

DISCUSSION  
GUIDE

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# Living with HIV



## What might a person feel after testing positive for HIV?

**Objective:** To create an understanding of how people might cope with the news that they are infected with HIV.

### GUIDELINES

1. **Ask:** What are a person's feelings after testing HIV positive? Ask participants to share their experiences and observations of the reactions and feelings of people who have tested positive. List them on a flip chart sheet. Typical comments include:

- Shock
- Depression
- Anger
- Wanting to take revenge
- Guilt
- Shame

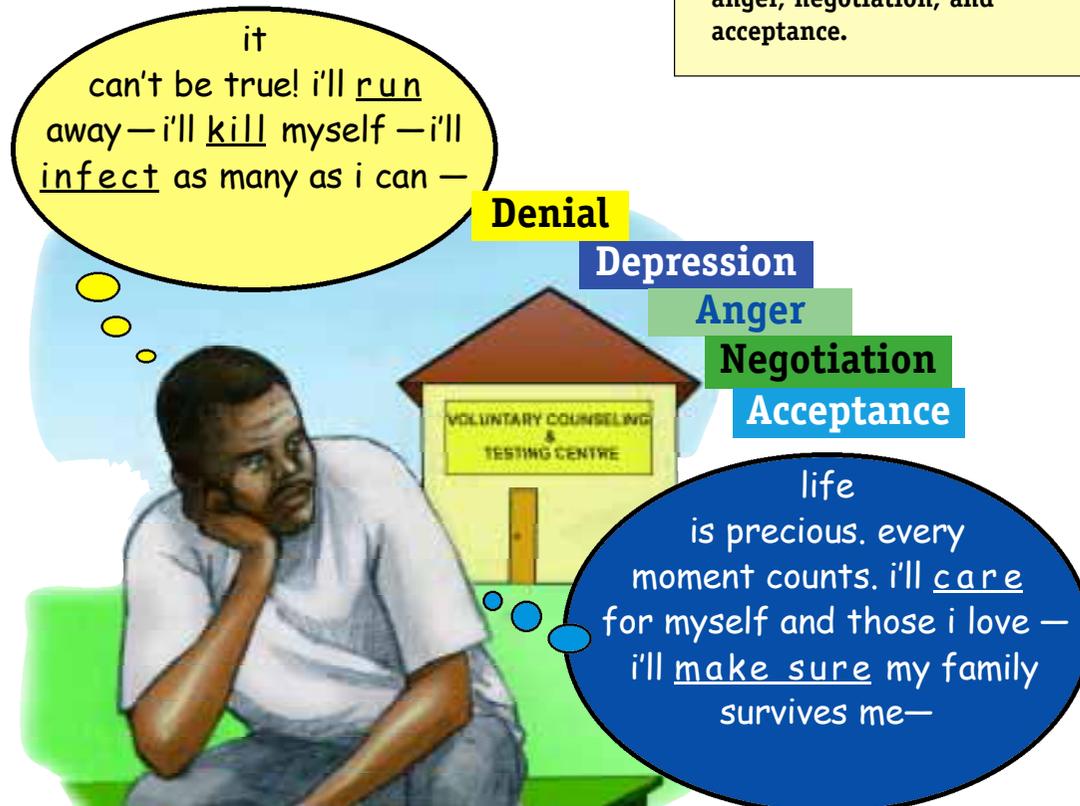
2. **Explain:** Studies of reactions of people who have learned that they have an incurable, fatal condition have revealed five common stages:

1. Denial
2. Depression
3. Anger
4. Negotiation
5. Acceptance

3. **Ask** participants to share stories that demonstrate how individuals behave when they are in denial, or depressed, or angry, or are negotiating, or have accepted the condition of being HIV positive.

**INFORMATION**

1. People who have been told that they have a fatal, incurable condition (such as cancer or HIV) have been known to pass through at least five emotional stages: denial, depression, anger, negotiation, and acceptance.



