.youtube.com/watch?v=ViLE9Wxqxr8&feature=youtu.be> – English  
[https://youtu.be/hj98M\\_W6ifY](https://youtu.be/hj98M_W6ifY) – Spanish
- ◆ Five Types of Depressive Disorders  
<https://www.youtube.com/watch?v=PjB02Zlh4w>
- ◆ Empowered: Stephanie  
<https://www.youtube.com/watch?v=2sgxsfyyFNo>
- ◆ Magic Johnson and Cookie on HIV and their Gay Son  
<https://www.youtube.com/watch?v=TUskKarbWKc>

### Competencies to be demonstrated

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***After this session, the client will be able to describe***

Ways to help with depression, anxiety or other mental health needs

- ◆ See a psychiatrist or counselor
- ◆ See/talk with friends & family
- ◆ Exercise
- ◆ Participate in support groups

## Instructions

Before you start this session: Research your local resources for mental health, domestic violence and wellbeing services. Know your clinic protocols for referring someone to behavioral health services. If you are concerned about a client's mental health, ask a social worker or counselor to join the session with you or to meet with the client after your session.

## Review and discuss the handouts:

- ✓ **Symptoms of Clinical Depression and Anxiety** – a bulleted list of symptoms of depression and anxiety.
- ✓ **Tips for dealing with Stress, Anxiety or Depression** – A bulleted list of strategies to help relieve mild stress, anxiety or depression, and free apps that can help with some of those strategies.

## Watch and discuss the videos:

- ✓ Empowered: Gina (domestic violence)  
[https://www.youtube.com/watch?v=ozOGgUY\\_vLU](https://www.youtube.com/watch?v=ozOGgUY_vLU)
- ✓ Managing Your Mental Health & HIV  
<https://www.youtube.com/watch?v=ViLE9Wxqxr8&feature=youtu.be> – English  
[https://youtu.be/hj98M\\_W6ifY](https://youtu.be/hj98M_W6ifY) – Spanish

## Session 6: HIV & Wellbeing

- 🔗 We all have situations that create stress in our lives. The stress of living with HIV and taking medications every day that may not make us feel great all the time is common, and can be challenging to live with.
- 🔗 Many people living with HIV experience depression, anxiety and/or stress that impact their mental wellbeing. You're not alone. Many people who are depressed are not even aware of it.
- 🔗 Many people may not like to talk about it because they fear what other people might say, or feel they may be treated differently if others know they're seeing a doctor/professional for depression.
- 🔗 Everyone experiences depression or anxiety at some point in their lives. Finding healthy ways to deal with it—and doing those things—is what's most important. There are many things we can do to address it.
- 🔗 I can share some tips with you on how to manage stress, such as exercising, talking with a trusted friend, writing in a journal, meditation, or attending a support group.
- 🔗 I am here to listen and if you are experiencing any of these symptoms I can help you find a professional to help you get the treatment you need.

### Competency Check:

At the end of the session, check in with the client about the information discussed today. Is the client able to describe the following?

- ✓ Symptoms of depression and anxiety
- ✓ Strategies for relieving mild depression and anxiety



# Client Case Studies

## Client Case Study: Bonita

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### Client Background

Bonita was referred to Project CAATCH in 2015 by the care coordinator. At the time Bonita was 36 years old and had been a MassCARE client for 10 years. She had been married for 10 years and had not told her husband of her HIV status. They also had 3 children together. The last child died shortly after birth, and this loss was devastating to Bonita. While pregnant Bonita was fully adherent to her medications, but between pregnancies Bonita used recreational drugs and alcohol and was not adherent to her medical care or medications. Her substance use and disengagement in HIV care only became worse after the loss of her child. In addition, Bonita was in an emotionally and physically abusive relationship with some of her extended family whom also supported her “partying” lifestyle. Her parents knew of her HIV status and were supportive and helpful to Bonita over the years.

Prior to starting Project CAATCH, Bonita asked her care coordinator for assistance in disclosing her status to her husband. The care coordinator worked with Bonita on how to share her status, and she facilitated this discussion with Bonita and her husband. She provided him with HIV information. He was tested for HIV and tested negative. He was advised on methods to protect himself from becoming infected, and was offered PReP, but he refused. Bonita’s husband was accepting of her diagnosis and this helped Bonita become more adherent to her medications and HIV care. With the support of her parents, her husband and the care coordinator, Bonita was making great personal progress and decided to go back to work. After a few weeks at her new job, Bonita started coming into work on Monday mornings hung over from partying on the weekend. It was discovered Bonita was actively using alcohol and crack. She was offered help through her employer several times. She denied using and needing help. Eventually she was asked to leave her job. In reaction to this setback, Bonita stopped going to her HIV care appointments and taking her medication. She stopped answering her phone and essentially disappeared. Her spiral into using drugs and alcohol led the Massachusetts Department of Child and Family Services (DCF) to become involved and they were forced to remove her children from her care. They were placed into the care of Bonita’s parents. This was the breaking point for Bonita. As described by her care coordinator, “she was devastated and broken.” She reached out to the clinic for help and the care coordinator referred her to Project CAATCH.



## Barriers to Care

Bonita started Project CAATCH with several barriers to care including:

- ◆ Past history of and current trauma
- ◆ Substance and alcohol use
- ◆ Engagement in unhealthy and abusive relationships
- ◆ Disclosure of HIV status and self-acceptance of her HIV status
- ◆ Loss of a child and removal of children by DCF
- ◆ Mistrust of the healthcare system

## Strategies Implemented

Once enrolled in Project CAATCH, Bonita was assigned a peer to work in conjunction with her care coordinator. Bonita's immediate need was to go to court and start working to get her children back. The team worked with Bonita to re-engage in HIV care as well as case management services. Bonita completed the core CAATCH sessions over the course of four months and was adherent to her medical appointments and medication. The peer and care coordinator then conducted the two additional sessions with Bonita—HIV and substance use and HIV and mental health. Over the course of the sessions, the team also supported Bonita's healthy relationships with her husband and mother. At Bonita's request, her mother participated in Project CAATCH sessions to better support her daughter in managing her HIV care. Once the sessions were completed, the team maintained weekly contact with Bonita and assisted her in getting into an outpatient substance use treatment program. The team stayed in weekly contact with Bonita, assessing her health and service needs over the course of 6 months and less frequently for the next 6 months. As the 12 months came to a close Bonita was still attending her medical appointments consistently and she was virally suppressed, so the team met with Bonita and they all decided she was ready to graduate from Project CAATCH.

## Lessons Learned

- ◆ **CAATCH provides structure and time to build trust with clients.** CAATCH is designed to meet clients where they are in a non-judgmental way. The six core educational sessions provide both knowledge and skills about management of and living with HIV infection and can be delivered in any sequence depending on the immediate need of the client. The continued weekly contact for six months with the client after the sessions are completed is key to keeping the client engaged. The peer-coordinator team use the weekly check-ins to assess and address client service needs, remind clients of upcoming appointments, and reinforce the messages of the six core education sessions.



- ◆ **Knowledge and support leads to confidence in engaging in health care.** Teaching Project CAATCH clients about HIV through the six core sessions over the course of 6-12 weeks –
  1. The HIV Viral Life Cycle and Medications at Work
  2. Communicating with Health Care Providers
  3. Understanding Lab Tests (CD4, viral load and others)
  4. Managing HIV Stigma and Disclosure
  5. Substance Use Disorders and Harm Reduction
  6. HIV and Wellbeing

Each session is conducted in person with a client and lasts approximately 45 minutes. The time allotted to each session and the time in between sessions is a comfortable learning pace for clients to take in and digest new material.

- ◆ **Clients have a feeling of accomplishment.** Clients who graduate from Project CAATCH feel a great sense of accomplishment in completing all the sessions. Graduations are a moment of celebration for the client, the Project CAATCH team, and the clinic staff and are treated as such. Clients are given a certificate of completion and recognized for the hard work and commitment to the project and their own HIV care.
- ◆ **You can always go back to CAATCH.** When a client experiences a setback or receives new information from a clinician you can always refer back to a CAATCH session. The session can be retaught or portions of it reviewed with the client. In addition, the sessions can be expanded upon as needed with current information and/or resources.

### Beyond CAATCH

Due to the support and services provided by Project CAATCH Bonita graduated from the program in 2016. She re-engaged in medical care and case management. She also graduated from an outpatient addictions program the following year, and is now working on becoming a peer navigator for an addictions program. Her kids are back home with her and she is doing very well. She credits Project CAATCH for consistently reaching out to her and providing services and support in an accepting non-judgmental way when she needed it and for empowering her through the educational sessions to actively engage in her health care. Project CAATCH provided her with information and skills and held space for her to make her own decisions about her care and life while being there to completely support her along her journey. She is virally suppressed and is attending client support groups at the clinic.



## Client Case Study: Holly

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### Client Background

Holly is a 28 year old woman who was diagnosed in 2017 with both HIV and Hepatitis C. She has been actively injecting drugs for 14 years and frequently sells her medications or sex in exchange for drugs. She believes she contracted HIV through her injection drug use. At the time of her HIV diagnosis, she had a CD4 cell count of less than 200 and was also diagnosed with AIDS. In addition to actively injecting drugs, Holly has a history of mental health disorders (schizophrenia and bi-polar disorder), attempted suicides and trauma. Her mother was also an injection drug user and abandoned Holly at a young age to be raised by her father. At 13, Holly gave birth to a daughter, who is now 16 and living with Holly's sister and has very little contact with Holly. The relationship between Holly and her sister and daughter is very strained and a constant emotional challenge for Holly. Holly is stably housed in a housing facility, however the facility is not sober housing.

### Barriers to Care

Holly started Project CAATCH with several barriers to care including:

- ◆ Long history of injection drug use
- ◆ AIDS diagnosis and co-infection with Hepatitis C at time of diagnosis
- ◆ Estrangement from her 16 year old daughter and other family members
- ◆ A history of trauma and current trauma
- ◆ Lack of support system
- ◆ Living in non-sober housing
- ◆ Mistrust of the healthcare system

### Strategies Implemented

Holly first met the care coordinator at a community meeting hosted by a local AIDS Service Organization. At the time, Holly was engaged in substance use treatment services and was living sober; however she was not accessing mental health or psychiatric services. After hearing about MassCARE and Project CAATCH Holly was interested in enrolling in the services. The care coordinator assessed Holly using the standard Massachusetts HIV Case Management Acuity tool and her acuity score was high, indicating she had acute issues that needed immediate attention. The care coordinator immediately enrolled her into Project CAATCH. They started with the optional substance use disorder and HIV session as this session best met Holly's immediate need. It took three meetings to cover the session



information because Holly's substance use history was extensive, difficult to discuss, and she had many questions about the relationship between HIV and substance use. After completing the substance use session, they moved on to the HIV and the Life Cycle session. This session took two meetings to complete. Holly was very concerned about her AIDS diagnosis and the care coordinator spent a lot of time teaching Holly about the viral life cycle so she could understand the importance of viral load and the relationship between the CD4 and viral load. At this time she was attending her medical appointments and was more receptive to the HIV nurse than her physician. This meant she was less likely to respond to messaging or instructions provided by her physician. The care coordinator worked closely with the HIV nurse to give and get updates on Holly's progress and to coordinate care.

Once Holly was engaged in care, the next session the care coordinator conducted with Holly was the optional mental health session. After completing this session, Holly agreed to start meeting with a mental health provider in the community. She was attending both her medical and mental health appointments for 3 months. Holly was steadily improving until Mother's Day. Holly's relationship with her daughter and sister have been difficult and she had not talked with her daughter in 6 months. The emotional toll of not being in contact with her daughter and Mother's Day was overwhelming and she relapsed and overdosed on Heroin. Because of the severity of the overdose, she was admitted into the hospital. Holly felt very guilty for her relapse and that she had let her care coordinator and HIV team down. The coordinator and HIV team rallied around Holly, provided support and helped get her into an inpatient treatment facility. The care coordinator is working with Holly and her inpatient treatment team. They are starting work on the CAATCH sessions to re-engage Holly into HIV care. She is currently virally suppressed but it is uncertain if she is completely adherent to her medication regimen.

### Lessons Learned

- ◆ **CAATCH provides structured and supportive relationships with clients.** CAATCH is designed to meet clients where they are in a non-judgmental way. The four core educational sessions provide both knowledge and skills about management of and living with HIV infection and can be delivered in any sequence depending on the immediate need of the client. The weekly contact is key to keeping the client engaged, and weekly check-ins are used to assess and address client service needs, remind clients of upcoming appointments, and reinforce the messages of the four core education sessions and two optional education sessions.
- ◆ **CAATCH supports a comprehensive team approach.** By design, the CAATCH dyad of the care coordinator and peer allows for increased client centered engagement. The CAATCH team assess the client needs and barriers to care, create a client centered goal plan and work in tandem with the client and providers (both in the clinic and the community) to coordinate care and services.



- ◆ **You can always go back to CAATCH.** When a client experiences a setback or receives new information from a clinician you can always refer them back to a CAATCH session. The session can be retaught or portions of it reviewed with the client. In addition, the sessions can be expanded upon as needed with current information and/or resources.

Currently, the care coordinator is in contact with Holly at least twice a week and with other providers who work with Holly three or more times a week to coordinate her care and services. She will continue to work with Holly while she is in inpatient treatment and after her release. Holly has one aunt who has been supportive and is trying to help her (within set boundaries) to not enable her substance use. Aside from her aunt, Holly does not have family or friends who are supportive of her and her recovery. In the past Holly had the option of moving to a sober housing facility, but she was not interested. The care coordinator continued to work with Holly to reassess her interest and weigh the benefits and cons of moving to sober housing. After finishing her recent substance use treatment program, she agreed to move into a housing facility that would be supportive of her sobriety. The care coordinator continues to work with Holly to address her barriers to care, complete the CAATCH sessions, and stabilize Holly in both HIV care and behavioral health services.



## Client Case Study: Amaka

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### Client Background

Amaka was 19 when she fled the Democratic Republic of the Congo (DCR) for Mozambique after experiencing violence. In Mozambique she lived in a refugee camp, was married and had two children, the last one in 2013. At that time she tested negative for HIV. In 2016, she immigrated to the United States with her sister and one son, leaving her other child behind in Africa. As a new refugee, she received healthcare services and screenings at the health center and was diagnosed with HIV.

After their move to Massachusetts, Amaka's sister decided to move to another state. Amaka and her son stayed in Massachusetts and lived with roommates. Her roommates provided overnight childcare for her son while she worked at night, but they also took advantage of her. Prior to starting Project CAATCH, Amaka had been seeing a counselor at the clinic to help her deal with stress but frequently missed her appointments due to transportation challenges and personal stress. In addition, she didn't disclose her HIV diagnosis to anyone, including her sister and roommates, because they're all part of the same close-knit African community in which there is a lot of stigma about having HIV.

Amaka was studying to be a Certified Nursing Assistant (CNA) however she failed to pass the exam. This was very hard on her and she binge-drank for three days. Her drinking and the roommate/childcare situation led the Massachusetts Department of Child and Family Services (DCF) to remove her son from her care. To meet the DCF requirements to get her son back, Amaka attended the mandated substance abuse treatment program, secured a new apartment, and started a second job. Ten months after having her son removed from her care, he was returned. At that point, she engaged in HIV care at the clinic and was enrolled in the CAATCH Program. At the time Amaka was 29 years old.

### Barriers to Care

Amaka started Project CAATCH with several barriers to care including:

- ◆ Leaving a child behind in Africa and removal of another child by DCF
- ◆ Trauma of violence in DCR and living in a refugee camp in Mozambique
- ◆ Unhealthy and stressful relationships
- ◆ Transportation
- ◆ Language barrier
- ◆ Alcohol use
- ◆ Cultural/community stigma about HIV



## Strategies Implemented

Having her son removed by DCF was a critical motivator to Amaka enrolling in the CAATCH Program. Once enrolled in Project CAATCH, she became very focused on improving and stabilizing her life so that she could take good care of her son. Other challenges she was experiencing such as her roommate problems and issues at work (she had allergic reactions to the chemicals she used) were revealed in the CAATCH sessions over time. The CAATCH team worked with her and her provider to address her issues and help her move into a better position at work where she didn't have to use chemicals. During periods when Amaka's depression or circumstances kept her from coming into the clinic, the CAATCH team reached out to her via phone every day. Amaka eventually called back and re-engaged with the program. The CAATCH team provided the support Amaka needed to continue therapy, evict her roommates, and parent her son.

Amaka completed the CAATCH sessions on a monthly basis. The CAATCH team provided transportation assistance (bus passes or rides) for her clinic visits, which she could use for the rest of the day for errands or appointments. After she lost her primary job (the overnight job), the CAATCH team helped her prepare for doing a job search. Amaka applied for rental assistance, and the CAATCH team helped her complete and submit the paperwork. To help her prepare for taking the CNA exam again, the CAATCH team provided referrals to free educational resources.

## Lessons Learned

- ◆ **The CAATCH team's consistent outreach is a lifeline that's there when clients are ready to re-engage with care.** Clients sometimes drop out of care when they get depressed or overwhelmed or are going through a crisis. The CAATCH team's outreach, even when clients are not responsive, keeps the lines of communication open for re-engagement in care when the client is ready.
- ◆ **The CAATCH educational sessions are flexible and support addressing the client's most acute needs first.** CAATCH is designed to meet clients where they are in a supportive and non-judgmental way that allows the CAATCH team to address a client's most acute needs first. By taking care of urgent issues first, the client is better able to focus on, absorb, and put into practice the CAATCH information they learn.
- ◆ **The CAATCH team's support helps clients address a variety of challenges to stabilize their mental and behavioral health.** In addition to teaching clients about HIV through the six core CAATCH sessions, the CAATCH team provides support and follow-up to address client issues that impact their mental and behavioral health. Support can be as simple as faxing an important document, providing a bus pass, t helping the client with writing a resume, or connecting them with legal services,



housing, or wellness services. These supports help clients attain greater mental and behavioral health stability, which helps them stay engaged in their HIV care.

- ◆ **You can always go back to CAATCH.** When a client experiences a setback or receives new information from a clinician you can always refer back to a CAATCH session. The session can be retaught or portions of it reviewed with the client. In addition, the sessions can be expanded upon as needed with current information and/or resources.

### **Beyond CAATCH**

With the support and services provided by Project CAATCH, Amaka's life stabilized and improved in many ways. Amaka left the overnight job position and secured two new jobs. She changed her living situation and now lives with one person who is a good, dependable roommate. She continues to be virally suppressed and engaged in her HIV medical care. She is no longer depressed or using alcohol and smoking to self-medicate. Amaka has her green card and is on top of all her paperwork. The CAATCH coordinator said "she is very articulate and self-aware. She identifies and communicates her needs." Amaka recently graduated from the program, and the CAATCH team took photos at her graduation so that she can look back anytime and see her accomplishment. Amaka's son is currently living temporarily with her sister, but will return to her this summer and is scheduled to start school in September. The CAATCH team is helping Amaka prepare for his return by helping to find the right summer and school programs. Finally, Amaka is saving money to purchase a car so that when her son returns she can pick him up from school when necessary.

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# Handouts

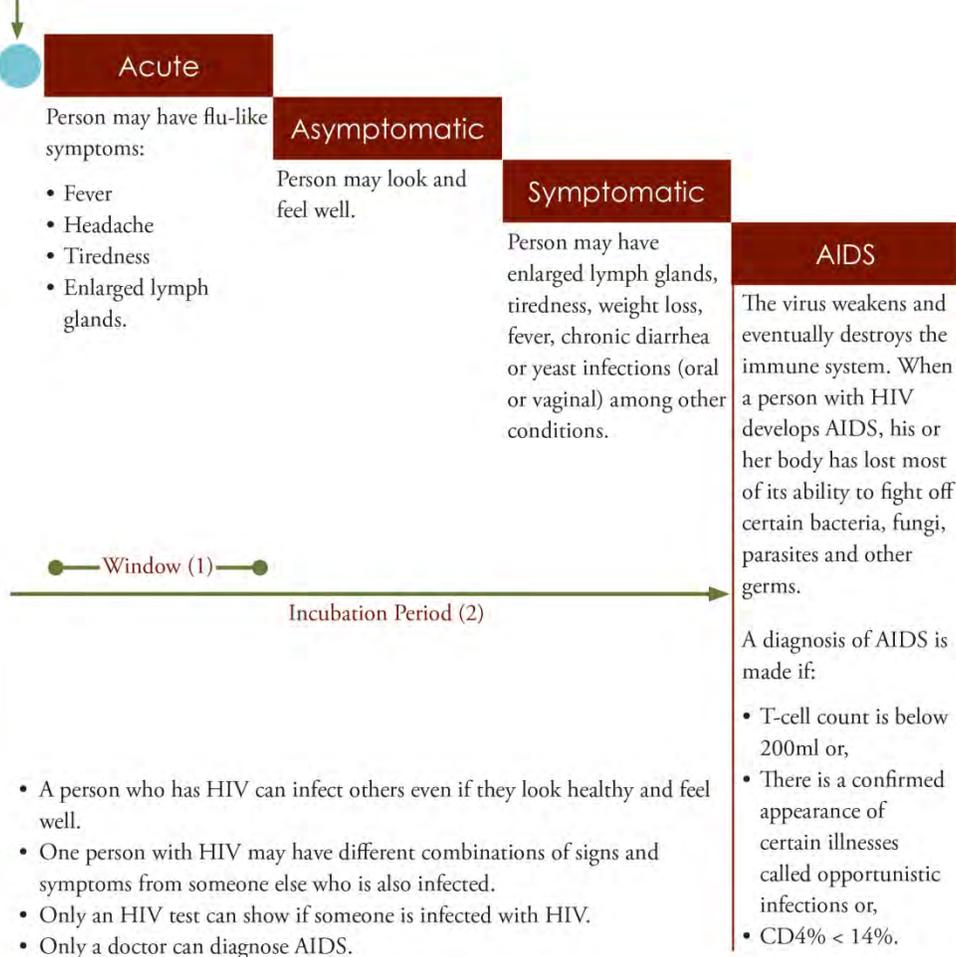


# Session 1 Handout 1: Stages of HIV Infection

# STAGES OF HIV INFECTION

## SESSION HANDOUT

Person becomes infected with HIV



- A person who has HIV can infect others even if they look healthy and feel well.
- One person with HIV may have different combinations of signs and symptoms from someone else who is also infected.
- Only an HIV test can show if someone is infected with HIV.
- Only a doctor can diagnose AIDS.

