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# LIFTING THE BURDEN OF SECRECY

A Training Module  
for  
HIV-Positive Speakers

Produced by



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## **FOREWARD**

If you are an articulate, highly motivated and passionate speaker, no doubt you have found great satisfaction in speaking out openly as a person living with HIV. You have seen what an effective AIDS educator you are. You now want to pass your skills on to other HIV-positive people who want to do public speaking. This training module is designed for you. It will help you to facilitate HIV-positive people to improve their communication and presentation techniques. After completing the module, participants will have increased skills and confidence to go out into the community and present their stories in a clear, structured manner.

This training module is an accompaniment to 'Lifting the Burden of Secrecy - A Manual for HIV-Positive Speakers Who Want To Speak Out In Public'. Copies of this training module and the manual are available from the HIV Focal Point in most UNDP Country Offices in Asia or by contacting the Asia-Pacific Regional Project Office via [benjamin.brown@undp.org](mailto:benjamin.brown@undp.org) or [angeline.ackermans@undp.org](mailto:angeline.ackermans@undp.org) or from APN+ via [apn@pacific.net.sg](mailto:apn@pacific.net.sg). The manual can also be downloaded from the UNDP website. If a hard copy of the manual is unattainable, a shortened version, which includes the major issues covered in the training, accompanies this module as Part B and can be photocopied and given to each participant.

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**APN+**

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# LIFTING THE BURDEN OF SECRECY

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# LIFTING THE BURDEN OF SECRECY

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## Part A - FACILITATORS' GUIDE

### WORKSHOP REQUIREMENTS

This training module is a two-day course divided into six 90-minute segments.

The two days may be delivered consecutively, or spaced over one week.

The ideal number of participants is 12 (minimum 6, maximum 16).

Unless there are less than 10 participants, two separate rooms are needed on Day Two.

### Facilitation

The module is designed so that two co-facilitators conduct the training. This allows for variety in style and pace. It also shares the load. For example, one facilitator can lead one session and the co-facilitator can lead the next. It enables one of you to focus on the group responses, whilst the other acts as the aide and writes responses on the board.

Because of the amount of material to be covered, you need to keep note of the timing and move through the material efficiently, still allowing enough time for participants to engage in the exercises and discuss any important issues that arise from them.

### Preparation

Before you start the training, read through this module carefully to make sure you know

- what you are doing in each segment
- why you are doing it
- how to do it
- which of you will deliver each training component.

### Materials

The essential materials needed to conduct this workshop are simple:

- large sheets of paper
- water-soluble felt-tip pens
- sticky tape and/or blue-tac
- participants' notebooks and pens.

The module assumes you have access to a whiteboard, although this is not essential.

An overhead projector is optional. If the unit on overhead projectors is taught, the facilitator will need to prepare two overheads before the workshop commences.

### The Workshop Space

If possible, familiarise yourself with the workshop space before the first training day.

On Day One, arrive with enough time to spare, say 45 minutes, to make the space hospitable and to relax before the workshop begins.

Rearrange the seating such that there is a complete circle. Do not have any empty chairs in the circle. If fewer participants arrive for the training than you expect, take away the extra seats. Otherwise you create an awareness that something is missing. You want to create a feeling of unity and cohesion within this group.

## WELCOME & INTRODUCTIONS (15 minutes)

### Purpose

*To learn participants names, find out where they are from, how long they have been diagnosed and how much speaking experience they have had as an openly positive person*

There are many different and creative ways in which you can introduce participants to each other. As you increase your training experience you can develop a catalogue of 'ice breakers' that are useful for different situations and different groups.

### Activity

Welcome all participants to the course. Ask everybody to form a circle so that they stand round in alphabetical order, A to Z, according to their first names. Once the circle is complete, check the order by going round and asking people their names.

Go round the circle again and ask each participant to repeat his or her name.

Tell participants that if they forget each other's names, they can try to remember where that person was standing in the circle.

Now ask the participants to form a line, from closest to most distant, depending on the distance they have travelled to attend this training session.

Go along the line and ask each person to state from where they have come.

Ask participants to repeat their name before they say where they are from.

Ask everybody to form another line according to the amount of time since his or her HIV diagnosis. Ask each participant to tell the group the year of their diagnosis and to explain very briefly any involvement they have had in the HIV/AIDS field since then.

Whilst still in the line, ask participants to put up their hands if they have done any public speaking as an openly positive person before.

Explain that this shows that there is no prescribed time for a person to make the decision to become an AIDS educator. It is different for everybody.

What is important is that everybody in the room is at that point now.

Thank everybody and ask them to come back into the circle and take a seat.

## COURSE OVERVIEW & GROUNDRULES (5 minutes)

### Purpose

*To ensure that all participants understand the parameters within which the workshop will operate*

#### Preparation

Before the session, write this course overview on large sheets of paper, on the whiteboard, or prepare it as an overhead.

#### Day 1

Introductions & Groundrules

Qualities of Good Speakers

Elements of Storytelling

#### Break

Body Language

Structuring Talks

#### Lunch

Question Time

Overhead Projectors

Contracts

Debriefing

#### Day 2

Using Breath & Voice Effectively

Practice at Speaking Out

Practice at Speaking Out

Summary of Lessons Learnt

Goal Setting

Debriefing

Evaluation

Show people the course overview and tell them at what times you will take breaks.

### Activity

Explain that groundrules are established so that everybody understands what to expect of each other during the workshop.

Ask people what groundrules they wish to adopt.

Write participants responses on a large sheet of paper.