## Is denial always the first reaction of a person who has tested HIV positive?

**Objective:** To create an understanding that different people have different **coping mechanisms** after they learn that they are HIV positive.

### GUIDELINES

1. **Ask:** Is the first reaction of a person to testing HIV positive always denial? Let participants share their views.
2. **Explain:** Reactions vary from person to person. Some deny the test results and continue life as though nothing were wrong. Some go into deep depression. Others react with anger. And so on.
3. **Ask:** If a person is in denial, is it the duty of a counselor or friend to force them to accept the test result? Is it wrong to deny the test result? Allow participants to discuss their opinions.
4. **Explain:** Denial, depression and other reactions to testing HIV positive are called **coping mechanisms**. By denying that he or she is HIV positive, a person gains some time to digest the information and

slowly come to terms with it. A trained and skillful counselor can help a person gradually move from denial to acceptance.

5. **Ask:** What behavior is implied by 'negotiation'? Let participants share views.
6. **Explain:** In negotiation, the person usually tries to bargain with God to add a few more days to his or her life, in return for being more devout, doing good deeds, being 'born again', undertaking service to the church, and so on.
7. **Ask:** What sort of behavior is implied by 'acceptance'? Let participants share views.
8. **Explain:** In acceptance, a person comes to terms with the fact that he or she has a virus that will finally kill him or her. Instead of adding more days to life, that person tries to add more life to his or her days through more positive, constructive living.

### INFORMATION

1. Denial, depression, anger and negotiation are normal human coping mechanisms for dealing with news of an incurable and fatal condition.
2. With skilful continuing counseling, a person may get over these stages and finally learn to accept his or her condition and make the best of the remaining years.

**Acceptance means adding more life to your days rather than trying to add more days to your life.**



# Touching feelings.

Living with HIV

**Objective:** To use role play to help participants understand the range of changing emotions that an HIV positive person may go through.

## GUIDELINES

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- Tell** participants that you are going to use role play to explore the emotional changes of a person as he or she slowly copes with the news of being HIV positive. Ask participants to suggest a name for this person.
- Select** a row of 10 participants, and explain that each of them represent the same person in different stages of coping with being HIV positive.

- Demonstrate:** Using the drawing below as a guide, move from participant to participant, letting each one represent a new emotional stage in the person's process of coping with HIV infection. Explain the way in which feelings and emotions can fluctuate over time between denial, anger, depression, negotiation and acceptance.
- Explain:** Describe each of these emotional states.

**Denial:** Refusal to accept the result. Asking for a re-test, refusing to talk about it, or telling themselves and others that it is a mistake.

**Depression:** Going into seclusion, feeling sad. Behaving as though they have opted out of life.

**Anger:** Blaming other people for the infection. Some persons could become vindictive, trying to infect others.

**Negotiation:** Bargaining with God, pleading for more time alive in return for living a model life.

**Acceptance:** Coming to terms with being HIV positive — and deciding to make the best use of the time left by living with hope, love, and courage.

**DENIAL**  
"Oh God! I'm HIV positive! It must be a mistake!"

**ANGER**  
"I'll have my revenge on them for doing this to me!"

**DENIAL**  
"Maybe I should go for another test to be sure."

**DEPRESSION**  
"What's the point of living? I might as well commit suicide."

**ANGER**  
"I'm going to infect as many people as I can before I die."

**NEGOTIATION**  
"Maybe God will save me if I become Born Again."

**ANGER**  
"I hate myself. It's all my fault. Let me drink myself to death."

**NEGOTIATION**  
"Dear God, add more days to my life, please. I will do your work on earth."

**DEPRESSION**  
"I will run away far from here to a place where no one knows me."

**ACCEPTANCE**  
"Let me learn to live positively and with hope — I will add life to my days."



## What would happen if a person took an HIV test without counseling before and afterwards?

**Objective:** To create an understanding of the role of Voluntary Counseling and Testing (VCT) in an individual's ability to cope with the result of an HIV test.