1. Window Period: Time it takes for antibodies to become detectable in the body; usually within three months.
2. Incubation Period: Time from point of infection to development of AIDS.



# Session 1 Handout 2: HIV Transmission Risk Activities

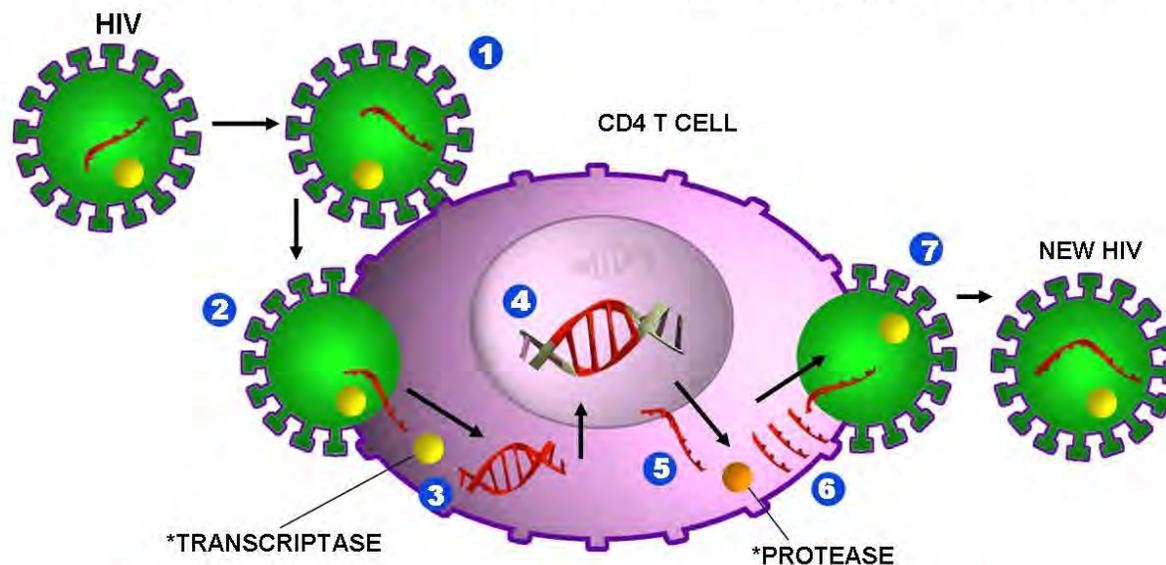
## HIV Transmission Risk Activities

Anal sex	Mutual Masturbation
Vaginal sex	Body rubbing
Oral sex	Sweaty body rubbing
Anal sex with orgasm	Kissing
Sharing needles/works	Breast feeding
Vaginal sex with orgasm	Kissing tears
Oral sex with orgasm	Kissing sweaty body
Anilingus (oral-anal contact)	Golden showers (urine play)
Masturbation	Massage



# Session 1 Handout 3: HIV Life Cycle Graphic

# HIV Life Cycle - The Big Picture



## Attachment

1. HIV binds to receptors on the CD4 T-cell.
- A message is sent to the CD4 T-cell to let the virus in.

## Fusion

2. Once bound, the virus is allowed to dump its contents into the CD4 T-cell.
- Included in its contents are HIV RNA and reverse transcriptase.

## Reverse Transcription

3. The HIV RNA is turned into double-stranded DNA within the CD4 T-cell.
- The enzyme *reverse transcriptase* aids in this process.

## Integration

4. Once the DNA is formed, it hides itself in the human DNA housed in the CD4T-cell nucleus.

## Transcription

5. Copies of HIV DNA are made and released from the nucleus in small packages'.
  - Each of the small packages' contains information for creating a new HIV.

## Assembly

6. The *protease* enzyme in the cell combines the DNA 'packages' to create active virus.

## Budding

7. Once the new HIV is formed, it pushes itself out of the CD4 T-cell
  - The virus steals part of the CD4 T-cell protective coating.



# Session 2 Handout 4: Preparing for a Visit with your Doctor

## Preparing for a Visit with your Doctor

✓	Task	Questions/Comments
	Keep a journal or calendar of your symptoms.	
	Be prepared to describe side effects including symptoms.	
	Bring a list of your medications or bring your medications in a bag.	
	Be prepared to let your provider know how many doses you missed in the past week and month.	
	Bring a list of questions.	
	Bring snacks and something to help you stay busy while waiting.	
	Bring a friend, family member or peer to help you during your visit.	

### Questions to ask your provider:

1. \_\_\_\_\_  
\_\_\_\_\_
2. \_\_\_\_\_  
\_\_\_\_\_
3. \_\_\_\_\_  
\_\_\_\_\_
4. \_\_\_\_\_  
\_\_\_\_\_



# Session 2 Handout 5: Symptoms Log

# Symptoms Log

NAME \_\_\_\_\_ DATE \_\_\_\_\_

**Use this log to note any symptoms or changes in your health you have encountered since your last visit with your provider. Use your answers to talk with your healthcare provider.**

1. Is it hard for you to take your HIV medicines the way your healthcare provider told you to?  
 Yes       No

2. How hard are your HIV medicines to take? Mark an X on the line below.



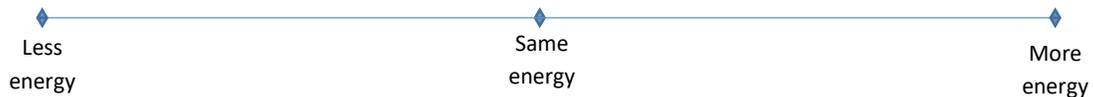
3. If you miss a dose, is it in the morning, evening, or middle of the day?  
 Morning       Evening       Middle of the day       I don't forget or skip doses
4. Do you ever skip a dose because the medicines make you feel bad?  
 Yes       No
5. Do you ever go a day without taking your HIV medicines?  
 Yes       No      why?
- 

6. Do you ever have any of these possible side effects?

Side Effect	How many times a month?	How long have you had this side effect?	How much does it affect your daily activities? 0=none; 1=somewhat; 2=always
Feeling sick to my stomach			
Vomiting			
Diarrhea			
Headache			

Side Effect	How many times a month?	How long have you had this side effect?	How much does it affect your daily activities? 0=none; 1=somewhat; 2=always
Feeling tired			
Rash			
Shortness of breath			
Trouble sleeping			
Change in skin color			
Bad dreams			
Nervousness			

7. Has your energy changed since you started taking your current HIV medicines?  
Mark an X on the line below.



8. Are you concerned that the HIV medicines you are taking now might cause either of these side effects?
- a. Weight loss in the arms, legs, buttocks, or face  Yes    No
  - b. Weight gain in the upper back and neck, breast, or trunk  Yes    No

Would you be interested in talking to your healthcare provider about whether a change to your HIV regimen is right for you?

Yes    No

9. If you could change one thing about your HIV treatment, what would it be?

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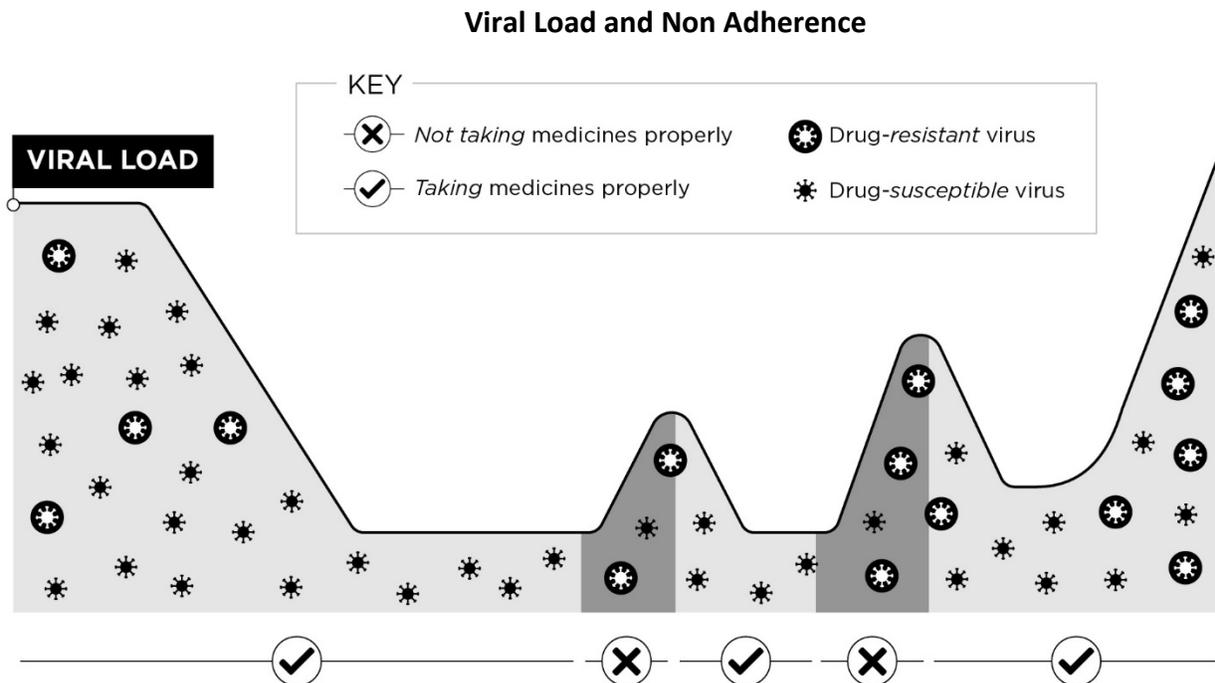
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# Session 2 Handout 6: Assessing Adherence

## Assessing Adherence: 11 Questions You Should Ask

1. Which medications are you currently taking?
2. How frequently do you have to take each of your medications?
3. What are the food restrictions for each of your medications (i.e. with or without food)?
4. Why do you think some medications need to be taken with food and some on an empty stomach?
5. Why do you think some medications are taken once a day and others twice a day?
6. What helps you remember to take your medications?
7. What do you do when you miss a dose?
8. What problems have you encountered from taking medications?
9. How soon before you run out of medications do you order refills?
10. Do you believe that the medications are helping you and, if so, how?
11. What substances do you use regularly? Alcohol, recreational drugs, etc.?





# Session 2 Handout 7: Tips for Remembering to Take Medications

## Tips for Remembering to Take Medications

- ☑ Fill a pill organizer once per week to make it easier to take your medications. Keep this box where you will see it.
- ☑ Get in the habit of taking your medications with an activity you do daily (eg, brushing your teeth).
- ☑ Use a cell phone, watch, computer application, or alarm to help remind you to take medications.
- ☑ Keep a back-up supply in a handbag, backpack, or at work, in case you forget your pills. Your health care provider may ask you to bring your pill bottles to your visit; this is a good way to be sure that you are taking the correct medication and dose and that your doctor is aware of ALL the medicines you take. Get a written copy of your treatment plan at the end of each visit.
- ☑ If your sleep, work or school schedule, or your responsibilities at home interfere with taking your medication on time, discuss it with your provider. Plan ahead for weekends, vacations, and other changes in your routine.
- ☑ Using alcohol or street drugs can make it hard to remember to take medications on time. Be honest about substance use with your provider before agreeing to a treatment plan.
- ☑ It is important to take all of the medications in your regimen each and every day. Taking only a portion of the HIV medications can lead to resistance. When resistance occurs, that medication is no longer effective against your HIV infection.
- ☑ Call your health care provider's office immediately if you have difficulty getting any of your prescriptions filled or you have run out of medications. To avoid interruptions, pay attention to renewal notices you get in the mail and requirements for medication insurance coverage.
- ☑ Always contact your health care provider if you feel you want to stop your pills or change the type of pills you are taking.
- ☑ There may be times that you are not able to take medication because of illness (e.g. nausea and vomiting). Contact your health care provider immediately to discuss these issues.
- ☑ Some HIV medications can interact with other medicines. Ask your pharmacist or other health care provider to determine if there are any interactions between medications and any other prescription, over-the-counter, or herbal medications that you take.

## Apps to Help You Remember to Take Medications

[Pill Reminder by Medisafe](#): Pill Reminder's mission is to give you the reminder tools, support, and info you need to safely take pills. Pharmacists rank Pill Reminder by Medisafe #1 out of 461 apps they've tested, and MyVCM recognizes Medisafe for HIPAA privacy "best practices in managing security and compliance."

[DoseCast](#): Dosecast is a medication management app. You enter information about each medication you take including the name, dosage and how and when you take the medication. Reminders can be set up, remaining quantities are tracked, and the app sends refill reminders. Also, the app logs medication adherence.

[Mango Health app](#) is a medication management app that helps the user manage medicines and create healthy habits. With the Mango Health app, the user can create a schedule for intake of medication. Mango Health alerts the user when it's time to take their medicine. The app uses drug information from LexiComp for drug interaction identification and provides general information concerning the medication to the patient.



# Session 2 Handout 8: Tips for Managing Side Effects Through Diet

## Tips for Managing Side Effects Through Diet

- Eat a BRAT diet: Bananas, Rice, Applesauce and Toast
  - Apple products like apple juice and apple sauce (without added sugar); skinless apples
  - Black or green decaf tea
  - Boiled white rice
  - Baked or mashed potato
  - White toast (use gluten free if necessary)
  - Ginger and ginger products like ginger tea, candied ginger, ginger ale, ginger snaps, etc.
  - Soda crackers
  - Chicken or beef broth; add skinless vegetables for a healthy soup
  - Coconut water for electrolytes
  - Medication: Imodium<sup>®</sup> AD (loperamide)
- Avoid these foods when you have diarrhea:
  - Dairy
  - High fat, high fiber foods
  - Sugar
  - Beans
  - Raw vegetables and fruit
  - Sodas



# Session 2 Handout 9: Managing Side Effects

## Managing DRUG SIDE EFFECTS

Most drug side effects are manageable with a few simple steps. If you are experiencing a serious side effect or one that won't go away, you should call your provider immediately.

Side Effect	What To Do
<p>Headache</p> 	<ul style="list-style-type: none"><li>• Make sure you are drinking plenty of water</li><li>• Take acetaminophen (Tylenol®) or ibuprofen (Motrin®, Advil®) as directed by your provider</li><li>• Keep lights dim, wear sunglasses, or stay in a darkened room</li><li>• Try to get plenty of rest</li><li>• Avoid alcohol, which further dehydrates your body</li></ul>
<p>Fatigue</p> 	<ul style="list-style-type: none"><li>• Try low-impact exercise like walking</li><li>• Drink plenty of water, and avoid caffeine in the afternoon/evening</li><li>• Take a short nap during the day (15 minutes or less)</li><li>• Eat well-balanced meals (protein, vegetables, fruits)—avoid junk food, soda, and sugar</li></ul>
<p>Insomnia</p> 	<ul style="list-style-type: none"><li>• Go to sleep and wake up at the same time every day</li><li>• Do not read or watch television in bed</li><li>• Limit daytime naps</li><li>• Avoid drinking anything 2 hours before bedtime, including alcohol</li></ul>
<p>Nausea/Vomiting</p> 	<ul style="list-style-type: none"><li>• Eat small meals</li><li>• Avoid foods or smells that trigger nausea</li><li>• Avoid greasy, spicy, acidic or sweet foods instead try crackers or toast</li><li>• Try ginger ale/ginger candy/ginger tea</li><li>• Drink fluids (water, Gatorade®, Powerade®, or Pedialyte® are best)</li></ul>
<p>Diarrhea</p> 	<ul style="list-style-type: none"><li>• Avoid foods that are spicy or acidic</li><li>• Avoid dairy products</li><li>• Eat rice, or toast</li><li>• Eat bananas</li><li>• Eat potatoes (no skin)</li><li>• Drink water, clear fluids and broths to stay hydrated</li></ul>



# Session 3 Handout 10: Lab Tests Tracking Form

**Lab Tests Tracking Form**

Client Name: \_\_\_\_\_ Date Completed: \_\_\_\_\_

Lab	Normal Range	Date of test	Value	Date of test	Value
<b>Immune Status</b>					
CD4	500 - 1500				
CD4%					
HIV-1 RNA (VL)					
<b>Liver Function</b>					
AST					
ALT					
<b>Kidney Function</b>					
BUN					
Creatine					
eGFR					
<b>Lipids-Fats</b>					
Triglycerides					
Total cholesterol					
Lipids - LDL (bad)					
Lipids - HDL (good)					
<b>Sugar Levels</b>					
Glucose					



# Session 3 Handout 11: What Do My Lab Results Mean?

## What do my lab results mean?

### What do my lab results mean? HIV and Laboratory Tests



**You want your CD4 count to be HIGH**

#### CD4 Cell Count

CD4 cells are specialized cells of the immune system destroyed by HIV. A CD4 cell count measures how many CD4 cells are in your blood. The higher your CD4 cell count, the healthier your immune system.

**HIV Viral Load Test**

An HIV viral load test, also called an HIV RNA test, tracks how many HIV particles are in a sample of your blood. This is called your viral load.

**You want your viral load to be LOW**

*Taking a combination of HIV medicines every day prevents HIV from destroying CD4 cells and helps lower your viral load.*

### What are some other important tests?

#### DRUG RESISTANCE TEST

HIV can change form, making it resistant to some HIV medicines. A drug resistance test helps your health care provider choose the HIV medicines that will work for you.



#### TESTS FOR OTHER INFECTIONS

HIV weakens the immune system, leaving people vulnerable to other infections. Health care providers test for tuberculosis, hepatitis B and C infections, and other potential illnesses. The treatment for another infection may affect HIV treatment.

#### COMPLETE BLOOD COUNT

This test measures how many red blood cells, white blood cells, and platelets are in your blood. This helps health care providers keep track of your overall health and spot infections or other potential medical problems, and analyze your CD4 cell count.



#### BLOOD CHEMISTRY TESTS

This group of tests measures several different chemicals in your blood to help monitor the health of your organs, especially your heart, liver, and kidneys. Health care providers use blood chemistry tests to look for side effects caused by HIV medicines.

**AIDSinfo**

For more information, visit: [aidsinfo.nih.gov](https://aidsinfo.nih.gov)



# Session 4 Handout 12: HIV Disclosure: Considerations Before You Disclose

## Disclosure: Considerations Before you Disclose Your HIV Status

Here are a few things you may want to think about before disclosing to someone:

- What do you need most from the person you are telling? Think about a person you would like to share this information with - how do you think he/she will react? Thinking about this person's life and situation - will knowing this information help the situation or make it worse?
- Who are you most comfortable telling? Can you think of someone who can support you in a non-judgmental way while coping with their own feelings?
- How important is privacy to you? Think about the person you might want to tell - how does he/she deal with other's confidential information? Do they tell you other people's personal information? Can you communicate your expectation about privacy to the person you want to disclose to? Do you want them to keep your confidence and do you think they can do it? Do you want them to just listen or talk things through with you?
- Prepare for reactions. Do you think the person you want to tell might get upset? Would it help to provide written information to the person? How will their upset impact you?
- Where will you tell them? What place is comfortable for you and the person to talk? Does it provide enough privacy?
- What are some of the risks of disclosing to a specific person? Have you considered the risk that might come with disclosing, such as jeopardizing your job, living situation, or telling someone who might become violent or hurtful?



# Session 4 Handout 13: How Stigma Leads to Sickness

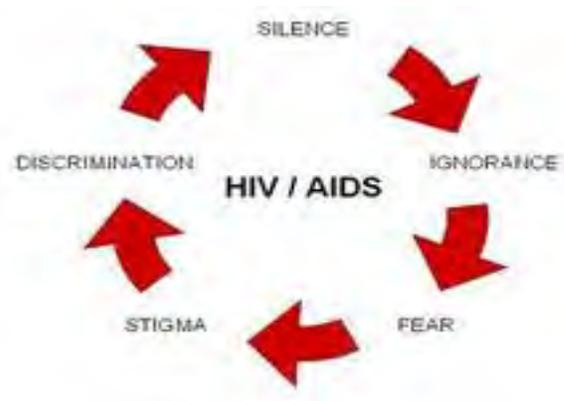
## How Stigma Leads to Sickness

### STIGMA - What is it?

- Negative feelings, beliefs and behaviors directed toward an individual or group due to a particular label or characteristic.
- People experience multiple forms of oppression, stigma, and discrimination based on
  - Gender
  - Race
  - Sexual identity
  - Socioeconomic status
- “Disqualification from full social acceptance”

### HIV-Related Stigma

- HIV Related Stigma refers to:
  - Prejudice, discounting, discrediting and discrimination
  - Directed at persons perceived to be living with AIDS or HIV
  - As well as their partners, friends, families and communities.
- HIV stigma affects a person’s self-worth, confidence, and self-identity.
- HIV stigma can also be internal – with feelings of self-judgement, shame, guilt, etc.
- Stigma can lead to sickness when it impacts your treatment. Taking your HIV medication as prescribed is the best thing you can do to stay healthy. If feelings of negative self-worth get in the way of taking your medication, you can become sick. If stigma from providers, family, or friends gets in the way of taking your medication, you can become sick.
- Stigma can be overcome by dealing with it internally and externally.



## Two Types of Stigma

Internal	External
Self-judgement and negative self-talk we hear/think in our heads and is developed by our life experiences.	Negative, judgemental or exclusionary words or actions about HIV or people with HIV that come from others like family, friends, groups, providers, media, etc.
Feelings may include: shame, lack of worthiness, silence, guilt, secrecy and judgment.	Can influence internal stigma

## To Reduce Stigma

Internal Work	External Work
Question and challenge the negative beliefs you have about yourself. Are they really true? Create an inventory of your strengths, positive characteristics, relationships, and qualities.	Join a support group for people living with HIV. This offers a safe environment to talk about HIV and can help you overcome stigma. You are not alone.
Find a counselor who can help you deal with any negative thoughts or feelings you have about yourself.	Take HIV medications as prescribed to maintain an undetectable viral load and to stay healthy and protect your partner.



