


DISCLOSURE: BENEFITS AND RISKS*

▶ ABOUT THIS ACTIVITY

 **Time:** 60 minutes

 **Objectives:** By the end of this session, participants will be able to:

- Understand that everyone has a unique experience with disclosure or partner notification;
- Empathize with others upon hearing their stories.

 **Training Methods:** Large Group Activity and Discussion

 **In This Activity You Will...**

- Review the difference between confidentiality and disclosure (15 minutes)
- Facilitate group activity around disclosure (30 minutes)
- Review disclosure brochures and the peer role (15 minutes)

 **Materials:**

- Flipchart
- Markers
- Cards: “I would never tell” and I would always tell” (two or three of each)
- Handout – Disclosure: Some Considerations Before You Disclose
- Brochure - Disclosure

 **Preparation:**

- Print handout and brochure

Instructions

Note: This module should be delivered after completing an introductory training on disclosure.

1. Introduce the activity.

- Disclosure and confidentiality are slightly different. Why or why not? (Answers could include—another person breaking your confidentiality vs. your telling another person about your HIV)
- In previous modules, disclosure and the importance of understanding people’s choices about disclosing his or her HIV status to family and friends has been discussed.
- Telling others about your HIV status is your personal choice. You have a right to keep it a secret with the exception of telling: current and past sex partners, anyone that you may have shared needles with, and your doctor or dentist.
- People have different reasons for telling or not telling others about their HIV status. There are some risks and benefits of disclosure.
- It is important to know that everyone has his or her own unique experiences with disclosure. This exercise will help us learn why people chose or do not chose to disclose their HIV status.
- Peer educators may not agree with, but need to respect, the decisions that others make about disclosure.
- At this time I will need you to think about an experience when you told someone about your HIV status. Think about who they are: your mother, partner, brother, friend, employee, your whole family, sister, aunt, child.
- In that experience was the person or group supportive, angry, violent, judgmental or confused? There are many reactions that may be associated with disclosure, some of which we could have never anticipated.

2. Explain the exercise.

- In a moment, I will hand out cards to several people in the room.
- We will begin by having someone with an “I would always tell...” card to share one person or group that s/he would always disclose to. Next, we’ll have someone with an “I would never tell...” card to

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- share a person or group s/he would never disclose to. You may add a reason why you would or would not tell this person/group if you choose.
- If I hand you a card and you don't wish to participate at this time, please let me know.
3. The trainer should ask for clarification of the instructions and repeat them and use the example below if needed.
 - The example to start could be: "I would always tell my employer because I may need to have time to go to my provider appointments."
 4. Allow each person who received a card to tell who s/he would or would not disclose to, and process the activity with the following questions.
 - Who were the people who were always told? Who were never told? What did you notice about these groups?
 - How do you feel about people choosing who they want to disclose to other than those they are required to tell?
 5. Allow participants to respond.
 - What is the best thing to do when a person tells you that they want to disclose to someone? [Possible answers include: ask if the person has a private place to disclose; ask person if s/he feels safe disclosing; prepare person for reactions.]
 6. Allow responses. Then go through the disclosure process. Have brochures available. [Record answers on a flipchart. Some responses could be:]
 - "Let's talk about this a bit."
 - "If you are anxious about this, you and I could role-play and then you can make a decision whether you want to disclose."
 7. Allow responses. Then go through the disclosure process.
 - Thank you all for sharing. It is important to remember that we all disclose to different people for different reasons. It is not up to peer educators to encourage others to disclose their HIV status, or to decide to whom their clients should tell.
 - Peer educators should encourage their clients to consider several things before disclosing to someone. These include:
 - What do you need most from the person you are telling? Have the peer think about how this person knowing can help their situation or make it worse.
 - Who are you most comfortable telling. Have the peer think of someone who can support them in a non-judgmental way while coping with their own feelings.
 - How important is privacy to you? Have the peer consider how the person s/he's considering disclosing to regularly deals with others' confidential information.
 - Prepare for reactions. Have the peer consider if the person s/he's going to tell might get upset. S/he might also provide written information on HIV to the person.
 - Where will you tell? Have the peer choose a place that is comfortable and provides enough privacy.
 - What are some of the risks? Have the peer think about the risks associated with disclosing, such as jeopardizing a job or telling someone who might become violent.
 8. Ask participants what some of the benefits of disclosure are. Allow responses.
 - Telling others about your status may take pressure off of you and relieve stress. This can help you stay healthy.
 - Some other benefits of disclosure may be:
 - Getting emotional support
 - Relief from the burden of secrecy
 - Connecting with others who are HIV+
 - Controlling your own disclosure on your own terms

DISCLOSURE: BENEFITS AND RISKS

▶ TRAINING TIP

Further instructions:

- In the handouts is included a brochure about how to tell someone about your HIV status.

Summary

- Disclosure is your personal choice;
- Peer educators may not agree with but need to respect the decision that others make about disclosure;
- Everyone has a unique experience with disclosure and partner notification.

* This module is part of the online toolkit *Building Blocks to Peer Success*. For more information, visit http://www.hdwg.org/peer_center/training_toolkit. This module comes from Duke University, Partners in Caring; Center for Creative Education, 2006.