### GUIDELINES

1. **Ask:** What would happen if a person took an HIV test without counseling before and after? Allow participants to express their views on this.
2. **Explain:** Without pre- and post-test counseling, a person may not be prepared for the difficult emotions that he or she may experience if he or she tests positive, and may do harm to himself or herself or others while feeling depressed, angry, or disturbed. Similarly, testing negative will produce different emotions, and will require appropriate counselling.
3. **Ask:** What was the sky like in the morning today? Let participants remember the color, the clouds, the light and so on of the morning's sky.
4. **Ask:** Is the sky right now exactly like this

morning's sky in every respect? Let some participants go out and look at the sky, and report back to the group.

5. **Ask:** Will the sky tomorrow morning be like this morning's sky? After participants have answered, **ask** "Does the sky ever repeat itself exactly in every respect?" Let participants realize that the sky is constantly changing, and is never the same on two different occasions.
6. **Explain:** A person's feelings are constantly changing, like the changing sky. If a person is depressed today, then a week later, he or she may be feeling cheerful. Another week later, the feeling may be anger.

Skilled counseling before and after the HIV test helps a person understand the full implications of the test results, and prepares him or her for these changing feelings. With support from family and friends, and continuing counseling, an HIV positive person can overcome his or her turbulent feelings, and return to life with new determination and optimism.

### INFORMATION

1. Professional counseling before and after an HIV test prepares a person to understand the full implications of the test results, whether they are positive or negative. **If the result is positive, then counseling also helps the person cope with the difficult emotions that will arise, and will guide him or her towards acceptance of the HIV positive result. With support from family and friends, and continuing counseling, an HIV positive person can overcome his or her turbulent feelings, and return to life with new determination and optimism.**
2. **If the result is negative, then the person will have different reactions and will require appropriate counselling.**

## Can person who is HIV positive have a normal and fulfilling sexual life?

### INFORMATION

1. For an HIV positive person, a 'normal' sexual life means taking the responsibility to prevent infecting his or her partner, and also protecting himself or herself from re-infect. This can be done through:

1. Abstaining completely from penetrative sexual intercourse.
2. Correctly and consistently using condoms during every act in which there is penetrative vaginal or anal sexual intercourse, or an exchange of body fluids.
3. Not having sexual intercourse with a person of unknown STI status.

**Objective:** To introduce the concept of normalcy with responsibility.

### GUIDELINES

1. **Ask:** Can a person who is HIV positive have a normal and fulfilling sexual life? Allow participants to share their views, and explore what they consider to be a 'normal' or 'fulfilling' sexual life. Some provocative questions which could help the discussion:

- Can a person with a cold and fever have a 'normal' sexual life?
- Can a person whose partner is sick with cold and a fever have a 'fulfilling' sexual life?
- Can a young man or woman who is busy preparing for an important examination have a 'normal' sexual life?

2. **Explain:** A person with a cold and fever may not feel in the mood for sex. Even if they felt like having sexual intercourse, they might decide against in case their partner gets infected with their cold. Similarly, if the partner is not feeling well, or does not feel like having sex, then the experience may not be satisfactory for both people, and

may not be 'fulfilling'.

3. **Explain:** Similarly, a person with HIV, who is going through stormy emotions and trying to come to terms with his or her infection, may simply not be in the mood for any relationships for some time, let alone a sexual relationship.

Even if they were in the mood for sexual intercourse, they would have to behave with **responsibility**, and take some precautions to prevent their partner from becoming infected, or themselves becoming re-infected by their partner. This can be done through:

1. Abstaining completely from penetrative sexual intercourse.
2. Correctly and consistently using condoms during every act in which there is penetrative vaginal or anal sexual intercourse, or an exchange of body fluids.
3. Not having sexual intercourse with a person of unknown STI status.

This is called **normalcy with responsibility**.