# Session 4 Handout 14: HIV: Internalized Stigma

# Internalized HIV-Related Stigma

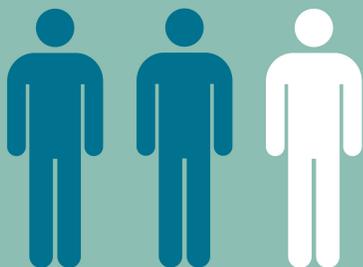
Almost 8 in 10 HIV patients in the United States report feeling internalized HIV-related stigma.

## What is internalized HIV-related stigma?

It is when a person living with HIV experiences negative feelings or thoughts about their HIV status. Here, it is defined as someone agreeing with one or more of the following statements:

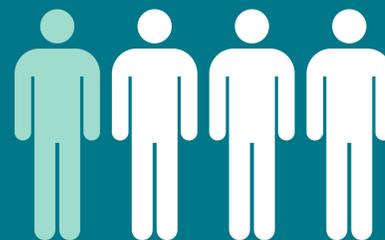


Nearly 2 out of 3 say that it is difficult to tell others about their HIV infection.



Roughly 1 out of 3 report feeling guilty or ashamed of their HIV status.

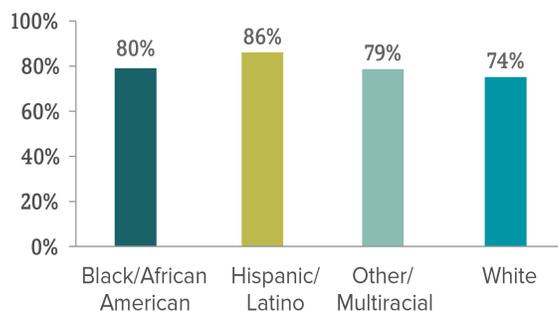
Nearly 1 in 4 say that being HIV-positive makes them feel dirty or worthless.



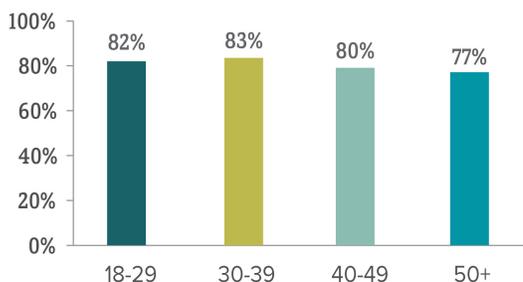
## Which groups are most affected by internalized HIV-related stigma?

### Percentage reporting internalized stigma:

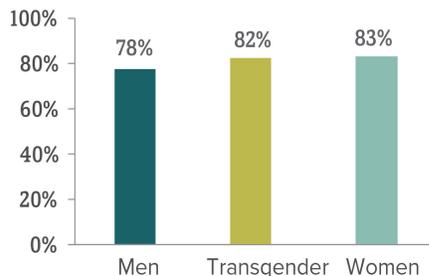
By Race/Ethnicity



By Age



By Gender



Learn more about the Medical Monitoring Project:  
[www.cdc.gov/hiv/statistics/systems/mmp](http://www.cdc.gov/hiv/statistics/systems/mmp)

**SOURCE:**  
 Baugher, AR et al. Prevalence of internalized HIV-related stigma among HIV-infected adults in care, United States, 2011–2013. *AIDS Behav* 2017;21(9):2600-2608.

### ADDITIONAL RESOURCES FOR REDUCING STIGMA:

**Let's Stop HIV Together Campaign**  
[www.cdc.gov/together](http://www.cdc.gov/together)

**National Prevention Information Network (NPIN)**  
<https://npin.cdc.gov/search/all/stigma>

## How can people living with HIV reduce internalized stigma?



Think about the negative beliefs you may have about yourself. Ask yourself if they are really true.



Find a counselor who can help you deal with any negative thoughts and feelings about your HIV status.



Take HIV medicine as prescribed to keep an undetectable viral load—that means the level of HIV in your body is so low that a test can't detect it. Getting and keeping an undetectable viral load can reduce internalized stigma by keeping you healthy and protecting your partner.



Join support groups and organizations that help people living with HIV. These groups offer a safe environment and can help you overcome the challenges of living with HIV.



## Live Well With HIV



Take HIV medicine as prescribed



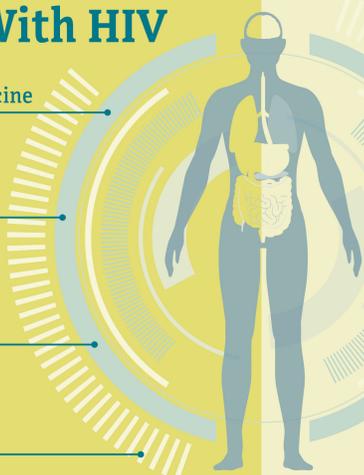
Stay in HIV care



Share your status



Protect your partners



## HIV TREATMENT CAN KEEP YOU HEALTHY AND PROTECT OTHERS

If you are living with HIV, get in care and start treatment as soon as possible. The sooner you start treatment, the more you benefit. Taking HIV medicine as prescribed can make the level of HIV in your blood very low (called *viral suppression*) or even undetectable. Getting and keeping an undetectable viral load is the best thing you can do to stay healthy. Also, if you stay undetectable, you have effectively no risk of transmitting HIV to an HIV-negative partner through sex. Learn more about living with HIV at [www.cdc.gov/hivtreatmentworks](http://www.cdc.gov/hivtreatmentworks).

For More Information

Call 1-800-CDC-INFO (232-4636)  
 Visit [www.cdc.gov/hiv](http://www.cdc.gov/hiv)



# Session 5 Handout 15: HIV and Substance Use

## HIV and Substance Use

### Drug Interactions

The liver is involved in metabolism of most HIV medications and recreational drugs. Metabolism is the body's mechanism for processing, using, inactivating and ultimately eliminating foreign substances (including both HIV medications and recreational drugs). When HIV medications and other substances are taken at the same time, there can be different effects. Drugs can act as **inhibitors** or **inducers** (or both), which determine the kind of drug interactions that occur.

Inhibitors	Inducers
<p><b>Competition</b></p> <ul style="list-style-type: none"><li>• When 2 drugs are “waiting in line” to be broken down by the liver, they must compete to be processed. The drug that wins this competition (usually HIV medications) is acting as an inhibitor.</li><li>• The liver is so busy processing the HIV medications (inhibitors), that recreational drug processing is delayed, eventually resulting in a high level of recreational drug being processed, and potential overdose.</li></ul>	<p><b>Enhancement</b></p> <ul style="list-style-type: none"><li>• Inducers are the drugs that, once present in the liver, have the effect of triggering more rapid clearance of drugs that follow leading to lower drug level (medications or other recreational drugs).</li></ul>

### Ritonavir and cobicistat

The two anti-HIV drugs most likely to be involved in harmful interactions with recreational drugs are ritonavir (Norvir) and cobicistat (Tybost).

Both of these are boosting agents, taken to boost levels of other antiretrovirals. Adding a small dose of one of these agents makes the liver break down the primary drug more slowly, so that it stays in the body for longer or at higher levels. Without the boosting agent, the prescribed dose of the primary drug would be ineffective.

The boosting mechanism can also affect recreational drugs. The liver processes the recreational drug more slowly, resulting in the recreational drug staying in the body for longer or in greater concentrations. Sometimes this can cause serious side-effects or an overdose.

If your HIV treatment includes a protease inhibitor, you are probably taking either ritonavir (Norvir) or cobicistat (Tybost). Protease inhibitors include darunavir (Prezista), atazanavir (Reyataz) and lopinavir (Kaletra).

Cobicistat is also taken with the integrase inhibitor elvitegravir (Vitekta). It is included in the combination pills Stribild (with elvitegravir, tenofovir disoproxil and emtricitabine), Rezolsta (with darunavir) and Evotaz (with atazanavir).

Ritonavir is also in a combination pill used to treat hepatitis C called Viekirax (with ombitasvir and paritapevir).

**A dangerous interaction is possible between ritonavir or cobicistat and several recreational drugs:**

- Crystal methamphetamine (crystal, tina, meth)
- MDMA (ecstasy, X, mandy)
- Mephedrone (miaw miaw, plant food, bath salts)
- Ketamine (K, vitamin K, special K)
- Erectile dysfunction drugs (Viagra, Cialis, Levitra)
- Benzodiazepines (benzos, Valium, Xanax)

The interaction may increase the intensity of the effect of the recreational drug, sometimes to unpleasant or dangerous levels.

Experts judge the potential for interactions with the first three drugs listed to be 'moderate' and with the last three to be 'high'. There have been a handful of documented cases of deaths and serious side-effects in people taking ritonavir alongside crystal meth, MDMA or ketamine.

Heavy use of ketamine can lead to damage to the liver and bile ducts. Overdoses of erectile dysfunction drugs are dangerous for the heart. An overdose of benzodiazepines could result in the person passing out.

Poppers may also interact with erectile dysfunction drugs, causing a potentially dangerous drop in blood pressure. This may be more likely if you are also taking ritonavir or cobicistat.

Source: <https://www.aidsmap.com/about-hiv/interactions-between-hiv-treatment-and-recreational-drugs>

## **HIV Medications and Opioids**

*Heroin* is an opioid used as an analgesic, but also used as a recreational drug. Frequent and regular use of heroin can increase tolerance and physical dependence, which can develop into addiction.

- HIV medications acting as inducers can decrease heroin levels in the blood by 50%, causing a more rapid onset of and/or more severe withdrawal symptoms.
- This also leads to a desire/need to increase the heroin dose to compensate for the lesser effect, leading to even more dependence.

*Methadone and Buprenorphine* are opioid analgesics (a.k.a. painkillers) used as treatment for heroin addiction because they reduce cravings and block the ability of heroin to produce euphoria, making it less desirable.

- Methadone as inducer and inhibitor: Hinders absorption of didanosine (ddI) and stavudine (d4T) (inhibitor), and increases AZT (inducer)
- Research has shown that methadone hinders absorption of the drugs didanosine (ddI) and stavudine (d4T), due to increased degradation in the gastrointestinal tract.
- When taken together, research has shown that protease inhibitors HIV medications (PIs) act as inducers (leading to reduced methadone/buprenorphine concentrations), or methadone acts as an inhibitor (causing PI toxicity).

PI-related toxicity (and other HIV medications-related toxicity) include nausea, vomiting, diarrhea, which are also symptoms of heroin or methadone/buprenorphine withdrawal.

### **HIV Medications and Amphetamines**

#### **Crystal Meth**

*Crystal meth* is one form of the drug methamphetamine. It increases dopamine production in the brain and has similar effects to cocaine. It is highly addictive, and long-term use can lead to impaired speech and motor skills. Sometimes known as ice or blue ice, it can be smoked in pipes, snorted, injected, swallowed, or ingested rectally.

- In combination with HIV medication, crystal meth may reach dangerous levels in the body. They can cause lasting damage to an important chemical in the brain that is related to hard to treat depression.
- Crystal meth can also effect whether or not you remember taking your medications and whether or not you have eaten. The ingredients in meth can cause sleeplessness, which impacts your body's ability to rest and recover and can increase viral load levels.

### **HIV Medications & Hallucinogens**

*Ketamine*, also called "K," is a mild hallucinogen. K causes feelings of mind/body separation, possible seizures, respiratory depression, mild hallucinations (referred to as 'K-Holes'), and increased heart rate (HR).

- HIV medications intensify the already harmful effects of K, including increased HR, blood pressure, increased sedation.
- K increases the likelihood of experiencing "chemical hepatitis," drug induced hepatitis: an inflammation of the liver that is permanently damaging.
- Norvir, Kaletra, Viracept, Agenerase, Lexica, Rescriptor and Sustiva have the greatest potential to cause toxicity.

*PCP* is a powerful hallucinogen which can cause feelings of empowerment and invulnerability. Potentially dangerous effects include seizures, hypertension, hyperthermia, and rhabdomyolysis.

- Mixed use with PIs, Delavirdine & possibly Efavirenz, may result in elevated PCP concentrations & resultant toxicity.

*LSD* is a powerful hallucinogen that is easily available which causes intense hallucinations, agitation, psychosis, perception disorders known as 'flashbacks.' Side effects of the drug include higher body temperatures, increased heart rate, blood pressure, sweating, sleeplessness & tremors.

- The likelihood of experiencing these effects is greater when mixed with HIV medications.

### **HIV Medications & Alcohol**

*Alcohol* is a drink containing ethanol which is a psychoactive drug that has a depressant effect. High blood alcohol content is considered to be drunkenness because it reduces attention and slows reaction speed. The state of alcohol addiction is known as alcoholism. There is some evidence that PLWH who drink the same amount as HIV-negative people, have higher blood alcohol levels than those who do not have HIV. While there are no significant interactions between alcohol the current HIV medications, alcohol can react badly with other medications such as anti-TB medications and some antibiotics.

- Chronic use causes liver damage, making it unable to perform its bodily function as effectively; weakens immune system; can cause peripheral neuropathy (meaning nerves don't work properly) and pancreatitis (inflammation of the pancreas).
  - Alcohol acts as an inducer, triggering the liver to process PIs more rapidly resulting in insufficient amounts to fight HIV.
  - When d4T or ddI are mixed with alcohol, there is an increased risk of pancreatitis.
- Acute use can cause alcohol poisoning.
  - HIV Medications act as inhibitors, preventing alcohol from being processed properly. The consequence is alcohol toxicity, and an elevated risk of alcohol poisoning.
  - Some cases have been reported of individuals experiencing increased levels of Ziagen because of acute alcohol use, which means an increased risk of corresponding side effects (life threatening body rash and fever)

### **HIV Medications & Erectile Dysfunction (ED) Drugs**

*Viagra*, *Levitra* and *Cialis* are all medications prescribed for ED which are also used recreationally.

- For example, many individuals mix ED drugs with crystal meth (which can cause a loss of erection) and engage in sexual activity for an incredibly long duration of time w/multiple partners. Individuals are less likely to use protection because crystal makes them less inhibited.
- When ED drugs, crystal meth, and HIV medications are mixed: extended half-life and drug toxicity (due to elevated drug levels in the blood) means there is a greatly increased likelihood of experiencing adverse side effects: stroke, changes in blood pressure and heart attacks.

**Updated References (1/16/20):**

<http://www.aidsmap.com/Alcohol/page/1045082/>

<http://www.aidsmap.com/Interactions-between-HIV-treatment-and-recreational-drugs/page/3009725/>

<http://www.aidsmap.com/Safer-drug-use/page/1323444/>



# Session 5 Handout 16: Harm Reduction Tips for Heroin Users

# Five Harm Reduction Tips for Heroin Users

<https://www.verywellmind.com/harm-reduction-tips-for-heroin-users-22064>

## 1. Choose smoking or snorting over injecting

- Many heroin users start out smoking heroin, then as they become addicted, switch to injecting heroin. Although smoking, snorting, and injecting are all harmful, there are greater risks associated with injection drug use. These include contracting HIV and hepatitis, which are transmitted through needle sharing, abscesses, vein damage, and severe bacterial infections.
- [Snorting](#) heroin doesn't have quite as instant an effect as smoking or injecting, but it will still take effect very quickly with much lower risk than injecting it. While all methods of heroin use carry the risk of overdose, it's less likely with smoking because you can stop once you feel high, whereas with injecting, once the drug is in your body, you can't do anything to reduce the effects or the overdose risk (see tip 3).

## 2. Always use a clean needle to inject

- Many of the harmful effects of heroin are related to reusing or sharing needles for injection. Make it a personal policy to never, ever use a needle that someone else has used, and conversely, to never offer a needle you have used to another person.
- Clean needles are freely available through [needle exchange](#) services. If you don't know where your nearest needle exchange is, read [how to find a needle exchange](#), which includes links to listings in several different countries.
- In an emergency, you can clean your needles by flushing them out with undiluted bleach, then flushing them with water three times. Remember, blunt needles cause vein damage.

## 3. Don't use alone

- Although many people are distressed by seeing another person using heroin, having someone nearby can save your life. Heroin carries a high risk of [overdose](#), but if identified quickly, the overdose can be reversed by a drug called naloxone ([Narcan](#)), which blocks the opiate receptors in the brain. Individuals can access naloxone through a pharmacist or from a trained outreach worker. They can teach you how to use it if someone has overdosed on heroin. If you or someone you are with may have taken a heroin overdose, administer Narcan (if you have it) and **CALL 911 IMMEDIATELY**.
  - Signs of overdose include:
  - Fewer than 12 breaths a minute
  - Loss of consciousness
  - Lack of response to pain

## 4. Use as low a dose as possible

- Keep your dose low, never increase the dose, and try to back off from heroin completely if you find your usual dose is not effective. Never use heroin two days in a row, and never use more to treat any [heroin withdrawal](#) symptoms

## 5. Consider treatment options

- There are many different treatment programs available, and your choices will depend on where you live and whether you can afford to pay. If you are a heavy heroin user, you might consider [methadone](#) as a way of getting off heroin and letting your body recover from the damage caused by injections. Although methadone is an addictive opiate, the dosages are precise, taken orally, and unlike heroin, it contains no contaminants.
- Another option to consider if you have difficulty controlling your impulses is naltrexone. This is an oral slow-acting drug that blocks the opiate receptors so you won't get high on heroin. [Suboxone](#), another option, combines buprenorphine and naloxone and works similarly to methadone to minimize withdrawal symptoms.



# Session 6 Handout 17: Symptoms of Clinical Anxiety and Depression

## Symptoms of Clinical Depression

Not everyone experiences clinical depression in the same way. Different people have different symptoms. The National Mental Health Association recommends you see a doctor or a qualified mental health professional if you experience five or more of these symptoms for longer than two weeks, or if the symptoms are severe enough to interfere with your daily routine.

### Symptoms may include:

- A persistent sad, anxious or “empty” mood
- Sleeping too little or sleeping too much
- Reduced appetite and weight loss, or increased appetite and weight gain
- Loss of interest or pleasure in activities once enjoyed
- Restlessness or irritability
- Persistent physical symptoms that don’t respond to treatment [such as headaches, chronic pain, or constipation and other digestive disorders]
- Difficulty concentrating, remembering, or making decisions
- Fatigue or loss of energy
- Feeling guilty, hopeless or worthless
- Isolating yourself and withdrawing from friends and family
- Thoughts of death or suicide
- National Suicide Prevention Lifeline provides 24/7 free confidential support for people in distress. 1-800-273-8255

## Symptoms of Anxiety Disorders

There are several types of anxiety disorders and not everyone experiences the same symptoms. An accurate diagnosis and treatment should be made by a qualified mental health provider.

### **Symptoms may include:**

- Excessive worry more days than not
- Inability to control worry
- Restlessness, feeling keyed up or on edge
- Fatigue, feeling easily tired
- Irritability, or sudden anger outburst
- Muscle tension
- Trouble falling asleep or staying asleep
- Fatigue or loss of energy
- Repeated, unexpected “anxiety attacks” when you are suddenly overcome by intense fear or discomfort, for no apparent reason
- Repeated, distressing memories or dreams of a life-threatening event you experienced
- Feeling “on guard”
- Feeling detached from other people
- Intense, persistent fear of a social situation in which people might judge you
- Extreme anxiety with pounding heart, trembling or shaking, sweating, nausea or abdominal discomfort, fear of losing control
- Feeling worthless or guilty



# Session 6 Handout 18: Tips for Dealing with Mild Depression and Anxiety

## Tips for Dealing with Mild Stress, Anxiety or Depression

- Talk to your provider about how you feel and ask for a referral to a mental health professional who can determine if your symptoms are related to a disorder and may require treatment
- Talk to a trusted friend, family member, peer, or spiritual or religious leader
- Exercise regularly (exercise has been found to be as effective as medication in treatment of depression.) Start with a long vigorous walk
- Buddy up with a friend to do activities like exercise, hobbies, or self-care to help you stay motivated and accountable
- Attend a support group meeting
- Avoid alcohol and drug use, which exacerbates stress, anxiety, and depression
- Keep busy, find something positive to do. Volunteer
- Write in a journal
- Take deep breaths and practice mindful breathing when stressed
- Spend time in nature
- Start a meditation, yoga, or prayer practice
- See a counselor who can support your efforts to reduce stress and handle depression
- Do creative projects, arts, crafts, hobbies, cooking, or gardening
- Take a hot bath with Epsom Salts. Add music and candles to help you relax
- Attend religious services or other gatherings
- Add self-care tips that work well for you

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## Resources for Dealing with Mild Stress, Anxiety or Depression

**Meditation** can help calm the mind and relax the body. When done regularly, it can help reduce negative self-talk and feelings, which contribute to stress, anxiety and depression. Guided meditations are a good way to start, because a narrator guides you through the meditation and breathing to help you focus. There are many free meditation apps available that make it easy to meditate on your own schedule and in your own space. Apps can be downloaded through your phone's app store.

[Insight Timer](#) free app has a huge library of free guided meditations and programs from a wide variety of teachers on topics like stress, self-esteem, relationships, sleep, mornings, improving work, and more. The app is a virtual meditation community, and you can rate meditations, follow the teachers you like, and leave comments. You can also tune in to 2,000 free talks and podcasts for life advice and inspiration, and music tracks to soothe your mind or help you sleep.

[Smiling Mind](#) free app that features hundreds of meditations, enough to keep you engaged without overwhelming you with choice. They are organized into structured programs like Mindful Foundations, Sleep, Relationships, and Workplace. You can choose where to start and easily jump between programs. Most meditations are in the five- to fifteen-minute range, with a few practices up to 45 minutes for advanced meditators.