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SESSION HANDOUT # 1 of 3

I would always tell	I would always tell	I would always tell
I would never tell	I would never tell	I would never tell

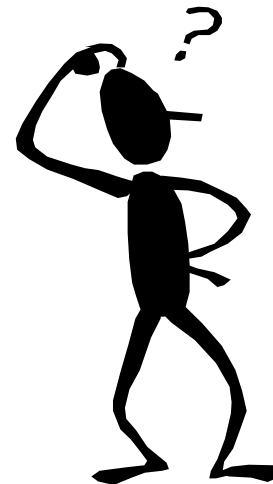
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SESSION HANDOUT # 2 of 3

DISCLOSURE: SOME CONSIDERATIONS BEFORE YOU DISCLOSE

Peer educators should encourage their clients to consider several things before disclosing to someone. These include:

- What do you need most from the person you are telling? Have the peer think about how this person knowing can help their situation or make it worse.
- Who are you most comfortable telling. Have the peer think of someone who can support them in a non-judgmental way while coping with their own feelings.
- How important is privacy to you? Have the peer consider how the person s/he's considering disclosing to regularly deals with others' confidential information.
- Prepare for reactions. Have the peer consider if the person s/he's going to tell might get upset. S/he might also provide written information on HIV to the person.
- Where will you tell? Have the peer choose a place that is comfortable and provides enough privacy?
- What are some of the risks? Have the peer think about the risks associated with disclosing, such as jeopardizing a job or telling someone who might become violent.



SESSION HANDOUT # 3 of 3



DISCLOSURE: BENEFITS AND RISKS

Disclosure is YOUR Choice

Telling others about your HIV status – disclosure – is a very personal decision. You do have the right to keep it secret from others, except from those who might be at risk of getting infected. It is important you share your status with these people:

- Current and past sex partners
- Anyone that you may have shared needles
- Your doctor and dentist

Benefits of Disclosure

Telling others about your status may take pressure off of you and relieve stress. This can help you stay healthy. Other benefits include:

- Getting emotional support
- Relief from the burden of secrecy
- Opportunity to connect with others with HIV
- Control over your own disclosure on your own terms

Risks of Disclosure

But disclosing may have serious risks for you at home or work. People may make fun of you, harass you or even try to hurt you. They may try to take away your job or place to live.

Even though there are laws to protect people with HIV, you would have to spend time and money to take these people to court or find other legal solutions. This might “out” you as HIV positive to many more people.

Telling Others About Your HIV

Peer Education Training Site
(PETS)
Duke University Medical Center
Box 3284
Durham, NC 27710

How to Tell

If you feel secure enough with your own emotions to disclose, it may help to think about the words you will say. Write them down and practice a few times. Consider the following:

- **What do you need most from the person you are telling?** Think about how this person knowing can help your situation or make it worse.
- **Who are you most comfortable telling?** Choose someone who can support you in a non-judgmental way while coping with their own feelings.
- **Will this person respect your privacy?** Think how this person regularly deals with others' confidential information.
- **How will this person react?** If they might get upset, give them written information on HIV. Tell them that HIV is a manageable illness.
- **Where would be the best place to tell this other person?** You might choose a place that is comfortable and provides enough privacy.

SESSION HANDOUT # 3 of 3 (cont.)

DISCLOSURE: BENEFITS AND RISKS

Telling a Child

You may delay disclosing to a child unless:

- Your health is at risk
- You are making frequent trips to the doctor
- You are taking medications
- Your energy level has declined, then your child may be aware the “something is wrong”.

You may want to avoid letting your child learn about your status from someone else. If you decide to tell them:

- Do it when you are physically and emotionally able to assist them in adjusting.
- Provide accurate information, both verbal and written, based on what your child knows about HIV.
- Identify people they can turn to for support.

Other Issues Pertaining to Children

When a child is infected:

- Disclosure to school officials is an individual decision in North Carolina, but may prevent accidental disclosure by the child
- Disclosure to the school can result in the HIV status being on the child's school record (unless medical records are kept separate)
- Disclosure to the school will result in disclosure about the mother's HIV status
- Disclosure to “play groups” or friends can provide an opportunity for friends to understand and be supportive
- Disclosure to these groups can result in the same issues as school issues.

Telling Your Employer

You may wish to tell your employer.

However, legal advisors often urge caution regarding disclosure of medical conditions to an employer. Consider your reasons for telling and how it would affect your job and health. Limited disclosure work for you. An example of this might be, “I need to schedule some breaks because I have to take medicines at certain times during the day.”

If you decide to tell your employer, use your human resources department. They are trained to handle difficult issues with confidentiality and professionalism. State clearly to your human resources specialist, “I know that you will keep my questions and concerns confidential.”

Get More Support

Support from others is an important aspect of living well with HIV. When you have people in your life you can talk with and rely on for help, you are better able to keep HIV in perspective and maintain a positive frame of mind.

If needed, consider ways to increase your sources of support, such as, support groups, social or volunteer activities. Many communities offer a variety of social support programs for those living with HIV.

Telling a Family Member or Romantic Partner

Disclosure rarely results in violence; but consider your personal safety, especially if there is a history of physical violence in a relationship. Seek out support and resources before disclosure. If you anticipate a violent response, you need to delay and reconsider. In such situations, a social worker or HIV case manager may be able to help you identify needed resources.

This brochure focuses on common issues related to disclosure of HIV. It was adapted from a brochure that was produced by the AIDS Clinical Trials Group Social Workers. Further discussion with a clinical social worker can provide additional guidance and understanding of individual issues related to disclosure. For assistance, call:

Gordon Lipscomb, Dionne Moore, or Mary Washington
Duke University Infectious Diseases Clinic (919) 681-4470