## If a person is already infected with HIV, why does he or she need to use condoms any more?

**Objective:** To introduce the concept of re-infection by another strain of HIV.

### GUIDELINES

- Ask:** If a person is already infected with HIV, why does he or she need to use condoms any more? Allow participants to express their views and list them on a flip chart sheet. Some or all of the following points may emerge:
  - To prevent an STI infection.
  - To avoid pregnancy.
  - To avoid infecting the partner with HIV.
  - To avoid re-infection.
- Ask:** If a person already has HIV, then can he or she become re-infected with HIV? Allow participants to share views.
- Explain:** If a person already has one type of HIV, then he or she could get re-infected by another type of HIV. Then the person's immune system would be fighting two battles against two slightly different forms of HIV.

### INFORMATION

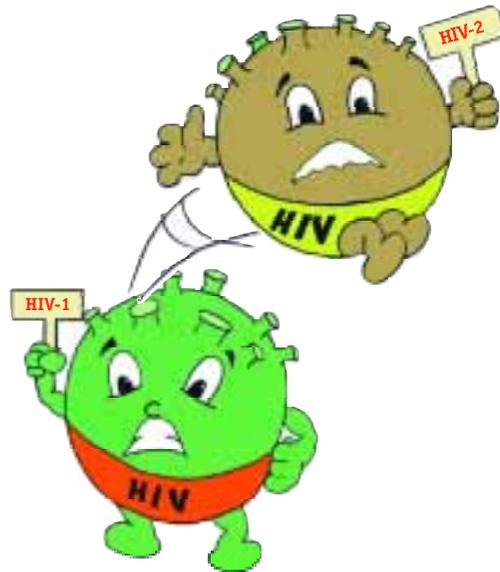
- An HIV positive person should use a condom with every act in which there is penetrative anal or vaginal sexual intercourse, or an exchange of body fluids, in order to:
  - Prevent an STI infection (including HIV)
  - Avoid pregnancy
  - Avoid infecting the partner with HIV
  - Avoid re-infection
- A person infected by one strain of HIV can become infected by a different strain. Then their immune system would be fighting two battles against two slightly different forms of HIV.

## How many types of HIV are there?

### INFORMATION

1. There are two strains of HIV, known as HIV-1 and HIV-2.
2. About 99 percent of the AIDS in the world is caused by HIV-1.
3. HIV-2 is believed to be active mainly in Africa and certain Asian countries.

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**Objective:** To create an understanding of the types HIV-1 and HIV-2.

### GUIDELINES

1. **Ask:** What is a 'type' of virus? How is one type of HIV different from another? Allow participants to express their opinions.
2. **Ask:** How many different Kenyan tribes can you name? As participants name different tribes, list them on a flip chart sheet.
3. **Explain:** Though each tribe is different from the others, they are all Kenyan, and have the same national identity.
4. **Explain:** Just as one tribe differs from another but they all share the same national identity of being Kenyan, similarly there may also be 'strains' or 'types' of a virus. So far, two strains of HIV have been identified, called **HIV-1** and **HIV-2**.

HIV1 and HIV2 both result in exactly the same condition called AIDS. However, they differ slightly from each other in

the shape of the chemicals on their surface. Thus the antibody that the immune system creates for fighting HIV1 cannot fight HIV2, and vice versa. A different antibody is needed for fighting HIV2. (**Note:** Ask participants to recall what they have learnt earlier about the shape of HIV and the chemicals on its surface.)

5. When HIV multiplies in a person's body, it produces imperfect copies with slight differences. These are known as **mutations**. One HIV-infected person may produce from 1 billion to 10 billion variations of HIV every day. Most of these will not continue, but a few may turn out to be resistant to HIV drugs.
6. HIV-1 was isolated in 1983. In 1985, a second type, labelled HIV-2, was discovered among West African prostitutes. About 99 percent of the AIDS in the world is caused by HIV-1. HIV-2 is believed to be active mainly in Africa and certain Asian countries.