Can't use an app? Try these free guided meditations online:

<https://awakeandmindful.com/free-guided-meditations-to-relieve-stress/>

**Regular exercise** helps to reduce stress, improve your mood and health, and boost energy. Free health apps can help you exercise each day, track your healthy habits, and stay motivated.

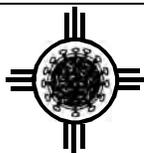
[MyFitnessPal](#) app helps users keep track of the food they eat and the activities they do. It provides exercises and helps you log your meals and exercise to stay on top of your progress.

The Couch to 5k [C25K](#) is an app and program designed to get just about anyone from the couch to running 5 kilometers or 30 minutes in just 9 weeks. It's a gentle introduction to getting the body moving, starting off alternating between walking and running small distances, and slowly building up until after 8 weeks, you're ready to run 5 kilometers or 30 minutes non-stop.

[7 Minute Workout](#) app helps users easily create custom workouts, log workouts and track progress. The power of this workout is that it's simple to do. Follow along with Chris Jordan, who will teach you the correct way to do each movement. You can also share a snapshot of your training with friends. See the days, number of cycles, and effort.



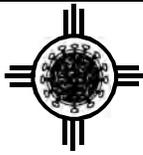
# Optional Handout 19: Normal Lab Values



# NORMAL LABORATORY VALUES, Page 1 of 2

**IMPORTANT NOTES:** Each commercial laboratory has its own set of "normal" values, called "Normal Range" or "Reference Range" on your lab report. These values depend on the equipment or method used. Compare your results to the range shown on your lab report. Results that are "out of range" may not represent a problem. Your test results can be affected by several factors, including your age or gender, if you are pregnant, the time of day when the sample was taken, active infections, stage of HIV disease, and food (some test samples need to be taken after you have fasted - not eaten anything - for several hours). Where normal values for men and women are different, they are indicated as W for women and M for men. **Discuss "out of range" results with your health care provider.** The table below compares the units used in the United States with the "Système International d'Unités (SI units), a metric system used in many parts of the world. The last column, "To Convert US to SI Units," is the factor to multiply US lab values to convert them to SI units. To convert SI units to US units, divide the SI value by the conversion factor. See page 2 for a terminology list.

Laboratory Test	Normal Range in US Units	Normal Range in SI Units	To Convert US to SI Units	
ALT (Alanine aminotransferase)	W 7-30 units/liter M 10-55 units/liter	W 0.12-0.50 µkat/liter M 0.17-0.92 µkat/liter	x 0.01667	
Albumin	3.1 - 4.3 g/dl	31 - 43 g/liter	x 10	
Alkaline Phosphatase	W 30-100 units/liter, M 45-115 units/liter	W 0.5-1.67 µkat/liter, M 0.75-1.92 µkat/liter	x 0.01667	
Amylase (Serum)	53-123 units/liter	0.88-2.05 nkat/liter	x 0.01667	
AST (Aspartate aminotransferase)	W 9-25 units/liter M 10-40 units/liter	W 0.15-0.42 µkat/liter M 0.17-0.67 µkat/liter	x 0.01667	
Basophils	0-3% of lymphocytes	0.0-0.03 fraction of white blood cells	x 0.01	
Bilirubin - Direct	0.0-0.4 mg/dl	0-7 µmol/liter	x 17.1	
Bilirubin - Total	0.0-1.0 mg/dl	0-17 µmol/liter		
Blood pressure	Normal: 120/70 to 120/80 millimeters of mercury (mmHg). Top number is systolic pressure, when heart is pumping. Bottom number is diastolic pressure when heart is at rest. Blood pressure can be too low (hypotension) or too high (hypertension).		No conversion	
C peptide	0.5-2.0 ng/ml	0.17-0.66 nmol/liter	x 0.33	
Calcium, serum	8.5-10.5 mg/dl	2.1-2.6 mmol/liter	x 0.25	
Calcium, urine	0-300 mg/24hr	0.0-7.5 mmol/24hr	x 0.025	
CO <sub>2</sub> (Bicarbonate)	20 - 32 mmol/L	20 - 32 mmol/L	No conversion	
Chloride	95 - 108 mmol/L	95 - 108 mmol/L	No conversion	
Cholesterol, Total & LDL Desirable Marginal High Very High HDL: Desirable Moderate Low (heart risk)	Total Cholesterol <200 mg/dL	LDL cholesterol <100 mg/dL	x0.02586	
	LDL cholesterol <100 mg/dL	Total Cholesterol <5.17 mmol/liter		
	200-239 mg/dL	100 - 159 mg/dL		5.17-6.18 mmol/liter
	>239 mg/dL	160 - 189 mg/dL		>6.18 mmol/liter
	--	>190 mg/dL		--
>60 mg/dL	>1.55 mmol/liter	>1.55 mmol/liter		
40 - 60 mg/dL	1.03 - 1.55 mmol/liter	1.03 - 1.55 mmol/liter		
<40 mg/dL	<1.03 mmol/liter	<1.03 mmol/liter		
Cortisol: serum free (urine)	0-25 µg/dl (depends on time of day)	0-690 nmol/liter	x 27.59	
	20-70 µg/dl	55-193 nmol/24hr	x 2.759	
Creatine kinase	W 40-150 units/liter, M 60-400 units/liter	W 0.67-2.50 µkat/liter, M 1.00-6.67 µkat/liter	x 0.01667	
Creatinine (urine)	W 0.6 - 1.8 g/day M 0.8 - 2.4 g/day	W 5.3-15.9 mmol/day M 7.1-21.2 mmol/day	x 88.4	
DHEA	W 130-980 ng/dl M 180-1250 ng/dl	W 4.5-34.0 nmol/liter M 6.24-43.3 nmol/liter	x 0.03467	
DHEA Sulfate	W Pre-menopause: 12-535 µg/dl W Post-menopause: 30-260 µg/dl M 10-619 µg/dl	W Pre-menopause: 120-5350 µg/liter W Post-menopause: 300-2600 µg/liter M 100-6190 µg/liter	x 10	
Eosinophils	0-8% of white blood cells	0.0-0.8 fraction of white blood cells	x 0.01	
Erythrocyte sedimentation rate (Sed Rate)	W ≤ 30 mm/h M ≤ 20 mm/h	W ≤ 30 mm/h M ≤ 20 mm/h	No conversion	
Folate	3.1-17.5 ng/ml	7.0-39.7 nmol/liter	x 2.266	
Glucose, urine	<0.05 g/dl	<0.003 mmol/liter	x 0.05551	
Glucose, plasma	70-110 mg/dl	3.9-6.1 mmol/liter		
Gamma glutamyl transferase (GGT)	W ≤ 45 U/L M ≤ 65 U/L	W ≤ 45 U/L M ≤ 65 U/L	No conversion	

**NORMAL LABORATORY VALUES, Page 2**

Laboratory Test	Normal Range in US Units	Normal Range in SI Units	To Convert US to SI Units
Hematocrit	W 36.0% - 46.0% of red blood cells M 37.0% - 49.0% of red blood cells	W 0.36-0.46 fraction of red blood cells M 0.37-0.49 fraction of red blood cells	x 0.01
Hemoglobin	W 12.0-16.0 g/dl, M 13.0-18.0 g/dl	W 7.4-9.9 mmol/liter, M 8.1-11.2 mmol/liter	x 0.6206
Lactate dehydrogenase (LDH) (total)	≤ 270 U/L	≤ 4.5 µkat/liter	X 0.016667
Lactic acid	0.5-2.2 mmol/liter	0.5-2.2 mmol/liter	No conversion
Leukocytes (WBC)	4.5-11.0x10 <sup>3</sup> /mm <sup>3</sup>	4.5-11.0x10 <sup>9</sup> /liter	No conversion
Lymphocytes	16-46% of white blood cells	0.16-0.46 fraction of white blood cells	x 0.01
Mean corpuscular hemoglobin (MCH)	25.0-35.0 pg/cell	25.0-35.0 pg/cell	No conversion
Mean corpuscular hemoglobin concentration (MCHC)	31.0-37.0 g/dl	310-370 g/liter	x 10
Mean corpuscular volume (MCV)	W 78-102 µm <sup>3</sup> M 78-100 µm <sup>3</sup>	W 78-102 fl M 78-100 fl	No conversion
Monocytes	4-11% of white blood cells	0.04-0.11 fraction of white blood cells	x 0.01
Neutrophils	45-75% of white blood cells	0.45-0.75 fraction of white blood cells	x 0.01
Phosphorus	2.5 – 4.5 mg/dL	0.81 – 1.45 mmol/L	X 0.323
Platelets (Thrombocytes)	130 – 400 x 10 <sup>3</sup> /µL	130 – 400 x 10 <sup>9</sup> /L	No conversion
Potassium	3.4-5.0 mmol/liter	3.4-5.0 mmol/liter	No conversion
Red Blood Cell Count (RBC)	W 3.9–5.2x10 <sup>6</sup> /µL M 4.4–5.8x10 <sup>6</sup> /µL	W 3.9–5.2 x 10 <sup>12</sup> /L M W 4.4 – 5.8 x 10 <sup>12</sup> /L	No conversion
Sodium	135-145 mmol/liter	135-145 mmol/liter	No conversion
Testosterone, total (morning sample)	W 6-86 ng/dl M 270-1070 ng/dl	W 0.21-2.98 nmol/liter M 9.36-37.10 nmol/liter	x 0.03467
Testosterone, Unbound	Age 20-40 W 0.6-3.1, M 15.0-40.0 pg/ml Age 41-60 W 0.4-2.5, M 13.0-35.0 pg/ml Age 61-80 W 0.2-2.0, M 12.0-28.0 pg/ml	W 20.8-107.5, M 520-1387 pmol/liter W 13.9-86.7, M 451-1213 pmol/liter W 6.9-69.3, M 416-971 pmol/liter	x 34.67
Triglycerides (fasting)	Normal 40-150 mg/dl Borderline 150-200 mg/dl High 200-500 mg/dl Very High >500 mg/dl	0.45-1.69 mmol/liter 1.69 - 2.26 mmol/liter 2.26 - 5.65 mmol/liter >5.65 mmol/liter	x 0.01129
Urea, plasma (BUN)	8-25 mg/dl	2.9-8.9 mmol/liter	x 0.357
Urinalysis: pH	5.0-9.0	5.0-9.0	No conversion
Specific gravity	1.001-1.035	1.001-1.035	No conversion
WBC (White blood cells, Leukocytes)	4.5-11.0x10 <sup>3</sup> /mm <sup>3</sup>	4.5-11.0x10 <sup>9</sup> /liter	No conversion

**TERMINOLOGY: UNITS:**

**gram:** common measurement of weight. Used in this table: pg (picograms), g (grams), mg (milligrams), etc. per liter

**katal (kat):** a unit of catalytic activity, used especially in the chemistry of enzymes. Used in this table: µkat (microkatal), nkat (nanokatal) per liter

**micrometer (µm):** a unit of length. Mean Corpuscular Volume is expressed in cubic micrometers

**mole:** also "gram molecular weight," a quantity based on the atomic weight of the substance. Many test results in the Système Internationale are expressed as the number of moles per liter. In US units, these measurements are usually in grams per liter. Used in this table: mmol (millimoles), µmol, (micromoles), nmol (nanomoles), pmol (picomoles) per liter

Some units of measurement include the following fractions and multipliers:

<b>mega (M):</b> 10 <sup>6</sup> or x1,000,000	<b>milli (m):</b> 10 <sup>-3</sup> or ÷1,000
<b>kilo (k):</b> 10 <sup>3</sup> or x1,000	<b>micro (µ):</b> 10 <sup>-6</sup> or ÷1,000,000
<b>deca or deka:</b> 10 <sup>1</sup> or x10	<b>nano (n):</b> 10 <sup>-9</sup> or ÷1,000,000,000
<b>deci (d):</b> 10 <sup>-1</sup> or ÷10	<b>pico (p):</b> 10 <sup>-12</sup> or ÷1,000,000,000,000

*Reviewed September 30, 2014*



# Optional Handout 20: PREP PEP Pregnancy and Breastfeeding

# Preventing HIV During Pregnancy/Breastfeeding: Using PrEP &/or PEP

## The Basics | Why do I need to think about preventing HIV during pregnancy and/or breastfeeding?

- Studies show the changes that take place in a pregnant woman's body may make it more likely to get HIV from a partner. This makes preventing HIV during pregnancy especially important for you and your baby.
- HIV can be passed on from a woman to a child during pregnancy or breastfeeding.
- Just after someone acquires HIV, the risk of passing on HIV to a partner or infant is highest.

## How can I prevent HIV during pregnancy and/or breastfeeding?

- Using a male or **female condom** with lube when you have vaginal sex or anal sex. Using condoms is effective at preventing HIV and other sexually transmitted infections (STIs). Using a female condom may give you more control.
- Engaging in ongoing prenatal care is a way to keep you and your baby healthy. Getting tested and treated for STIs will also reduce your risk of getting HIV. It's important to get tested for HIV and STIs often.
- If you have a partner or partners living with HIV, it is nearly impossible for them to pass on HIV to you if they are taking their antiretrovirals (HIV medications) consistently and maintaining an undetectable viral load.
- Using PrEP (Pre-Exposure Prophylaxis). Talk to your medical provider about the possibility of starting PrEP.
- Using PEP (Post-Exposure Prophylaxis) if you may have been recently exposed to HIV.

## WHAT ARE PrEP AND PEP?

### PrEP (Pre-Exposure Prophylaxis)

- PrEP (pre-exposure prophylaxis) is medication that an HIV-negative person takes to keep from getting HIV.
- Currently, the approved PrEP medication is Truvada.
- PrEP works if taken daily.
- PrEP is an HIV prevention method that gives you choice and control. It can also give you privacy as it does not have to be discussed with your partner(s).
- The decision to take the pill is yours.

### PEP (Post-Exposure Prophylaxis)

- If you have been exposed to HIV recently, there is another option for you. **PEP (post-exposure prophylaxis)** is an emergency medication available by prescription that can stop HIV infection if started within 72 hours of exposure. If you are HIV negative and may have been exposed to HIV within the last 72 hours, go to a clinic or emergency room immediately and ask for PEP.

## Is PrEP Right for Me? Consider PrEP if you are an HIV-negative woman who:

- Worries about getting HIV
- Has sex without a condom with partners of unknown HIV status
- Recently had gonorrhea, chlamydia, syphilis, or a new herpes diagnosis
- Injects drugs and shares needles or works
- Exchanges sex for \$/food/housing/drugs
- Has a male sex partner who:
  - Has vaginal or anal sex with other partners without a condom
  - Has sex with men
  - Injects drugs
  - Has HIV or sexually transmitted infections (STIs)

You and your medical provider can discuss the pros and cons of being on PrEP, as well as other prevention options during pregnancy and breastfeeding.

# BEYOND THE BASICS: MORE ABOUT PrEP

## IS PrEP EFFECTIVE?

PrEP is safe and effective. PrEP can help reduce the chance of getting HIV by over 90% when taken daily.

## WHAT ABOUT SIDE EFFECTS?

Most people tolerate PrEP very well, although Truvada may have side effects. Anyone taking PrEP should be followed by a medical provider. Some people experience nausea when first starting Truvada. Rarely, PrEP causes reversible changes in the kidney. This is why labs are checked regularly while on PrEP. Truvada is usually well tolerated by pregnant women, as well.

## IS PrEP SAFE DURING PREGNANCY?

Engaging in medical care and talking to your provider are essential to good health for you and your baby. If you decide to take PrEP, your baby will be exposed to Truvada. However, the medicines in Truvada have been studied among pregnant women living with HIV and hepatitis B and there is no known increased chance of birth defects, growth problems, or complications during pregnancy, including preterm birth and miscarriage.

## IS PrEP SAFE TO TAKE WHILE BREASTFEEDING?

Research with women taking Truvada as PrEP or as treatment for HIV or hepatitis B suggests that Truvada is safe during breastfeeding. Only a very small amount of Truvada gets into the baby through breastmilk, so babies do not likely experience side effects when their mother is taking PrEP.

## CAN I AFFORD PrEP?

Many insurance companies cover the cost of PrEP. There are also assistance programs for those who qualify. Almost everyone who needs PrEP is able to get it.

## HOW CAN I GET PrEP?

To find a PrEP provider near you, check out [www.PleasePrEPMe.org](http://www.PleasePrEPMe.org)



## FOR PROVIDERS:

In a meta-analysis of 26 articles, no statistically significant differences were observed between tenofovir disoproxil fumarate (TDF - one component of Truvada) and comparison non-TDF regimens in pregnancy incidence, stillbirth/pregnancy loss, preterm delivery less than 37 weeks, low birth weight <2500/<1500 g, small size for gestational age, birth defects, or infant (>14 days) or maternal mortality. A 2018 NEJM study was also reassuring.

Given available safety data, there does not appear to be a safety-related rationale for prohibiting PrEP during pregnancy/lactation or for discontinuing PrEP in HIV-negative women receiving PrEP who become pregnant and are at continuing risk of HIV acquisition.

## Other resources and considerations for providers:

- For resources, provider tools, and more information, visit: [HIVE's Provider Resource page](#) and [HIVE's PrEP4Women page](#)
- Any pregnant woman prescribed an antiretroviral should be added to [the Antiretroviral Pregnancy Registry](#)
- Free 24/7 telephone consultation for providers from the [Clinician Consultation Center](#): (888) 448-8765



# Optional Handout 21: TeenSpeak about Sexual Health

# TeenSpeak

## About Sexual Health



The Real Truth from Real Teens

**NYC**  
Health



Special thanks to the Bronx Teens Connection's Youth Leadership Team

# › What is sexual health?

It's a lot of things. It's knowing how to prevent pregnancy and sexually transmitted diseases. It's knowing where to get health services and understanding your right to confidential care. It's also about learning what it takes to have a healthy relationship.

We're TeenSpeak. We're New York City teens who know how hard it can be to get the help and information you need. We hope this booklet provides answers to your questions about sexual health.

# › TeenSpeak About...

- Relationships ..... 4
- Birth Control ..... 8
- The Right to Sexual Health Services ..... 10
- Sexual and Reproductive Health Services ..... 12
- Sexually Transmitted Diseases (STDs) ..... 14



# › TeenSpeak About...

## Relationships

**Treat** your partner the way **you want** them to treat you.

My man really understands me and **encourages** me to go after **my dreams**.

**Good communication** is important. When you talk with your partner, you **understand** each other better and make the relationship **stronger**.



## › What You Should Know

Whether you're straight or gay, a healthy relationship means you:

- can express yourself honestly, without fear
- make decisions together
- have sex only when you both feel it's right
- feel respected and valued
- feel supported to follow your goals and dreams

Signs you're in an unhealthy relationship include a partner who:

- calls, texts or IMs you constantly
- checks your email without your OK
- embarrasses or insults you in front of other people
- doesn't let you spend time with anyone else
- criticizes the way you look
- threatens to hurt you if you break up

## › Looking for More Info?

- › [nyc.gov](http://nyc.gov) and search for **Healthy Relationship**
- › [loveisrespect.org](http://loveisrespect.org)
- › [dayoneny.org](http://dayoneny.org)



# Which Side Describes



# Your Relationship?

Tells me how smart I am

Tells me I'm not worth anything

Arm my baby holds onto when we walk in the park

Arm that's criticized for being 'too skinny'

Leg my baby touches when we watch TV

Leg that was bruised when I smiled at someone else



# > TeenSpeak About... Birth Control

You should use **both**  
birth control **and** condoms  
**every time** you  
have sex.

The pill, patch and IUD  
are **great ways** to  
**avoid** getting pregnant.

There's a method  
for **you**.  
**Explore** your options.



# › What You Should Know

## Choose birth control + condoms

If your partner is of the opposite sex, use BOTH EVERY TIME to help prevent pregnancy, HIV and STDs.

There are many safe and effective birth control methods. Choose one that's right for you.

Your options	How often you use it	Effectiveness in preventing pregnancy
<ul style="list-style-type: none"><li>• IUD</li><li>• Implant</li></ul>	<ul style="list-style-type: none"><li>• Can be left in place for up to 3–10 years</li><li>• Can be left in place for up to 3 years</li></ul>	<b>99+%</b> effective
<ul style="list-style-type: none"><li>• Shot</li><li>• Ring</li><li>• Patch</li><li>• The Pill</li></ul>	<ul style="list-style-type: none"><li>• New shot every 3 months</li><li>• Leave ring in for 3 weeks, remove for week 4</li><li>• New patch once a week for 3 weeks, no patch for week 4</li><li>• One pill at same time, every day</li></ul>	<b>91-94%</b> effective
<ul style="list-style-type: none"><li>• Diaphragm</li><li>• Cervical Cap</li><li>• Sponge</li></ul>	<ul style="list-style-type: none"><li>• Every time you have sex</li><li>• Every time you have sex</li><li>• Every time you have sex</li></ul>	<b>71 - 88%</b> effective
<ul style="list-style-type: none"><li>• Spermicide</li></ul>	<ul style="list-style-type: none"><li>• Every time you have sex</li></ul>	<b>72%</b> effective

## What is emergency contraception?

- Emergency contraception (often called Plan B) is a pill you take to help prevent pregnancy after unprotected sex or if a condom breaks.
- The sooner you take it, the better it works.
- It prevents pregnancy 9 out of 10 times if you take it within 72 hours after sex.
- Get it now so you can take it when you need it. You can get it over the counter at a pharmacy, no matter how old you are. You can also still get it from your doctor or clinic.

# › Looking for more info?

- › [nyc.gov](http://nyc.gov) and search for **NYC Teen**
- › [nyc.gov](http://nyc.gov) and search for **Condoms**
- › Download the free **Teens in NYC** app on your iPhone or Android
- › [stayteen.org](http://stayteen.org)

# › TeenSpeak About...

## The Right to Sexual Health Services

My boyfriend and I go to the clinic **together**. I'm **glad** he's there, but it's good to know I can go **alone** without anyone knowing.

I know I can go to the clinic on my own, but I wanted to **talk** to my mom about it. She was **great** and **encouraged** me to get health services.

I always thought my parents needed to give the OK to get birth control. I was **wrong**. I **can go myself** to the clinic by **myself** and get it there.



## › What You Should Know

You have a legal right to get any of these health services without the permission or knowledge of your parents, guardians, boyfriend or girlfriend or anyone else:

- birth control
- emergency contraception (often called Plan B)
- pregnancy tests
- HIV tests
- testing and treatment for STDs
- abortion

These services are confidential, meaning that no one at the clinic can tell anyone when or why you were there – unless you say so.

## › Looking for More Info?

› [nyclu.org/TAP](http://nyclu.org/TAP)



# › TeenSpeak About... Sexual and Reproductive Health Services

I was **scared** about going to a clinic. What would they **ask?** I didn't have to be afraid at all. **No one judged** me. The staff listened and **helped** me get the services I needed.

My visit to the **clinic** was nothing like I thought it would be – the doctors were **mad cool** and all of my information was kept **private**.

Through the **Teens in NYC app**, I found out about **so many** teen-friendly **clinics** around the city.



## › What You Should Know

There are many clinics in the city that provide teens with confidential, free or low-cost services, including:

- condoms
- birth control
- emergency contraception (also called Plan B)
- STD testing and treatment
- HIV testing
- pregnancy testing
- abortion

Confidential services mean that no one will know that you attended the clinic or what services you received unless you tell them.

When you go to the clinic, you may be asked for:

- photo ID, like a school ID card
- insurance card, if you have one

**The staff can answer any questions you have about sex, your body, condoms, birth control or STDs.**

When meeting with the doctor, be honest. It's important that the doctor knows everything so he or she can give you the best care.

## › Looking for More Info?

**For a clinic near you:**

- › Download the free *Teens in NYC* app on your iPhone or Android
- › Call **311** or text **311NYC**
- › [nyc.gov](http://nyc.gov) and search for **NYC Teen**



# › TeenSpeak About... Sexually Transmitted Diseases (STDs)

The **best** way to  
**protect** yourself

Sex without a  
condom can be **risky**.  
Even if you don't see  
**bumps** on your  
penis or vagina, go  
**get checked**.



I was really **scared**  
I might have an STD.  
I talked with my girl  
and, together, we  
went to the clinic and  
**talked** to the doctor.  
She helped us **relax**,  
and we **got** the  
**help** we needed.

## › What You Should Know

- You can get an STD, also called a sexually transmitted infection (STI), from any kind of unprotected sex (sex without a condom):
  - vaginal sex (when the penis enters a partner's vagina)
  - anal sex (when the penis enters a partner's anus or butt)
  - oral sex (when you put your mouth on a partner's vagina, penis or anus or butt)
- Chlamydia and gonorrhea are the most common STDs. They're easy to treat. But if left untreated, they can cause serious damage to your body.
- HIV is another serious infection you can get. If you're having sex and don't know your HIV status, ask the doctor for a test.
- Many people with an STD have no symptoms. If you're having sex, get checked – even if you don't feel sick or are in a steady relationship.

If you are having sex, using a condom is the best way to help prevent STDs, including HIV. Use one every time you have sex.

## › Looking for More Info?

### For a clinic near you:

- › Download the free *Teens in NYC* app on your iPhone or Android
- › Call **311** or text **311NYC**
- › [nyc.gov](http://nyc.gov) and search for **NYC Teen**

### For condoms:

- › Download the free *NYC Condom Finder* app on your iPhone, Android, BlackBerry or Windows phone
- › Call **311** or text **311NYC**
- › [nyc.gov](http://nyc.gov) and search for **Condoms**

### To learn more about STDs:

- › [nyc.gov](http://nyc.gov) and search for **NYC Teen**
- › [teenwire.org](http://teenwire.org) and search for **STD**



## For clinics serving teens:

Search **NYC Teen** at [nyc.gov](http://nyc.gov), call **311**,  
download the **Teens in NYC** app or scan here



For more copies, call **311**.





# Optional Handout 22: Parent Guide for Talking to Teens about Sex

# Hey, What Do I Say?

A PARENT TO PARENT GUIDE ON HOW  
TO TALK TO CHILDREN ABOUT SEXUALITY



## Dedication

This booklet is dedicated to the Adult Role Models—past, present, and future—for their commitment to help parents and other caring adults throughout New York City improve their communication about sexuality and build strong relationships with their children.

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# Introduction

Talking to the children in your life about **sexuality** is a lifelong process, and this guide can help you to start or continue that process!

As parents, we know we have all received different messages about sexuality. Some of us may or may not have received education about sexuality from our own parents. Regardless of what we were taught when we were young, it's important to give our children accurate information, along with our family values, in order to help them make healthy decisions about sexuality.

With the high rates of sexually transmitted infections, HIV, and unplanned pregnancy among teens in the United States, we know that children need information about sexual and reproductive health from trusted sources. And with too many potentially untrustworthy sources on TV, in movies, and on the Internet, parents are needed more than ever to be the primary and most trusted sexuality educators of their children. We realize that for some parents, figuring out how to do this can be tricky. That's where the Adult Role Models program comes in.

In 1998, Planned Parenthood of New York City (PPNYC) created the Adult Role Models (ARM) program to help parents learn skills and techniques to keep the lines of communication open with their children about sexuality. As Adult Role Models, we've undergone extensive training that showed us how to speak openly and honestly with our children about sexuality and use techniques to improve communication with our children.

We hope the information, skills, and techniques in this guide will make it easier for other parents and caring adults to share accurate information and their family values with the children in their lives. Talking to the children in your life about sexuality is a lifelong process, and this guide can help you to start or continue that process. Good luck!

— PPNYC Adult Role Models

# Talking to Children about Sexuality...

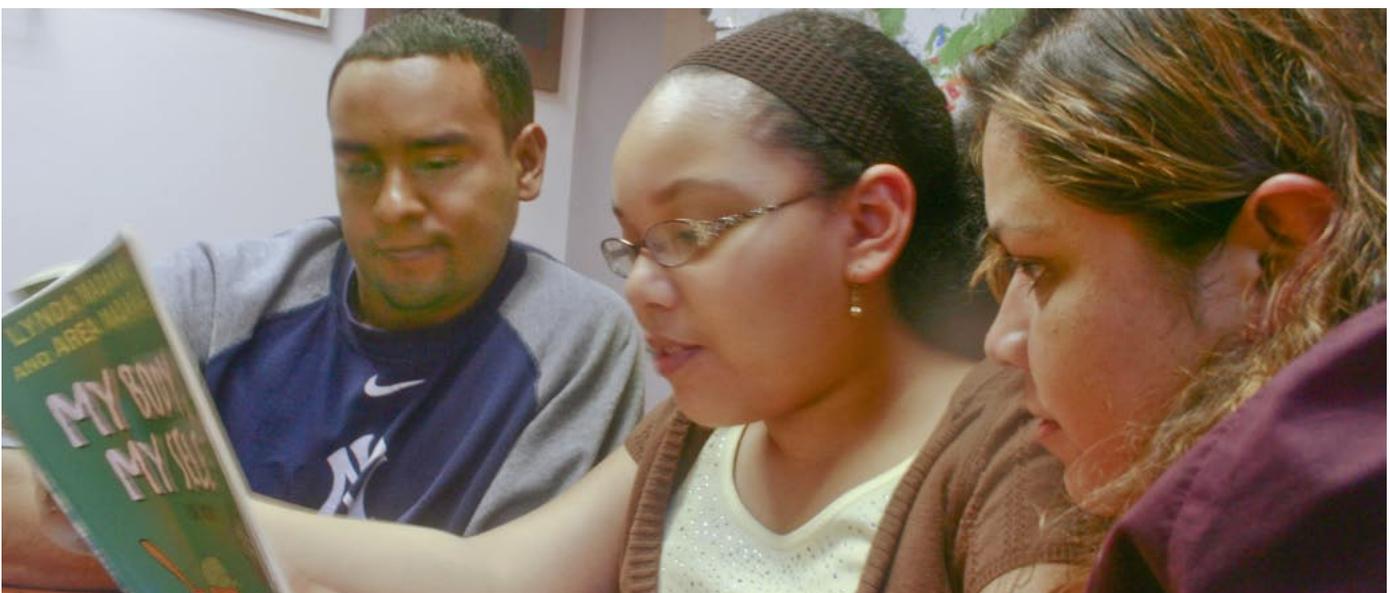
Based on our own experience and what we hear from other parents, the main **barriers** that prevent us from openly talking to our kids about sexuality are:



Whatever the reason that holds us back, the bottom line is that **our children need to have us talk to them about sexuality**. We want to be the ones they come to for advice and guidance. Let's be real: it can be difficult to talk about sexuality in general. Talking to our children about sexuality just takes it up a notch!

So, if you are a parent who is uncomfortable talking about sexuality or a parent who is comfortable but can use some more tips, we are here to share information and techniques to help you get your message across to your children.

This guide answers questions that we've been asked by parents of children who range from infants to adults. You may find that you have some of the same questions or that you can learn something new that will open up the lines of communication even more.



Before we answer some of the most common questions we hear from parents, **we have to clear up some of the myths** that can get in the way of open communication with children about sexuality.



## True or False?

**TRUE OR FALSE: Parents have to know a lot about sexuality before they can begin to talk with their children about it.**

**FALSE!** Although it is great to learn as much as you can about sexuality, you do not need all the answers to begin talking with your children. Just letting your children know they can come to you with their questions and concerns will help them to feel more comfortable talking with you about sexuality, which is a huge step in the right direction.

It is always okay to admit you do not know or are not sure of the answer to a question. After being honest about what you do and do not know, you can look it up and get back to them with an answer. Or better yet, look it up together! On Pages 18–20, we've listed some resources that can help you to find out more information about sexuality, including resources that you and your children can use together.

**TRUE OR FALSE: Talking to children about sexuality will encourage them to have sexual intercourse earlier.**

**FALSE!** We hear this all the time and we can definitely understand parents' concerns about this issue because none of us want to encourage our children to experiment with sexual intercourse early. The good news is that studies have shown that when parents talk with their children about sexuality—providing accurate information and sharing their values—their children are **more likely to delay sexual intercourse and use protection when they do have sex.**

## True or False?

In fact, our conversations with our children about sexuality should go beyond how to take care of one's body, how to abstain from sex, and how to use protection. They should also include:

- The importance of feeling good about oneself.
- How to have healthy, respectful relationships.
- Clear messages from you about your values and expectations about sexual decisions.

With this information, our children are better prepared to resist peer pressure and other influences and to make healthy decisions.

**TRUE OR FALSE: Children want to talk to their parents about sexuality.**

**TRUE!** Young people **do** want to talk to their parents about sexuality; many just fear their parents' reaction. (Think for a moment about when you were in their shoes.)

As a parent, you can help your children to feel comfortable talking to you about sexuality by answering their questions openly and honestly. It is important for you to use a calm, encouraging tone of voice, to be patient, and to be willing to listen, even if you are shocked by what they say.

Still don't believe us? In a recent survey by The National Campaign to Prevent Teen and Unplanned Pregnancy, teens said that parents (not friends or the media) **most** influence their decisions about sex! That's great news.

**TRUE OR FALSE: Teens who ask their parents questions about sex are probably sexually active.**

**FALSE!** Not necessarily so. Many teens ask questions about sex because they are curious and want to know their parents' views and values.

We know that messages about sex are everywhere: television, movies, videos, the Internet, and music. Often the messages that teens receive from the media and other sources are unrealistic, unhealthy, or confusing. Trust us: you probably have different values than those you see in many of the music videos and talk shows on daytime TV. If you don't know what we mean, sit through a few music videos and talk shows—you'll get the point!

So, when your child asks you a question about sex, try to remain calm (take a deep breath if you have to) and resist making assumptions or jumping to conclusions. Many teens say that the biggest barrier to talking to their parents about sex is that they think their parents will assume that they are sexually active. Don't make that mistake.

# Questions and Answers

Here they are—the **12** most common questions that parents ask about how to talk to kids about sexuality.

## 1. When should I start talking to my child about sexuality?

You may not realize it, but you have probably already given your child a lot of information about sexuality. Giving a child information about his/her body and what it means to be a boy or girl is talking about sexuality! Sexuality is related to much more than you may think, including:

**Anatomy and reproductive health**—Biological sex, puberty, menstruation, contraception, safer sex, sexually transmitted infections (STIs), HIV, pregnancy, childbirth, hygiene, and general health care.

**Gender identity and gender role**—How we see ourselves as male or female, and how we're taught that men and women should act.

**Relationships**—Behaviors, expectations, satisfaction, and abuse.

**Love and affection**—How we express love and affection to friends, family, and romantic partners.

**Body image**—How we feel about our bodies, how we treat our bodies, and how attractive we feel.



## Values

Our values are personal beliefs that affect how we think, feel, and act. Values can change over time with new knowledge and life experiences.

Some values that we want to teach our kids may come easy to us because we feel strongly about them, while others may need more thought. One way that you can start to think about your values is to look at the definition of sexuality in Question 1 and come up with a value that you would like to teach your children for each component of sexuality.

**Sexual orientation**—Physical and emotional attraction to a man, woman, or both.

**Sensuality and pleasure**—Accepting and enjoying our own bodies and accepting and enjoying the bodies of our sexual partner(s).

**Sexual activity**—Acts of intimacy such as hugging, kissing, touching, and sexual intercourse.

You may have already started speaking with your children about at least a few of these components of sexuality. It's important to remember that **sexuality is more than just sex and that each component is equally important**.

As your child becomes older, you will continue to teach him or her about sexuality, through role-modeling and verbal communication as well as body language.

For example, if your child starts playing with his or her genitals while sitting on the toilet, how you respond sends a message that may affect his or her body image in a positive or negative manner. If you get upset or show anger, your child may get the idea that the genitals are a bad or dirty part of the body.

After considering all that makes up sexuality, it is easy to see how talking and teaching about sexuality is a lifelong process. Talking with your children about sexuality should not be limited to a one-time event. Keep reading and you'll find more tips and techniques to help you to effectively communicate the information and values that you want your child to learn.

## 2. How do I answer my child's questions about sexuality?

One of the great things about teaching our children about sexuality is that they often keep us on our toes by asking questions. When your child asks you a question, try to remain calm and answer the question. By remaining calm and **not avoiding** the question, you are sending your child the message that you are open to talking about sexuality. This will enable your child to become comfortable talking with you about sexuality and to continue to come to you for answers.

A lot of parents worry more about exactly what they will say when asked a sexuality question, instead of **how** to say it. Your tone is just as important, if not more so, than what you say. A child will more vividly remember your warm, welcoming tone than the content of what you said.

When answering your child's question, be sure to give your child **accurate information** while also letting him or her know your **views and values**. When you think about it, who could be better to teach your child values about sexuality than you!



Keep your answers brief and uncomplicated. Start with a simple answer and give your child more information if he or she continues to ask more questions. If you happen to ramble (as we tend to do when caught off guard) or give your child incorrect information, you can always go back and clarify. And remember, if you don't know the answer, it's okay to admit you don't know, then look it up, and get back to your child. Teaching your child about sexuality is an ongoing process.

Here are four basic steps for answering your child's questions about sexuality that we suggest and have regularly used ourselves. These steps will help you to give your child the right amount of information and share your views and values. In addition, these steps give you some stalling time so that you can communicate effectively.

**STEP 1. Normalize and validate the child's question and then ask the child why he or she is asking you this question:** "That's a really good question. How come you're asking that today?" This step reassures the child that his or her question is normal. It will also give you a sense of what caused your child to ask that question and where he or she is getting information (Did he or she see something or hear something? Who was involved?).

**STEP 2. Ask your child what he or she thinks the answer is:** "What do you think?" This gives you an idea of what your child already knows and the sort of language he or she uses to express it.

**STEP 3. Answer the question honestly based on the child's response and your values.** Take advantage of the opportunity to introduce your views and values as well as to give your child honest, accurate information about his/her question.

**STEP 4. Ask the child if he or she understands the answer:** "Does that answer your question?" This step allows a parent to make sure the child understood the answer. Try different words or resources if your child doesn't understand the first time.



## The Four Steps Really Work!

I was walking through my house... and out of nowhere my daughter says to me “Mom, do you get horny?” I wanted to keep walking, but I stopped and did the 4 steps with her.

The first question broke the ice: “Why are you asking that question today?” She began to explain that her friends are always saying they are horny and that she didn’t feel that way. She wondered if there was something wrong with her. After I knew where she was coming from, we were able to have a great talk and I was able to reassure her and share my values with her.

— Crystal

We suggest that you also use “Teachable Moments” to educate your child about sexuality. Teachable Moments are everyday opportunities that can be used to talk to our children about sexuality and other tough topics without seeming obvious. During Teachable Moments, you may come across issues related to sexuality and then engage your child in conversation while:

- Watching television and movies
- Listening to music
- Looking at an Internet site
- Talking about personal experiences and other people’s experiences (family members, friends, etc.)
- Reading the newspaper or magazines

The most important part of Teachable Moments is asking your child what he or she thinks about a sexuality issue and then being ready to listen! That way, you can share your thoughts and values with your child after hearing what he or she thinks.

Here’s an example of how you can use a Teachable Moment. You and your pre-teen child are watching a television show. In one scene the characters are passionately kissing and, bam, they end up having sex. During a commercial or after the show is over, you can start a conversation with your child by asking **what he or she thinks** about the couple having sex. Then you can follow up with one or two more specific questions such as:

Do you think that situation was realistic?

Do you think they were ready to have sex?

How do you think having sex might affect their relationship?

What are some of the consequences that they may have to deal with?

Did they protect themselves against unplanned pregnancy and/or sexually transmitted infections?

Did the couple know each other well enough to have sex?

Did they act responsibly?

Do you believe that only people who are in love or married should have sex?

## They just might ask...

If your child hasn't asked you a sexuality question, chances are he or she will. In addition to using the four steps to answer your child's questions, you may want to think in advance about your answers to some of the common "kid" questions.

For example: Where do babies come from? What's sex? Do you have sex? Why do boys and girls look different? Why is my body different from yours? If these questions make you anxious, there are a lot of resources available for parents that can help you to simplify information for your child according to his/her age or stage of development. *See our list of resources on Pages 18–20.*

In my culture, we never used the word "vagina." However, after my ARM training, I realized how important it was to use the proper terms and to teach my daughter to do the same. After I became an ARM, my mom participated in one of my workshops and now she knows why proper terms are important and she uses them with my daughter too!

—Luz

*For more on Teachable Moments, see # 6 in Questions and Answers on Page 10.*

After you have listened to your child's thoughts and feelings, you can then share your thoughts concerning the situation, including your values on sexual activity and dating. Many times during a Teachable Moment, parents will realize they have a lot in common with their children, and often a parent will simply need to affirm his/her child's thoughts and feelings because their values are already in agreement.

### 3. Aren't words like "penis" and "vulva" too complicated for pre-schoolers to understand?

No, the words "penis" [PEE-niss] and "vulva" [VUL-vah]\* really aren't that complicated for children to understand. The fact is, we teach our children even more complicated words such as "stomach" and "shoulders." We tend to feel less comfortable talking about the genitals compared to other parts of the body because we relate genitals to sex. Really, **genitals are just another part of the body.**

Teaching your children the correct names for their genitals gives them a couple of advantages. First, it encourages a healthy and positive attitude toward their body. Secondly, because nicknames for genitals tend to be specific to the family ("pee-pee," "wee-wee," and "down there" to name a few), teaching your children the correct names for their genitals will give them language they can use to express themselves clearly. This becomes particularly important in a medical situation and in reports of abuse.

*\*The "vulva" is the entire area of a female's genitals. Although the vulva is commonly called the "vagina," the vagina is actually the canal stretching from the vaginal opening to the cervix.*

### 4. Should I talk to my girls and boys differently about sexuality?

Both boys and girls need the **same important information** to become healthy adults. It is important for both boys and girls to understand their own body's development as well as the development of the other sex.

Both boys and girls also need to know that sexual feelings are normal, how to take care of their bodies, how to protect themselves from disease and unplanned pregnancy, and how to have healthy, respectful relationships. Both boys and girls can become infected with a sexually transmitted infection, including HIV. They can also both experience the stresses and consequences of an unplanned pregnancy or an STI. **The more information your children have, the more choices are available to them to stay safe.**



One parent in a workshop thought that her young son was watching “sex movies” on TV because he was waking up with an erection every morning. I was able to explain to her that it was just a normal part of development that her son was experiencing. She was relieved, and I felt good that I could help her and know that she would be able to support her son through his sexual development.

— Bernice

## 5. What’s the harm in telling children myths about where they come from? Don’t we tell them “myths” about Santa Claus and the Tooth Fairy?

Let’s think about myths—they’re false or half-accurate information that can create confusion or fantasies. As your child’s most important and first sexuality educator, you want to provide your child with actual facts so that he or she will see you as a [reliable source of information](#).

Santa Claus and the Tooth Fairy are fairy tales that can be fun for both parents and children. These myths [cannot](#) lead to health consequences such as unplanned pregnancy or sexually transmitted infections; but lack of information about sexuality [can](#).

## 6. My child avoids conversations about sexuality. How can I make my child comfortable talking to me about sexuality?

Some children feel uncomfortable talking about sexuality, and that’s okay. In order to create a comfortable environment without seeming pushy, you may want to talk with your child about something that interests him or her and relate that topic to sexuality.

We also recommend that parents [take advantage of the Teachable Moments mentioned previously](#), such as listening to music, watching television, looking at Internet sites, etc., to start a conversation about sexuality and to keep the lines of communication open. To use a Teachable Moment, find issues that are relevant to your child. Then [ask](#) your child to share his or her feeling about the issue by asking, “What do you think about that?” Teachable Moments can help you to find out your child’s views and will give you the opportunity to share your own thoughts and values in a more subtle way. Most importantly, you want your child to know that you are approachable and open to discussions about sexuality.

## Other Important Tips for a Successful Teachable Moment

- Show interest in his or her thoughts and feelings.
- Avoid distractions when listening to and speaking with your child.
- Don't interrupt when your child is speaking to you.
- Try not to react by getting angry or upset or by making assumptions.
- Answer your child's questions openly and honestly.
- Keep the conversation private if your child asks you to do so.
- Don't give up. Every time you try, it sends the message that you care and are open to talking about sexuality.

For pre-teens, body image is so important. So many of my daughter's classmates have begun to menstruate and develop breasts that my daughter began to worry that there was something wrong with her. Although we would like our children to appreciate their uniqueness, I could understand her concern. I used magazines and books to illustrate how bodies develop differently and encouraged her to appreciate the beauty of her body going through its changes.

— Sandra

## 7. My child is starting to develop. How do I help my child to deal with puberty and body changes?

Preparing children for puberty before they begin to develop makes it easier for them to make the transition. It also helps you to get in touch with the fact that one day your “baby” will start to look more like an adult.

But, if your child has already started to develop, we recommend that you let him or her know that **the process is normal and healthy**, and that **each person develops at his or her own pace**. You may have to repeat this a few times because kids' self-esteem can be very fragile at this age. You want to make sure that you give your child information about the changes he or she is going through and what to expect at each stage of development. If you don't feel confident guiding your child through puberty on your own, there is a lot of information available through libraries, videos, and the Internet. *(See Pages 18–20 for a list of resources.)*

Another way that you can help your child to deal with the changes of puberty is to **avoid teasing** or publicly commenting about your child's body changes (and also instruct other family members to do the same). Teasing and public comments can cause embarrassment, shut down future communication with your child, and affect your child's self-esteem.

Try to remember how you felt during puberty. We encourage parents to take off their “adult glasses” when communicating with their children about puberty and other sensitive sexuality topics. Try to see their questions and experiences through their eyes and in the context of their age and stage of development. If we don't take off the “adult glasses,” we may forget that their worries about puberty and body changes are perfectly normal and appropriate for their age.

Lastly, be prepared for your child to experience a range of emotions and interact with you differently during puberty and adolescence. Some kids withdraw a bit, some express very intense emotions, and others go back and forth. You may feel that you do not even recognize your own child! This is a time when your child will be adjusting to physical changes as well as developing his or her own identity and testing limits (although this can be a pain in the you-know-what, it is totally normal).

Continue to talk to your child about his or her feelings and experiences, because it is important that you remain connected to what's happening in his or her life. And, remember, even if your child is trying to pull away, don't take it personally.

When my oldest daughter had her first kiss, at fourteen years old, she talked to me about it. I was really glad to see that she felt comfortable enough to confide in me. She shared with me how she felt both physically and emotionally. I took advantage of that moment to talk with her about kissing and relationships. Looking back, I realize how important it is to have open communication with your children about sexuality.

— Wanda

On one occasion I walked into my bedroom to find my nine-year-old masturbating on my bed. We were both surprised; she because I found her and I because I didn't think she was masturbating yet. Later, I explained that masturbation is normal, but needs to be done in the privacy of her room.

— Luz



## 8. My child has had a “first kiss.” How do I talk to my child about relationships and setting boundaries?

Although it may set off an alarm in parents, it is perfectly normal for young people to begin experimenting with kissing and touching. As parents, we can help our children to deal with the emotions involved in receiving and giving affection and setting boundaries.

We recommend that you begin by having a conversation with your child about the feelings that go along with kissing. Ask your child, with an **open mind**, how the kiss made him or her feel. This is a good time to introduce your values concerning kissing, touching, and relationships. You may want to help your child practice what he or she can do and say in different situations to set limits. For example, ask your child: “If your friend wants to do more than kissing, how would you handle that?” Again, **an open mind makes for an open conversation**.

## 9. How do I encourage my children to abstain from sex when there is so much pressure around them to have sex?

As parents, this can be an intimidating issue for us...but we don't have to feel defeated. Parents are powerful. Sometimes we just have to remind ourselves that **we do influence our children**.

So, even though there is pressure out there to have sex, your message can sink in. Recent studies have shown that when parents give clear messages about delaying sex, their children are more likely to postpone sexual intercourse.

Here are some steps that you can take to encourage your children to abstain from sex:

**Be open-minded.** Ask your child his or her opinion, and then be prepared to listen! Try to resist the urge to lecture. Instead, have ongoing two-way discussions with your

## Here are a few suggestions for how you can get to know your child's friends and their families:

- Make sure that you are always around when your children's friends are visiting, and get to know them by talking with them.
- Invite your children's friends to family gatherings.
- Invite the parents of your children's friends to your children's parties.
- Drop your children off and/or pick them up when they visit their friends so that you can get to know their friends' parents. As your children get older, they may beg you not to drop them off because they feel embarrassed. If this is the case, consider allowing them to call you when they get to where they are going and when they are leaving.
- Before your child visits a new friend, call the friend's home to introduce yourself to the parents or guardians. During your conversation, you can talk about what you're comfortable or uncomfortable with when your child visits their home or goes out with their child.

For example, you can mention what time you would like your child to return home, you can ask whether a parent or adult will be around during the visit, and you can exchange phone numbers. Most parents will appreciate your call because they probably want to get to know the parents of their children's friends as well.

children about your values, expectations, and how to have healthy, respectful relationships. Your children may be facing the pressure to have sex to keep their partners or to make them feel mature or even accepted among their peers. Ask questions and create Teachable Moments in order to talk to them about these issues.

It is also important to understand and accept that many children may choose to have sex during their teen years. For this reason, it is essential to discuss safer sex methods like condoms to protect against sexually transmitted infections and birth control methods to protect against unplanned pregnancy.

**Be aware of your child's whereabouts and activities.** Now, that doesn't mean strap an electronic monitoring device on your kids (although secretly some of us would like to if we could get away with it). It means know where your children are and whom they are with when they go out. Make sure that there is responsible adult supervision if they are visiting a friend. It's a good idea to have their friends' home and cell phone numbers.

Monitor them when they are on the Internet and ask them to tell you about who they communicate with and what sites they visit. Keep in mind that even if you block sites at home, kids can access the Internet at a friend's house or at the library. It's important to let your child know your expectations concerning Internet use.

**Become familiar with your child's friends and their families,** particularly if there is a "love interest." Since children can have a strong influence on each other, you want to make sure that your children's friends and their parents share your values or at least respect your values and expectations for your children.

**Encourage your child to avoid dating someone much older.** Try to set a limit of no more than two to three years difference. Dating an older teen or adult can seem very "cool" to both girls and boys. There is often glamour associated with attracting someone significantly older, and an older person will tend to have more money and material possessions such as a car or apartment.

However, research shows that when a pre-teen or teenager is dating someone at least two years older, the older person has more power in the relationship and it is much harder for the younger person to stand firm on a decision to abstain from sex or to practice safer sex.\*

*\* "Safer sex" refers to using condoms and dental dams (a rectangular sheet of latex) to protect yourself and your partner from HIV and other sexually transmitted infections that can be contracted during sexual activity such as oral, anal, or vaginal sex. It can also refer to using birth control methods to avoid unplanned pregnancy.*



**Help your child to develop self-confidence and goals.** Studies have shown that children are more likely to abstain if they have high self-esteem and goals for the future. Acknowledge the ways in which your children are special and wonderful, help them to develop their talents and skills, emphasize the importance of education, encourage them to take healthy risks like trying out for a sports team or running for student government, and work with them on a plan to achieve their goals.

**Be a role model.** Children learn not only from the information we give them, but also from our example. Our children observe our actions on a regular basis; it's like having a surveillance camera on you at all times! So, be mindful that your actions reflect the values that you want your children to have.

## **10. How can I tell my teen to wait to have sex until he or she is older when I was sexually active as a teen?**

Regardless of what we did when we were young, we have to help our children get the information they need to make their own decisions about sexual activity. Some parents feel comfortable sharing their experiences when they were teens to highlight a particular message and communicate a family value.

For example, one parent may say: "When I was your age, I waited until I was in a loving and trusting relationship to have sex and we used condoms and birth control every time. If you decide to have sex, I hope you will talk to your partner about how you will both protect yourselves from pregnancy and STIs." Another parent with a different value may say: "I regret having sex in high school. If I could do it again, I would wait until I was in college and felt more secure about myself. I would like you to wait until after you graduate from high school to have sex."

## Some reasons why teens don't use birth control or practice safer sex...

“don't feel at risk”

they're misinformed

can't easily get protection

“get caught in the heat of moment”

“don't like condoms”

can't talk to partner

Other parents do not feel comfortable sharing a personal story, and that is okay as well. In fact, it is perfectly fine to tell children “That’s a personal question” if they ask you directly about your sexual experiences. Whether or not you feel comfortable telling your child when you became sexually active, sharing your hopes and expectations about sexual activity for him or her will still send an important message to your child. Always remember to encourage your children to come to you with concerns about the sexual decisions they face.

You can also help your children to brainstorm ways to talk with their romantic partners about delaying sex or about safer sexual activity. It is important that you provide your children with support to avoid unplanned pregnancy and sexually transmitted infections. [Talking to our children about safer sexual activity does not encourage them to have sex.](#) It keeps them safe from STIs and protected against unplanned pregnancy whenever they choose to have sex.

### 11. I know my child is sexually active. How do I bring up “safer sex” and pregnancy prevention without putting my child on the defensive?

Regardless of whether your children are sexually active or not, it’s important to speak with them about safer sex. Be subtle: try bringing up the conversation without asking about their current behavior. You can do this by using a Teachable Moment to find out how much your child knows about using protection. Once you know how much information your child has, you can fill in the gaps.

Make sure he or she knows where to get safer sex supplies, birth control, and sexual and reproductive health services. Offer to go with your child to a sexual and reproductive health center. And remember that educating our children about protection goes beyond giving them information about safer sex and birth control. It also includes teaching them about their responsibility and how to feel comfortable and confident talking to their partners about using protection.

### 12. I talk to my child about using protection and being safe. Yet, I know that my child is not using protection. What can I do?

First, find out why your child is not using protection. There are many reasons why teens, or people in general for that matter, don’t use birth control or practice safer sex.

Some of the more common reasons: they don’t feel at risk, they are misinformed, they are not committed to practicing safer sex or using birth control, they cannot easily get methods of protection, and they are not able to talk to their partners about using protection. Also, some people will say that they get “caught in the heat of the moment” or that they “don’t



like condoms.” Depending on the reason why your child is not using protection, you may want to use one of these strategies:

- Share factual information with your child, such as the rates of unplanned pregnancy and STI and HIV infections among teens.
- Share the experiences of young people who have suffered consequences from having unprotected sex.
- Make sure your child is familiar with safer sex methods, birth control, and emergency contraception\* and can get them easily. You may want to keep a supply of condoms in a place in your home where your child will not have to ask for them.
- Talk to your child about what gets in the way of discussing protection with his or her partner. Don’t hesitate to get help from a professional if you get stuck. For instance, Planned Parenthood of New York City provides counseling on safer sex and birth control options that includes suggestions about how to talk to one’s partner about using protection.

Finally, you may also need to call on the support of other family members and people who are important to your child. Sometimes receiving the same message from a different messenger can make a big difference!

*\* “Emergency contraception” is a type of hormonal birth control that is taken up to five days after unprotected sex, but before pregnancy occurs, to help prevent a pregnancy from occurring.*

# A Few Last Words

Don't beat yourself up if you don't feel comfortable talking to your children about sexuality right away. It doesn't happen overnight—it's an ongoing process.

Always remember that talking to your children about sexuality is an opportunity to share your views and values with them, to stay involved with what's going on in their lives, and to help them to grow up healthy. Children want to know about sexuality, and they want to learn about it from you!

We have found the information and techniques that we have included in this guide to be helpful to our families, and we hope that you will also find them helpful in conversations with the children in your life.

But don't let this be the end of your search for information on how to talk to your children about sexuality. Take a look at Pages 18–20 for more resources. You can also turn to a trusted friend or family member who has been successful in talking with his or her children about sexuality. We can all learn from each other. Good luck!





# Where To Go For Help

## Telephone, Internet, and Print Resources

### Telephone Lines:

Planned Parenthood of New York City's  
Appointment Line  
**212-965-7000**

Planned Parenthood National Appointment  
Hotline  
**800-230-PLAN**  
**(800-230-7526)**

HIV/AIDS Hotline  
**800-TALK-HIV**  
**(800-825-5448)**

Hetrick Martin Institute  
**212-674-2400**  
(services for gay and lesbian youth)

Sexually Transmitted Diseases (STD)  
Information Line  
**212-427-5120**

National STI Resource Center Hotline  
**800-227-8922**

Safe Horizon (Domestic Violence) Hotline  
**800-621-HOPE (4673)**  
**or 212-577-7777**

NY Child Abuse Hotline  
**800-342-3720**

### Websites:

**[www.ppnyc.org](http://www.ppnyc.org)**  
Planned Parenthood of New York City

**[www.plannedparenthood.org](http://www.plannedparenthood.org)**  
Planned Parenthood Federation of America

**[www.pflag.org](http://www.pflag.org)**  
Parents, Families, and Friends of Lesbians and  
Gays

**[www.thenationalcampaign.org](http://www.thenationalcampaign.org)**  
The National Campaign to Prevent Teen and  
Unplanned Pregnancy

**[www.advocatesforyouth.org](http://www.advocatesforyouth.org)**  
Advocates for Youth

**[www.siecus.org](http://www.siecus.org)**  
Sexuality Information and Education Council  
of the United States

**[www.familiesaretalking.org](http://www.familiesaretalking.org)**  
Sexuality Information and Education Council  
of the United States

**[www.tnpc.com](http://www.tnpc.com)**  
The National Parenting Center

**[www.talkingwithkids.org](http://www.talkingwithkids.org)**  
Children Now and the Kaiser Family Foundation

**[www.neahin.org/canwetalk/index.html](http://www.neahin.org/canwetalk/index.html)**  
National Education Association Health  
Information Network

### Print Resources:

*Beyond the Big Talk: Every Parent's Guide to Raising Sexually Healthy Teens from Middle School to High School and Beyond.* Debra W. Haffner. New York, NY: Newmarket Press, 2001.

*Body Drama: Real Girls, Real Bodies, Real Issues, Real Answers.* Nancy Redd. New York, NY: Gotham, 2007.

*Everything You Never Wanted Your Kids to Know about Sex (But Were Afraid They'd Ask): The Secrets to Surviving Your Child's Sexual Development from Birth to the Teens.* Justin Richardson and Mark Schuster. New York, NY: Three Rivers Press, 2004.

*From Diapers to Dating: A Parent's Guide to Raising Sexually Healthy Children.* Debra W. Haffner. New York, NY: Newmarket Press, 2004.

*It's Not the Stork! A Book about Boys, Babies, Bodies, Families, and Friends.* Robie Harris. Cambridge, MA: Candlewick Press, 2006.

*It's Perfectly Normal: A Book about Changing Bodies, Growing Up, Sex, and Sexual Health.* Robie Harris. Cambridge, MA: Candlewick Press, 1996.

*It's So Amazing! A Book about Eggs, Sperm, Birth, Babies, and Families.* Robie Harris. Cambridge, MA: Candlewick Press, 2002.

*Our Daughters and Sons: Questions and Answers for Parents of Gay, Lesbian, and Bisexual People* (booklet). Washington, DC: Parents, Families, and Friends of Lesbians and Gays, 2006. Available at [www.pflag.org](http://www.pflag.org).

*Parent Power: What Parents Need to Know and Do to Help Prevent Teen Pregnancy*. Washington, DC: The National Campaign to Prevent Teen and Unplanned Pregnancy, 2001. Tel: 202-478-8500. Also available at [www.thenationalcampaign.org](http://www.thenationalcampaign.org).

*Sexuality: Your Sons and Daughters with Intellectual Disabilities*. Karin Melberg Schwier and David Hingsburger. Baltimore, MD: Paul H. Brooks Publishing Company, 2000.

*Talking Back: Ten Things Teens Want Parents to Know about Teen Pregnancy* (pamphlet). Washington, DC: The National Campaign to Prevent Teen and Unplanned Pregnancy, 1999. Tel: 202-478-8500. Also available at [www.thenationalcampaign.org](http://www.thenationalcampaign.org).

*Ten Tips for Parents to Help Their Children Avoid Teen Pregnancy* (pamphlet). Washington, DC: The National Campaign to Prevent Teen and Unplanned Pregnancy, 2008. Tel: 202-478-8500. Also available at [www.thenationalcampaign.org](http://www.thenationalcampaign.org).

*The Subject Is Sex*. Pamela M. Wilson, Marcia Quackenbush, and William M. Kane. Santa Cruz, CA: ETR Associates, 2001. Tel: 800-321-4407.

*Third Base Ain't What It Used to Be: What Your Kids Are Learning about Sex Today—and How to Teach Them to Be Sexually Healthy Adults*. Logan Levkoff, M.S. New York, NY: New American Library, 2007.

*What Every 21st-Century Parent Needs to Know: Facing Today's Challenges with Wisdom and Heart*. Debra W. Haffner. New York, NY: Newmarket Press, 2008.

*What's Happening to My Body? Book for Boys: A Growing-up Guide for Parents and Sons*. Lynda Madaras. New York, NY: Newmarket Press, 2000.

*What's Happening to My Body? Book for Girls: A Growing-up Guide for Parents and Daughters*. Lynda Madaras. New York, NY: Newmarket Press, 2000.

*With One Voice 2007: America's Adults and Teens Sound Off about Teen Pregnancy*. B. Albert. Washington, DC: The National Campaign to Prevent Teen and Unplanned Pregnancy, 2007. Tel: 202-478-8500. Also available at [www.thenationalcampaign.org](http://www.thenationalcampaign.org).

**For additional resources in Spanish, flip this guide over.**

**Print Resources Available from Planned Parenthood Federation of America**

**Tel: 877-478-7732 Website: [www.ppfastore.org](http://www.ppfastore.org)**

*How to Talk with Your Child about Sexuality: A Parent's Guide* (pamphlet)

*The Facts of Life: A Guide for Teens and Their Families* (pamphlet)

*Human Sexuality: What Children Need to Know and When They Need to Know It* (pamphlet)

## ABOUT PLANNED PARENTHOOD OF NEW YORK CITY

At Planned Parenthood of New York City, we have more than 90 years of experience providing high-quality sexual and reproductive health services and education in a safe, supportive environment. We offer services to women, men, and teens, regardless of age, income, or immigration status. For confidential appointments at our health centers located in Brooklyn, Manhattan, and the Bronx, call [212-965-7000](tel:212-965-7000) or [800-230-PLAN](tel:800-230-PLAN).

### VISIT PPNYC ON THE NET!

Check out our website, [www.ppnyc.org](http://www.ppnyc.org), to find out about sexual and reproductive health topics.

You can also follow us on our blog, <http://unratedunfiltered.com>, and on [Facebook](#), [MySpace](#), [Twitter](#), and [YouTube](#).

### ADULT ROLE MODELS (ARM) PROGRAM AT PPNYC

In the ARM program, PPNYC trains local parents to lead workshops for other parents and caring adults on how to talk with their children about sexuality. The ARM program operates in the Bronx, Manhattan, and Brooklyn. For more information about it, call [212-274-7362](tel:212-274-7362) or e-mail us at [ppnycadultrolemodels@ppnyc.org](mailto:ppnycadultrolemodels@ppnyc.org).

### FOR MORE INFORMATION, CONTACT

Planned Parenthood of New York City  
Margaret Sanger Square  
26 Bleecker Street  
New York, New York 10012-2413  
Tel: 212-274-7200  
Fax: 212-274-7300  
[www.ppnyc.org](http://www.ppnyc.org)



# Optional Handout 23: Coming Out Transgender

# TRANSGENDER VISIBILITY: A GUIDE TO BEING YOU



HUMAN  
RIGHTS  
CAMPAIGN  
FOUNDATION

“ Remember, there’s no right or wrong way to be yourself or live openly and authentically. You decide how, where and when based on what’s right for you. ”



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# Welcome

**From the time they are born, children are taught that there are girls and there are boys. But our history books, like our communities, are rich with people who have blurred, blended or crossed those lines.**

While gender is traditionally presented to us as either male or female — mutually exclusive and unchangeable opposites — the truth is that gender is a rich, broad spectrum that comes in as many forms as there are people.

For many, expressing gender is unconscious. It's as simple as styling your hair or tying a tie. It causes no angst or uncertainty.

But for those whose gender identity or innate sense of their own gender doesn't match with that assigned to them at birth, unraveling and expressing it can be complex and difficult.

Many of these individuals come to identify as "transgender," an umbrella term that describes a wide range of people who experience or express their gender in different, sometimes non-traditional ways.

Those of us who identify as transgender must make deeply personal decisions about when and even whether to disclose and be open about who we are with ourselves and others — even when it isn't easy.

We express that openness by being our full and complete selves among our friends, our family, our co-workers and, sometimes, even strangers.

Each of us makes decisions about meeting this challenge in our own way and in our own time. Throughout the process of self-discovery and disclosure, you should always be in the driver's seat about how, where, when and with whom you choose to be open.

This guide aims to help you and your loved ones through that process in realistic and practical terms. It acknowledges that the experience of coming out or disclosure covers the full spectrum of human emotion — from paralyzing fear to unbounded euphoria.

The Human Rights Campaign Foundation hopes this guide helps you meet the challenges and opportunities that living as authentically as possible can offer to each of us.

## **A Special Note**

No resource can be fully applicable to every member of the lesbian, gay, bisexual and transgender community. Beyond this general guide, the Human Rights Campaign Foundation has published *Transgender Americans: A Handbook for Understanding*, with the supporting partnership of the National Center for Transgender Equality and the Transgender Law & Policy Institute. The handbook offers a more comprehensive look at the many issues faced by transgender Americans. Download it by visiting [www.hrc.org/transgender](http://www.hrc.org/transgender).

The National Center for Transgender Equality also offers a range of resources at [www.nctequality.org](http://www.nctequality.org) that can help transgender people and their friends, family and co-workers wherever they are on the path to understanding and acceptance.

The Human Rights Campaign Foundation's other resources include materials specifically designed for transitioning in the workplace, coming out in places of worship and coming out in African-American, Latino/a and other communities. See [www.hrc.org](http://www.hrc.org).



# Being Open with Yourself

**From birth, most of us are raised to think of ourselves as fitting into a certain mold. Our culture and often our families teach us that we are “supposed to” look, act and carry ourselves in certain ways.**

Few of us were told that we might have a gender identity that differs from the body into which we were born or that we might feel compelled to express our gender in ways that aren't traditionally associated with the gender we were assigned at birth.

That's why so many of us are scared, worried or confused when facing these truths in ourselves. We can spend a lifetime attempting to hide it, hoping against hope that it's not true or that it might someday simply go away.

There is no one moment when it's “right” to be open with yourself. Some transgender people have long struggled to live the lives they think they're supposed to live instead of the lives they know they were meant to live. And some come to question or recognize their gender identities and expressions suddenly.

Transgender people come out during all stages and walks of life — when they're children or teens; when they're seniors; when they're married, when they're single; when they have children of their own.

Some transgender people come out simply by having the courage to be different. This can range from women who express themselves in traditionally masculine ways to men who do things that are generally considered feminine. For them, there is often no question of disclosure. They live openly and authentically by simply embracing their difference.

Some transgender people may feel little need to disclose themselves to others. Some cross-dressers, for example, may only express this aspect of themselves in private, considering it a fulfilling and beneficial part of their personalities.

Other transgender people may have a sense of gender that does not match the sex they were assigned at birth. Whether by asking friends, family and co-workers to call them by another name and pronoun, or by undergoing medical transition, disclosure to others is both critical and stressful.

Given the diversity among transgender people, there's no single rule to be applied as to whether a person will or even should disclose this aspect of themselves to others.

But one thing we all have in common is that we take our first step by being open and truthful with ourselves.

**Throughout the disclosure process, it's common to feel:**

- Scared
- Unsafe
- Confused
- Guilty
- Empowered
- Exhilarated
- Relieved
- Proud
- Uncertain
- Brave
- Affirmed

## FINDING A COMMUNITY

For many of us who identify ourselves as transgender, it is important to find others who share similar experiences and emotions. Finding a community of peers can help us feel less alone on our new paths and can answer questions we might have about next steps.

If you live near a major city, you may find support or social groups nearby. For those living in suburban or rural areas, finding a formal group might be more difficult. But transgender people live in every corner of the world, and you are not alone. One place to start is the Internet. A wide range of transgender communities exists online. Whether by subscribing to an e-mail group, reading or participating in blogs or joining an online community, you can find numerous resources on the Web.

# Deciding to Tell Others

**Some transgender people who wish to disclose this truth about themselves to others have reached a breaking point in their lives where it's too difficult to hide who they are any longer.**

Whether it's the cross-dresser burdened with a secret he or she has hidden from their spouse or a young lesbian who feels she doesn't fit into a traditional gender role, transgender people often feel compelled to share who they are in order to build stronger and more authentic relationships with those closest to them.

After disclosure, many people feel as if a great weight has been lifted from their shoulders. In the process of sharing who they are, they may also break down stereotypes and other barriers by living more open lives.

While there are benefits, there can also be serious risks and consequences involved. The decision is yours and yours alone. It's important to weigh both risks and rewards before making a choice to tell others.



**“There are just as many gender identities as there are individuals. Being transgender is just one part of who I am.”**





### **Some Benefits of Disclosure:**

- Living an authentic and whole life
- Developing closer, more genuine relationships
- Building self-esteem from being known and loved for who we really are
- Reducing the stress of hiding our identity
- Having authentic and open friendships with other transgender people
- Becoming a role model for others
- Making it easier for younger transgender people who will follow in our footsteps
- Being more productive at work

### **Some Risks/Consequences of Coming Out:**

- Not everyone will be understanding or accepting
- Family, friends and co-workers may be shocked, confused or even hostile
- Some relationships may permanently change
- You may experience harassment, discrimination or violence
- You may be thrown out of your home
- You may lose your job
- Some young people may lose financial support from their parents

Remember, there's no right or wrong way to disclose being transgender or to live openly. It may not mean you have to be out at all times or in all places. You have the right and the responsibility to decide how, where, when and even whether to share your identity with others, based on what's right for you.

# A Note on Transitioning

**It's important to remember that "transgender" is a broad term describing many different people who express gender in many different ways, each as authentically as the next.**

For many transgender people, the process of transitioning, and the period of time when a person changes from living in one gender to living in another, is when we feel most exposed and the decision to disclose becomes most critical to our lives.

Transitioning does not always involve medical treatment. By dressing in preferred-gender clothing, changing their bodies through exercise, adjusting mannerisms and speech patterns or requesting that friends and family address them with preferred names and pronouns, transgender people can use non-medical options to live their gender identities or expressions.

Others who transition pursue medical treatment hormone therapy, surgery or both — to align their bodies with the gender they know themselves to be.

In many parts of the world, the accepted clinical guidelines for those who undertake medical transition are known as the Standards of Care. These standards are developed by the World Professional Association for Transgender Health, or WPATH (formerly known as the Harry Benjamin International Gender Dysphoria Association), a widely recognized professional organization devoted to the understanding and treatment of gender identity disorders. Information on the WPATH Standards of Care can be found online at [www.wpath.org](http://www.wpath.org).

Another increasingly common treatment protocol is known as Informed Consent. Through this protocol, transgender people are made aware of the effects of medical treatment and then asked to provide consent, much like with other medical procedures. Some doctors supervise medical transitions through a combination of both protocols.

Regardless of how a person lives his or her gender identity, transitioning can be a very public “outing.” It involves disclosing to family, friends, employers and healthcare providers. For most transgender people, transitioning by its very nature is not something that can be hidden from everyone.

When it comes to transitioning, a broad range of medical personnel — from psychologists or psychiatrists to surgeons, endocrinologists and/or voice therapists — may be consulted. If possible, it’s very helpful to find healthcare professionals in your geographic area who are experienced in serving transgender patients. If there are no such providers in your area, an open-minded provider who is willing to learn about the specific health needs of transgender people and who is willing to speak with more experienced providers may be sufficient.

### **Questions for Healthcare Providers:**

- Have you treated transgender patients in the past?
- Do you understand hormone regimens appropriate for transgender patients?
- What treatment protocol do you follow for transitions?

Remember: Do your research first. Even doctors who have had transgender patients in the past may not be experts on transitioning. Many websites and advocacy groups can offer guidance on medical transitioning. It’s key to be your own health advocate.

While this guide is primarily for transgender people who are in the early stages of disclosure, some of us may confront the issue again after transitioning, among new friends, family and co-workers.

Some transgender people choose to lead “stealth” lives. While they may or may not disclose their transgender status to healthcare professionals, they either do not discuss or are very selective in disclosing their transition or gender assigned at birth with others.

Other transgender people find that being more open about their lives and stories can be safe and affirming, as many lesbian, gay and bisexual people do.

Some even choose to speak out publicly about being transgender, becoming advocates for other transgender people by sharing their stories in media interviews or by speaking to students at local colleges and universities or to business and community groups.

The pages that follow can help you decide which path is right for you, no matter where you are on your journey.

**“ I made the personal decision not to go through sex-reassignment surgery. The only person who can decide what’s right for you is you. ”**



# Making a Disclosure Plan

When you're ready to tell that first person — or even those first few people — give yourself time to prepare. Think through the options and make a deliberate plan of whom to approach, the right time to do so and how to do it. Ask yourself the following questions:

## **Do I know what I want to say?**

Particularly at the beginning of the disclosure or coming out process, many people are still answering tough questions for themselves and are not ready to identify as transgender. Or they may know they are transgender without knowing exactly what that means to them or to others. That's OK. Maybe you just want to tell someone that you're starting to ask yourself these questions. Even if you don't yet have all the answers, your feelings and your safety are what matter. To get a better idea of what it is you want to communicate, try writing it down to help organize your thoughts.

## **Who should I tell first?**

This can be a critical decision. You may want to select people whom you suspect will be most supportive, as their support can help you share with others. If you're coming out at work, who is the point person, or who can be your champion? Your human resources representative? A manager or co-worker? Someone at another transgender, LGBT or social justice organization? Do your homework before deciding. Also, know that this

kind of news can travel quickly. If you'd prefer that the people you tell keep your news confidential, be sure to tell them so, and plan for the chance that someone you tell may not stay silent. Don't be surprised if someone, intentionally or not, shares your news with others before you have a chance to do it yourself.

### **What kinds of signals am I getting?**

Sometimes you can get a sense of how accepting people will be by the things they say. Maybe a transgender-themed movie or a transgender character on a TV show can get a discussion started. Or maybe someone in your life has told you that they joined an LGBT rights organization. But don't read into these conversations too closely. The most LGBT-friendly person in the office may react negatively, and the person who said something insensitive about transgender people might end up being your strongest supporter.

### **Am I well-informed and willing to answer questions?**

People's reactions to the news that you're transgender can depend largely on how much information they have about transgender issues and how much they feel they can ask. While more and more people are familiar with lesbian, gay and bisexual people and issues of sexual orientation, issues surrounding gender identity and expression aren't yet as widely understood. If you're well-informed and open to answering questions, it can go a long way toward helping others to understand. Some helpful facts and frequently asked questions can be found later in this guide. More information is available at [www.hrc.org](http://www.hrc.org) and at other sites referenced there.

### **Is this a good time?**

Timing is key, and choosing the right time is up to you. Be aware of the mood, priorities, stresses and problems of those to whom you would like to come out. If they're dealing with their own major life concerns, they may not be able to respond to your disclosure constructively.

## **Can I be patient?**

Just as it took you time to come to terms with being transgender, some people will need time to think things over after you disclose that news to them. The reason you've chosen to be open with these people is that you care about them or that you found it necessary. If they react strongly, it's probably because they care about you, too. Be prepared to give them space and time to adjust. Rather than expecting immediate understanding, work to establish an ongoing, non-judgmental, respectful dialogue.

## **Is it safe to disclose?**

If you have any doubt at all as to your safety, carefully weigh your risks and options. Transgender people face the real threat of harassment and violence, and some transgender people choose to disclose being transgender in a safe space with friends by their sides to ensure their safety. Also, while more and more localities are passing laws that ban discrimination against transgender people, most transgender Americans are not legally protected from workplace discrimination. As a result, disclosure to someone at work could cost you your job and sometimes your livelihood. Visit [www.hrc.org/workplace/transgender](http://www.hrc.org/workplace/transgender) for a comprehensive guide to being transgender in the workplace.



# Having the Conversation

It's common to want or hope for positive reactions from the people you tell, but that may not happen immediately. It might help to try to put yourself in their shoes to try and understand their likely reactions, potential questions and next steps.

## **The person to whom you disclose being transgender might feel:**

- Surprised
- Honored
- Uncomfortable
- Scared
- Unsure how to react
- Distrusting
- Supportive
- Skeptical
- Relieved
- Curious
- Confused
- Angry
- Uncertain what to do next

You may want to verbalize the range of feelings they might be having and reassure them that it's OK to ask questions. People will generally take their cues from you as to how they should approach things, so if you're open and honest, you're more likely to get openness and honesty in return.

Appropriate and gentle humor can also go a long way toward easing anxiety for both you and the person with whom you're speaking. Always remember to give them time. It has taken you time to get to this point. Now they might need time to understand things, too.



**“It’s up to you to decide when and where you come out. Coming out as transgender is just one step along the path toward living openly.”**



## **Telling Parents**

Regardless of your age, you may be afraid your parents will reject you if you tell them you are a transgender person. The good news is that most parents are able to come to a place of understanding. Some may never quite get it, but others may surprise you by becoming advocates themselves. However, if you are under 18 or financially dependent on your parents, consider this decision very carefully.

### **Some reactions you may want to prepare for:**

- Parents may react in ways that hurt. They may cry, get angry or feel embarrassed.
- Some parents will need to grieve over the dreams they’ve had for you before they see the new, more genuine life you are building for yourself.
- Some parents may say things like, “Well, you’ll always be a daughter to me — never a son.” Or they may be unkind about the way you express your gender. It may take time for them to get used to seeing you as you know you are.
- They may ask where they “went wrong” or if they did something to “cause this.” Assure them they did nothing wrong and didn’t cause you to be transgender.
- Some may think of being transgender as a sin or attempt to send you to a counselor or therapist in hopes they can “change” you.
- Some parents or family members may already know or have an inkling that you are transgender. For some, hearing your news may come as a sense of relief.
- Supportive or not, their initial feelings may not reflect their feelings over the long term. Keep in mind that this is big news and there’s no timetable for how long it takes parents to adjust.

## **Telling Partners and Spouses**

One of the biggest reasons transgender people don't disclose being transgender is fear of how a partner or spouse will react. They wonder if their spouse will ask for a divorce or if their partner will suddenly stop loving them.

The good news is that love is hard to stop suddenly. But even a relationship built on the strongest love may confront insurmountable challenges when a partner discloses being transgender. In these cases, separation may be inevitable. A husband or wife may find it difficult to trust a spouse who has kept their feelings secret, or that they're no longer able to have a romantic relationship with a partner who is transitioning. But there are many others who discover that they can. More and more couples and families are staying together through transition, and disclosing that you're transgender to those you love the most doesn't have to lead to separation.

Before disclosing to a partner or spouse, it's important to remember that they'll need time and patience — just as you'd expect time and patience while working through your own feelings. Counseling can be helpful to many couples, as can talking with other couples who have been through similar situations.

## **Telling Children**

There's no one right or wrong way to have this conversation. Coming out to children can seem a daunting task. Depending on their ages, you may be worried about them rejecting you or about their safety at school if they tell friends.

If you have a partner, spouse, ex-partner or ex-spouse who is involved in your children's lives, you may want to have the conversation together, if that's possible. Or you might find that bringing a grandparent into the conversation is a good idea. Your children may have questions that they feel more comfortable asking someone else for fear that they'll hurt your feelings. Older children, especially, may need more time to think about the news you've shared with them before they're ready to talk.

It may be helpful to arrange a family counseling session to sort through feelings. Giving your children the ability to talk to other children of transgender parents can be enormously helpful.

# For Family and Friends

**If your friend or family member has come out to you as transgender, you may be wondering how to respond. Everyone does so differently. Many are confused and have questions. Some are relieved they know what's been on their loved one's mind, and others are hurt they weren't told sooner. You may feel a mixture of all three emotions and more. You may not even be able to understand what it is that you're feeling.**

Regardless of how you're feeling, it's helpful if you can reassure your family member or friend that your feelings for them have not suddenly disappeared. Let them know you will try your best to support them through this process. It's OK to tell them it's going to take some time to adjust. Be honest with them if you have questions you'd like to ask as they, too, had questions they had to answer along the way.

If you have questions you're uncomfortable asking, you can find resources elsewhere. Support groups — both online and in many cities and towns across the country — can help you get the answers you're looking for. There is also a range of books and websites that offer more information. You can find resources and answers to some common questions at the end of this guide.

In the end, knowing that you still care is what matters most to your friend or family member.

## **A Note for Parents of Transgender or Gender-Questioning Children**

While some transgender people only come to understand their identity as adults, there are many who deal with these questions at very young ages. If you're reading this guide, it means you're already well on the way toward providing a supportive environment for your child.

It's important to let your children explore their gender without trying to change or pressure them toward one mode of gender expression. There are some circumstances where this may prove difficult — if your child refuses to wear the school uniform for their sex assigned at birth, for example.

While you can't allow your children to get their way in every situation, these may be more than small refusals. Talk to your child to gauge how important these issues are to them. It may also help to talk to school authorities and work out a solution.

Many parents also pursue counseling with their children. But it's important to let your child know that there's nothing wrong with them if you decide counseling is necessary. Seeking out a supportive therapist who has experience with gender issues in children is also a wise step.

Above all, reassure your children that differences are to be celebrated and you love them no matter what. Acceptance of diversity is an important value for all children — and adults.

Specific resources and support groups for parents of transgender children are available to you.

**“ You are on a journey of self-disclosure that is ongoing. It’s one that unfolds at your own pace and gets exponentially easier with time. ”**



# The Disclosure Continuum

**The world is not the same today as it was 20, 10 or even five years ago for transgender people.**

For those who transitioned years ago, it was often a danger to do anything but move to another community and begin new lives. The pressure to stay in the closet about a gender transition could become almost as oppressive as the pressures they once felt to hide their true genders. But with a newfound sense of community, more and more transgender people are choosing to live openly and disclose to others their unique stories.

In the past, there were fewer safe options for people who felt confined by the traditional understanding of gender as “either-or.” Today, there are more and more people who choose to identify as neither male nor female and who express their gender in less traditional ways.

Regardless of where you fit on the spectrum of transgender identities, you are on a journey that is uniquely yours and that is ongoing. It’s one that can unfold at your own pace and that gets easier with time.

Living openly and authentically doesn’t mean that the sole or even primary aspect of who you are is your gender identity or expression. It just means that this part of your life is as natural and acceptable as your eye color, your height or your personality.

But it’s not just about you. Living openly teaches others that there’s more to gender than they might have ever known. It paves the way for future generations of transgender youth to live better lives. And it shows others, especially those who are biased or judgmental, that their attitudes are theirs alone.

Almost every day, you will face decisions about where, when and how to disclose that you are transgender — or where, when and why not to. Always remember, this is your journey. You get to decide how to take it.

# Ten Things Every American Ought To Know

Seventy-eight percent of American voters believe it should be **illegal to fire someone just because they are transgender.**

(September 2005 Human Rights Campaign/Hart Research poll)

Nearly half of the Fortune 100 — America's most profitable businesses — offer **non-discrimination policies that cover gender identity.** More and more companies add these protections every year. (Human Rights Campaign, 2007)

Eighty-four percent of lesbian, gay, bisexual and transgender students **report being verbally harassed** — name-calling, threats, etc. — at school. (Gay, Lesbian and Straight Education Network, 2003)

**Hate crimes** against LGBT Americans are on the rise, even as other violent crimes continue to decline, and current federal laws do not protect LGBT Americans from hate violence. (FBI Hate Crimes Statistics, 2004)

Military regulations deny **transgender Americans the right to serve openly**, and transgender veterans face significant discrimination in the Veterans Administration medical system. (Transgender American Veterans Association/Palm Center study, August 2008)

In the majority of states, it is **still legal to fire someone** from his or her job simply for being transgender.

While challenges exist, there are many transgender and **transgender-friendly faith leaders** and communities throughout the United States and beyond.

Throughout history and across cultures, people have expressed themselves in ways that we might consider transgender. Some Native American cultures identify **“two-spirited” people as a revered class.**

According to some estimates, **0.25 to 1 percent of the U.S. population is transsexual.** But the actual percentage of transsexual people, and especially those who identify under the broader transgender identity, is thought to be much higher.

Transgender non-discrimination protections in colleges and universities are on the rise, with more and more focus on full protection among institutions of higher learning for students, faculty and staff, including all eight Ivy League institutions. Many colleges and **universities now offer gender-neutral housing options** for students living on campus.



# Glossary of Terms

Many Americans don't talk about gender identity and expression because they feel it's taboo or are afraid of saying the wrong thing. This glossary was written to provide people with the words and meanings to help make conversations easier.

**cross-dressers** — Transgender people who wear clothing and/or makeup and accessories that are considered by society to correspond to a gender other than the one they were assigned at birth.

**female-to-male transsexual (FTM) or trans man** — Someone who was born female and transitions to a male gender identity.

**gender expression** — How a person behaves, appears or presents oneself with regard to societal expectations of gender.

**gender identity** — The gender that a person claims for oneself, which may or may not align with the gender assigned at birth.

**gender variant, gender diverse, or genderqueer** — Terms people use to describe their own nonstandard gender identity or expression.

**GLBT or LGBT** — Acronyms for “gay, lesbian, bisexual and transgender” or “lesbian, gay, bisexual and transgender.”

**male-to-female transsexual (MTF) or trans woman** — Someone who was born male and transitions to a female gender identity.

**sexual orientation** — A person's enduring emotional, romantic, sexual and relational attraction to someone else, which is different from an innate sense of gender.

**transgender** — An umbrella term that applies to a broad range of people who experience and/or express their gender differently from what most people expect.

**transition** — A process through which some transgender people begin to live as the gender with which they identify, rather than the one assigned at birth. This may or may not include hormone therapy, sex reassignment surgery and other medical components.

**transsexual** — A person who — with or without medical treatment — identifies and lives his or her life as a member of the gender other than the one assigned at birth.

**transvestite** — An outdated term — often considered pejorative — used to refer to people who cross-dress.

The Gay and Lesbian Alliance Against Defamation also offers a more detailed glossary, tailored for the media but also helpful for individuals who would like to learn more, at [www.glaad.org/media/guide/transfocus.php](http://www.glaad.org/media/guide/transfocus.php).

### **A Note on Pronouns**

Transgender people should be identified with the pronoun that corresponds with the gender with which they identify. If you are unsure of someone's gender, it's appropriate to respectfully ask their name and what pronoun they prefer you use. In general, it's considered insensitive to refer to someone by the incorrect pronouns once you have established which set of pronouns they prefer.



**“‘Transgender’ is a broad term describing many different people who express gender in many different ways.”**



# Some Myths and Facts

**Note:** This is by no means a comprehensive guide to transgender concepts. Instead, it is geared toward people who are just learning about transgender issues.

**Here are some common myths and facts about transgender people:**

**Myth:** Transgender people are confused.

**Fact:** Transgender people are no more and no less confused than most people. Gender is a much more complicated issue than most people are aware, and sorting through gender differences can be challenging. But by the time someone is ready to come out as transgender, they have thought long and hard and are generally secure in their feelings.

**Myth:** Being transgender is a “choice.”

**Fact:** Being transgender is no more a choice than being gay or straight, having brown eyes or blue, or being left- or right-handed. The choice is deciding whether or not to live your life honestly with yourself and others.

**Myth:** Transgender people are really gay.

**Fact:** Gender identity and sexual orientation are two different subjects. Some transgender people are lesbian, gay or bisexual in their sexual orientation, and some are straight.

**Myth:** Transgender people are sinners.

**Fact:** Many transgender people are people of faith. While some find hostility in their churches, synagogues, mosques or worshipping communities, still others are embraced by their spiritual peers. The number of transgender-friendly places of worship is large and growing.

**Myth:** Transgender people can't have families.

**Fact:** Whether they come out before a relationship or while in one, countless transgender people find love and happiness in their lives. In fact, most transgender people will tell you that after coming out, they feel a new sense of wholeness and happiness that makes them a better partner and parent.

**Myth:** Transgender people can be cured.

**Fact:** There's no "cure" for transgender people, although some do try to repress it. The most reputable medical and psychotherapeutic groups say you should not try to keep from expressing your true gender identity. Instead, they say to focus on ways to come to an understanding of yourself and share your life openly with those you love.

**Myth:** All transgender people have surgery.

**Fact:** Many transgender people have no desire to pursue surgeries or medical intervention. At the same time, many transgender people cannot afford medical treatment or have no access to it. Considering these truths, it's important that civil rights are afforded to all transgender people equally, regardless of their medical histories.

**Myth:** There are more male-to-female transgender people than female-to-male transgender people.

**Fact:** There are no reputable statistics on how many transgender people there are in the world, nor on how many people identify as male-to-female or female-to-male. But even the best estimates show there are more or less equal numbers of MTF and FTM transgender people.

## RESOURCES FOR MORE INFORMATION

The Human Rights Campaign Foundation maintains a catalog of resources for transgender people as well as their families, friends, employers, clergy and other allies online at [www.hrc.org/issues/transgender.asp](http://www.hrc.org/issues/transgender.asp). You can also find resources specific to transgender issues in the workplace at [www.hrc.org/workplace/transgender](http://www.hrc.org/workplace/transgender), and to issues in communities of faith at [www.hrc.org/religion](http://www.hrc.org/religion).

You may also find the following websites helpful:

### Legal Issues

National Center for Transgender Equality [www.nctequality.org](http://www.nctequality.org)

Transgender Law Center [www.transgenderlawcenter.org](http://www.transgenderlawcenter.org)

### Health Issues

The Gay and Lesbian Medical Association [www.glma.org](http://www.glma.org)

The World Professional Association for Transgender Health [www.wpath.org](http://www.wpath.org)

### Resources for Families and Children

Trans Youth Family Allies (for families of transgender children) [www.imatyfa.org](http://www.imatyfa.org)

COLAGE Kids of Trans Program (for children with transgender parents) [www.colage.org/programs/trans](http://www.colage.org/programs/trans)

### Spiritual and Religious Issues

TransFaith Online [www.transfaithonline.org](http://www.transfaithonline.org)



# A Message from Joe Solmonese

President,  
Human Rights Campaign Foundation

## Thank you for turning to *Transgender Visibility*.

We know that any progress on issues of equality begins with the simple yet profound step of sharing our lives with others. It is, in fact, the greatest political action any of us can take. When people — and that includes voters and elected officials — know something about our lives, about our hopes, our aspirations and, yes, our struggles, we begin to see a shift. We begin to change hearts and minds.

It's how we move issues of gender identity and expression into law, whether that's at the city, state or federal level. It's how we continue to move corporations to include gender identity and expression into their employee protection and benefits programs. It's about more than just facts and figures — it's about the hard work of stepping forward, of telling our stories.

We know that as more people come to know transgender Americans, the myths and fears surrounding gender identity will give way to understanding and support.

That's why I'm so pleased that the Human Rights Campaign Foundation has created this booklet. We hope *Transgender Visibility* provides some guidance on this journey.

Sincerely,

Joe Solmonese



# A Message from Allyson Robinson

Associate Director of Diversity,  
Human Rights Campaign Foundation

## I did it — and you can, too.

It took me many years to understand who I was and to embrace that part of me that seemed so different from everyone else. Looking at myself in the mirror and saying “I am transgender” was one of the hardest things I’ve ever had to do, and saying those same words to my family and friends was even harder. I was so afraid!

Maybe you feel the same way. If so, let me offer you these words of encouragement from the other side: I’m so glad I did it.

Today, I know a sense of contentment and peace greater than I ever thought possible. Every day, I get to experience the joy of living an open, honest life and engaging in relationships as a whole and authentic person — proud of who I am and proud of the transgender community to which I belong. Have I suffered some losses along the way? I have — but in the end, the things I have gained have made it all worthwhile.

Whether you’ve just come to understand yourself as a transgender person, or you’ve waited for years to share what you know to be true about your gender identity with the people around you, my hope is that this guide will help you take the next step into the kind of wholeness and fulfillment I and so many other transgender people have discovered.

Your companion on the journey,

Allyson Robinson

**The Human Rights Campaign Foundation** believes that all Americans should have the opportunity to care for their families, earn a living, serve their country and live open, honest and safe lives at home, at work and in their community. Through pioneering research, advocacy and education, the HRC Foundation pursues practices and policies that support and protect lesbian, gay, bisexual and transgender individuals and their families in education, healthcare, corporate, public and private organizations across the country. Visit [www.hrc.org](http://www.hrc.org) for more information.

*All photos in this guide are the work of photographer Mariette Pathy Allen. The Human Rights Campaign Foundation thanks her for providing these powerful images.*



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# Optional Handout 24: Tips for Working with Transgender People

## Introduction to the transgender community

**Gender identity** is our internal understanding of our own gender. We all have a gender identity. The term “**transgender**” is used to describe people whose gender identity does not correspond to their birth-assigned sex and/or the stereotypes associated with that sex. A **transgender woman** is a woman who was assigned male at birth and has a female gender identity. A **transgender man** is a man who was assigned female at birth and has a male gender identity. For many transgender individuals, the lack of congruity between their gender identity and their birth sex creates stress and anxiety that can lead to severe depression, suicidal tendencies, anti-social behavior, and/or increased risk for alcohol and drug dependency. **Transitioning** - the process that many transgender people undergo to bring their outward gender expression into alignment with their gender identity - is a medically necessary treatment strategy that can effectively relieve this stress and anxiety.

## Transgender people are medically underserved

Access to affordable, quality health care is central to avoiding negative health consequences, yet most insurance companies exclude medically necessary care and services for transgender people, including mental health therapy, hormonal therapy, and surgeries. In addition, many transgender people have had negative experiences in health care settings, including providers and office staff who have lacked the information necessary to provide sensitive services. Discrimination in the provision of services causes transgender people to delay or avoid necessary health care, including care that is not transition-related, often to the point of putting their overall health at severe risk.

## MEDICAL PROTOCOLS

The World Professional Association for Transgender Health (WPATH) publishes Standards of Care for the treatment of gender identity disorders, available at [www.wpath.org](http://www.wpath.org). These internationally recognized protocols are flexible guide lines designed to help providers develop individualized treatment plans with their patients.

Another resource is the Primary Care Protocol for Transgender Patient Care produced by Center of Excellence for Transgender Health at the University of California, San Francisco. You can view the treatment protocols at [www.transhealth.ucsf.edu/protocols](http://www.transhealth.ucsf.edu/protocols). These protocols provide accurate, peer reviewed medical guidance on transgender health care and are a resource for providers and support staff to improve treatment capabilities and access to care for transgender patients.

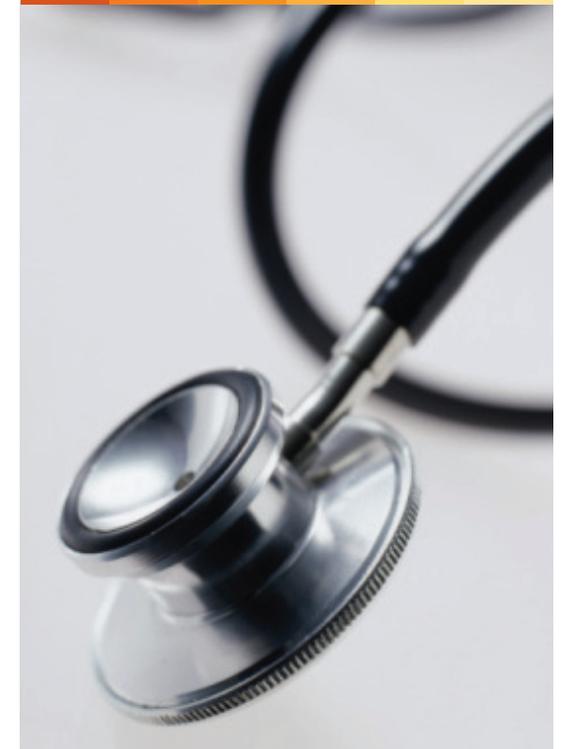
**Transgender Law Center** advocates in courtrooms, boardrooms and legislatures as the legal and policy heart of the grassroots movement to create a world where people who don't fit narrow gender stereotypes are free from prejudice and we can all live as our authentic selves.

This publication is made possible with support from: Community Clinics Initiative - a joint project of Tides and The California Endowment, David Bohnett Foundation, Horizons Foundation, Liberty Hill Foundation, The California Endowment, and The California Wellness Foundation.

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## 10 Tips for Working with Transgender Patients

*An information and resource publication for health care providers*



# 10 TIPS

for improving services for transgender people

Transgender Law Center recognizes that many health care providers are eager to provide a safe, welcoming treatment environment for members of the transgender community, yet may not have had the opportunity to access information about the needs and experiences of this marginalized population. With this barrier in mind, we have created this pamphlet to work in partnership with providers to improve quality of care and provider-patient outcomes.

**1. WELCOME TRANSGENDER PEOPLE BY GETTING THE WORD OUT ABOUT YOUR SERVICES AND DISPLAYING TRANSGENDER-POSITIVE CUES IN YOUR OFFICE.** You can use LGBT community centers, services, newspapers, and Internet resources to advertise your services. Posters, buttons, stickers, and literature about transgender people can demonstrate that you are transgender-friendly. You can rewrite your intake form to include “chosen name” in addition to “legal name,” as well as a third, blank option for “sex/gender” where someone can more accurately describe their gender. And single-use restrooms are a welcome addition for many, including transgender people.

**2. TREAT TRANSGENDER INDIVIDUALS AS YOU WOULD WANT TO BE TREATED.** You can show respect by being relaxed and courteous, avoiding negative facial reactions, and by speaking to transgender clients as you would any other patient or client.

**3. REMEMBER TO ALWAYS REFER TO TRANSGENDER PEOPLE BY THE NAME AND PRONOUN THAT CORRESPONDS WITH THEIR GENDER IDENTITY.** Use “she” for transgender women and “he” for transgender men, even if you are not in the patient’s presence.

**4. IF YOU ARE UNSURE ABOUT A PERSON’S GENDER IDENTITY, OR HOW THEY WISH TO BE ADDRESSED, ASK POLITELY FOR CLARIFICATION.** It can be uncomfortable to be confused about someone’s gender. It can also feel awkward to ask someone what their gender is. However, if you let the person know that you are only trying to be respectful, your question will usually be appreciated. For instance, you can ask, “How would you like to be addressed?” or “What name would you like to be called?” In order to facilitate a good provider-patient relationship, it is important not to make assumptions about the identity, beliefs, concerns, or sexual orientation of transgender and gender non-conforming patients.

**5. ESTABLISH AN EFFECTIVE POLICY FOR ADDRESSING DISCRIMINATORY COMMENTS AND BEHAVIOR IN YOUR OFFICE OR ORGANIZATION.** Ensure that all staff in your office or organization receive transgender cultural competency training and that there is a system for addressing inappropriate conduct.

**6. REMEMBER TO KEEP THE FOCUS ON CARE RATHER THAN INDULGING IN QUESTIONS OUT OF CURIOSITY.** In some health care situations, information about biological sex and/or hormone levels is important for assessing risk and/or drug interactions. But in many health care situations, gender identity is irrelevant. Asking questions about a person’s transgender status, if the motivation for the question is only your own curiosity and is unrelated to care, is inappropriate and can quickly create a discriminatory environment.

**7. KEEP IN MIND THAT THE PRESENCE OF A TRANSGENDER PERSON IN YOUR TREATMENT ROOM IS NOT ALWAYS A “TRAINING OPPORTUNITY” FOR OTHER HEALTH CARE PROVIDERS.** Many transgender people have had providers call in others to observe their bodies and the interactions between a patient and health care provider, often out of an impulse to train residents or interns. However, like in other

situations where a patient has a rare or unusual finding, asking a patient’s permission is a necessary first step before inviting in a colleague or trainee. Many transgender patients wish to maintain control over who sees them unclothed. Therefore, when patients are observed without first asking their permission, it can quickly feel like an invasion of privacy and creates a barrier to respectful, competent health care.

**8. IT IS INAPPROPRIATE TO ASK TRANSGENDER PATIENTS ABOUT THEIR GENITAL STATUS IF IT IS UNRELATED TO THEIR CARE.** A person’s genital status—whether one has had surgery or not—does not determine that person’s gender for the purposes of social behavior, service provision, or legal status.

**9. NEVER DISCLOSE A PERSON’S TRANSGENDER STATUS TO ANYONE WHO DOES NOT EXPLICITLY NEED THE INFORMATION FOR CARE.** Just as you would not needlessly disclose a person’s HIV status, a person’s gender identity is not an item for gossip. Having it known that one is transgender can result in ridicule and possible violence towards that individual. If disclosure is relevant to care, use discretion and inform the patient whenever possible.

**10. BECOME KNOWLEDGEABLE ABOUT TRANSGENDER HEALTH CARE ISSUES.** Get training, stay up to date on transgender issues, and know where to access resources.



For more information or to get help, please contact Transgender Law Center.



# Optional Handout 25: Transgender Non-Conforming Card

# TGNC CARD

## How to use the TGNC Card

1. Fill it out.
2. Give this card to your provider, medical assistant, or nurse, or keep it. It's up to you!
3. See accompanying handout for ideas about things that may help you be comfortable during medical visits.
4. Bring it to your next healthcare appointment.
5. Talk to your provider about privacy & confidentiality.
6. Discuss your general concerns and sexual health concerns with your provider.
7. Let us know how it went at [qcardproject.com](http://qcardproject.com)

*Being open about your gender with your provider is a personal decision, and we encourage you to consider your comfort, safety and resources before taking this step.*

## For Providers

Like with any other patient, you may want to ask me about these other aspects of my health:

- Depression and anxiety symptoms
- Housing situation
- sexual experiences and safer sex practices
- Religion and spirituality
- Experiences of discrimination/harassment
- Smoking (tobacco, marijuana, vapes, etc.)
- Drug and alcohol use
- Family and social relationships
- Intimate partner violence and sexual assault
- Family planning
- Intersecting/other experiences of oppression (race, size, class, ability, etc.)
- Gender affirmation steps, choices and needs (hormones, surgeries, documentation, etc.)

Please call me: \_\_\_\_\_  
*insert name*

My gender pronouns are: \_\_\_\_\_

My gender identity is:  
*circle all that apply/ fill in the blank*

TRANS WOMAN      TRANS MAN      AGENDER  
NON-BINARY      GENDERQUEER  
WOMAN      MAN

---

My sex assigned at birth was:  
*circle all that apply/ fill in the blank*

INTERSEX      FEMALE      MALE      I do not care to say

---

Check one:

- Please talk to me about what words I use to talk about my body parts.
- I am okay with using medical terminology for my body parts.
- Please use gender-neutral terms such as chest and genitals.

I engage in sexual activity with: *circle all that apply*

- Trans women
- Trans men
- Nonbinary/  
Genderqueer people
- I am asexual and do not  
engage in sexual activity
- Cisgender women
- Cisgender men
- Agender people
- I have not ever had sex
- I do not wish to talk about  
my sexual activity at this visit

Things that might help me be more comfortable during medical visits are: \_\_\_\_\_

See accompanying handout for some ideas.



# Printout 26: Video List and Links

# Video List and Links

## Session 1: HIV Viral Life Cycle and Medications at Work

- HIV: What's Going on Inside Your Body
  - <https://www.youtube.com/watch?v=tVE5APDgrpc> – English
  - <https://www.youtube.com/watch?v=hB-B0zpEZ-c> – Spanish
- HIV: The Goal of Undetectable
  - <https://www.youtube.com/watch?v=mZ1bIphjxbw> – English
  - <https://www.youtube.com/watch?v=dN8RGgjon08> - Spanish
  - How medications work:
- HIV: Avoiding Resistance
  - <https://www.youtube.com/watch?v=H1zLcJZxeE> – English
  - <https://www.youtube.com/watch?v=ZvUdL8ACAZ4> – Spanish
- HIV Treatment Works: Ryan's story  
[https://www.youtube.com/watch?v=BD\\_4Js08qxs](https://www.youtube.com/watch?v=BD_4Js08qxs)
- Understanding HIV treatments  
<https://www.youtube.com/watch?v=8003tTj2XfE>
- Tips for Treatment  
<https://www.youtube.com/watch?v=pJ6NgWv98DE&feature=youtu.be>
- Personal Stories from People Living with HIV  
<https://www.youtube.com/watch?v=2y84PSXayyY>

## Session 2: Treatment Adherence and Communication with Your Provider

- Speak Up: Tips for Talking to your Doctor  
<https://www.youtube.com/watch?v=rEt8xfQ9z1U>
- Five Reasons to Adhere to HIV Treatment  
<https://www.youtube.com/watch?v=tIPjEsJVxXk>
- Empowered: Jen  
[https://www.youtube.com/watch?v=uYuV10\\_vR10](https://www.youtube.com/watch?v=uYuV10_vR10)
- Being Open with Your Healthcare Provider  
<https://youtu.be/8vJ68G2flW4>
- Clear Communication with Your Provider
  - <https://youtu.be/YBNOtvADAPY> - English
  - <https://youtu.be/EK-xPFkqHG8> - Spanish
- HIV: Treat to Prevent  
<https://www.youtube.com/watch?v=65KKqTMhf2s>

## Session 3: Understanding Lab Values

- HIV Lab Tests

- <https://youtu.be/zKSw8B6yy30> - English
- <https://youtu.be/OCr8riEbJxc> - Spanish
- HIV: Fighting Inflammation  
<https://www.youtube.com/watch?v=FGDHVGRQFCo>
- HIV: The Goal of Undetectable  
<https://www.youtube.com/watch?v=mZ1blphjxbw>
- Living with HIV: Dante: I'm HIV Undetectable  
<https://www.youtube.com/watch?v=SIODn9q50cE>

#### Session 4: Managing Stigma and Disclosure

- HIV Disclosure: The Right Time is in Your Time  
<https://www.youtube.com/watch?v=cjggnBYk2YY>
- HIV and Disclosure  
[https://www.youtube.com/watch?v=sbZA\\_IAl6zM](https://www.youtube.com/watch?v=sbZA_IAl6zM)
- Tips for Disclosing Your Diagnosis  
[https://www.youtube.com/watch?v=3YwSzzJ7\\_YA&feature=youtu.be](https://www.youtube.com/watch?v=3YwSzzJ7_YA&feature=youtu.be) – English  
[https://youtu.be/zyM\\_JUd\\_lhQ](https://youtu.be/zyM_JUd_lhQ) - Spanish
- The Stigma Around HIV  
<https://www.youtube.com/watch?v=i8ZOxdSNYb4>  
Amaze.org's educational videos on youth sex education  
<https://amaze.org/>

#### For Transgender Clients:

- Transgender Youth 101:  
<https://youtu.be/fuZ7AlsTczl>
- Empowered Trans: Phoebe  
<https://youtu.be/6hTDmfOCDhM>
- Empowered Trans: Victory  
[https://youtu.be/4x8ul\\_fQiOU](https://youtu.be/4x8ul_fQiOU)
- CDC's HIV Treatment Works: Whitney's Story  
<https://youtu.be/8qWKY5-UpBs>
- CDC's HIV Treatment Works: Jada's Story  
<https://youtu.be/kpRXMEGdvec>

#### Session 5: Substance Use and Harm Reduction

- The Harm Reduction Approach to Substance Use  
<https://www.youtube.com/watch?v=25UK-luJo-0&feature=youtu.be> – English

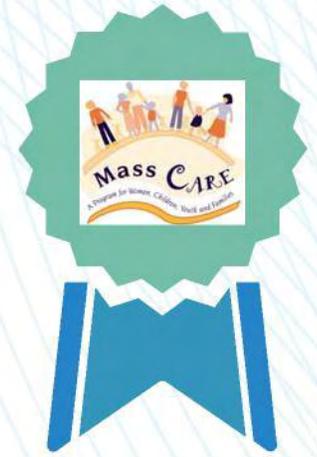
<https://youtu.be/eAWCkwLfXCM> - Spanish

### Session 6: HIV and Wellbeing

- Empowered: Gina (domestic violence)  
[https://www.youtube.com/watch?v=ozOGgUY\\_vLU](https://www.youtube.com/watch?v=ozOGgUY_vLU)
- Managing Your Mental Health & HIV  
<https://www.youtube.com/watch?v=ViLE9Wxqxr8&feature=youtu.be> – English  
[https://youtu.be/hj98M\\_W6ifY](https://youtu.be/hj98M_W6ifY) - Spanish
- Five Types of Depressive Disorders  
<https://www.youtube.com/watch?v=PbJB02Zlh4w>
- Empowered: Stephanie  
<https://www.youtube.com/watch?v=2sgxsfyyFNo>
- Magic Johnson and Cookie on HIV and their Gay Son  
<https://www.youtube.com/watch?v=TUskKarbWKc>



# Handout 27: Certificate of Completion



# *CERTIFICATE OF COMPLETION*

*awarded to*

---

*In recognition of your completion of Project CAATCH and your commitment  
improving your health and well-being through work and participation.*

---

*MassCARE Coordinator*

---

Back page: Insert HRSA funding statement here

Line 2

Line 3

Line 4

Line 5