The list may include such things as:

- Participants will be punctual
- Only one person speaks at any time
- Others listen when one person is speaking
- We will respect the opinions of others of the group
- We will not be judgemental of or abusive to others
- We will respect the confidentiality of all that is shared over these two days
- We will own our statements by starting sentences with 'I ...'
- We will enjoy ourselves.

Attach these groundrules to the wall so that they are prominently displayed.

Refer to this throughout the workshop if/when groundrules are not followed.

## **MOTIVATION (10 minutes)**

### **Purpose**

*To understand why people speak out and the link between protecting human rights and preventing new infections.*

Explain that most people who do public education are very motivated to do so, either because of the shock of their own diagnosis and their wish that others will not become HIV-positive or because they have experienced discrimination and want to fight AIDS-related stigma.

### **Activity**

On the whiteboard write two headings: SUPPORT and PREVENTION.

Ask people why they want to do public speaking.

Write up the responses under either heading, depending on whether they primarily want to address AIDS-related discrimination and support other people living with HIV or whether they primarily want to prevent new infections.

Some answers will span across both categories so write these in the centre of the board.

### **Review**

After all people have contributed, ask them to review the link between fighting stigma and fighting new infections.

Explain that because HIV/AIDS carries with it so much stigma and moral judgement, people stereotype those living with HIV and deny that it can affect them. Putting a human face to HIV helps to break down the stereotypes, challenge community norms, decrease discrimination and get people talking about HIV.

As well as leading to improved prevention efforts, speaking out also enriches the lives of the speakers. They gain respect from others by lifting the burden of secrecy and challenging the myths surrounding AIDS and this usually has a beneficial impact on speakers' health and wellbeing.

## WHAT MAKES A GOOD SPEAKER (20 minutes)

### Purpose

*To examine the qualities that speakers needed to communicate effectively and to set goals for participants*

### Preparation

For this exercise you will need a 2-metre length of paper or several sheets taped together and several felt tip pens.

### Activity

Tell participants that they are now going to move around the room.

Place a 2-metre length of paper on the floor. Ask for a volunteer to lie down on the paper so that we can draw the outline of a person's body. Ask another participant to draw around the outline of the person who has volunteered to lie on the paper.

(If participants are too shy to do this or it is inappropriate for the group, draw around your co-facilitator or simply draw a life-size outline of a body.)

Ask participants to think about the qualities that make an effective speaker.

Ask them to write down each of these qualities on the paper, next to the body part that seems most appropriate. If participants are unsure where to write, give them some guidelines. For example: clear minded - head, appropriate language - mouth, no distracting mannerisms - hands, sound preparation - feet, eye contact - eyes.

If at the end of this exercise nobody has done so, write, in the centre of the body, 'open heart' and 'passion'.

Now ask participants to go and stand next to a quality that they believe they have.

### Review

Discuss where each person is standing and why.

### Activity

Ask people to look at the outline again and go and stand next to the quality that they most want to work on for themselves.

### Review

Go around the circle and ask people what goals they hope to achieve from this training. Write participants' responses up on a large piece of paper.

Explain that goal setting is a continual process. It is people's choice whether to participate in the learning process. It is up to them to get the most out of the workshop.

Attach the final product to the wall. Tell people that we will review these goals at the end of the course and set new goals for the future.



## ELEMENTS OF GOOD STORYTELLING (30 minutes)

### Purpose

*To discover the elements of good storytelling*

### Activity

Invite participants to find a partner with whom they feel comfortable to share a personal story. If there is an odd number, one co-facilitator will take part in the exercise.

Ask everybody to take some time to think of one of the most embarrassing things that has ever happened to them. Then, in pairs, turn to share their stories with their partner.

Ask them to spend about three or four minutes telling their story and then change over. After four minutes have elapsed, remind everybody to swap over and listen to the other person's story, if they have not already done so.

Ask participants to come back to the circle and sit down. Go around the circle and let each person share their partner's story with the group (allow about 2 minutes each). Their partner is not allowed to interrupt the speaker.

As a group, brainstorm the following questions. (Brainstorming means asking people to give their responses without placing any value judgement on them. Each and every contribution is valid and the facilitator should not filter the responses or alter the words. When brainstorming, aim for a large quantity of responses.)

1. Which were the interesting stories?
2. What was it that kept your interest in the story?
3. Did you want to ask questions when anybody told a particular story? Why?

Write every response on the board (eg: humour, simple, clear, believable, can relate to it, honesty).

### Review

Tell participants that the qualities that they have articulated and are now written up on the board are some of the elements of good storytelling.

In particular, to create and maintain interest, they have to ensure that the audience can relate to them. The story must be relevant to the person listening.

A good speaker presents simply and clearly, has a sense of humour and, perhaps most importantly, tells their story with passion.

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## BODY LANGUAGE (20 minutes)

### Purpose

*To understand the messages we give by our body language*

#### Preparation

Prepare four sheets of paper, each with one of the following headings:

FEAR, EXCITEMENT, ANGER, SUSPICION, JOY.

Attach blue-tac onto the back of each sheet.

Explain that we are now going to explore how we physically react to different feelings.

Ask participants to try and work alone on this next exercise.

### Activity

Ask everybody to stand and find a space in the room. Ask them to avoid looking at other people and focus just on themselves. Ask them to imagine a situation in which they once felt very afraid of something. They can close their eyes if it helps. Ask them to recreate that feeling, really get into the emotion and let the fear enter their body. Encourage them to move around the room, by moving around yourself. Continually remind participants to work by themselves as they move, ignoring the people around them. Get them to focus on the feeling in their own being. Ask participants to observe what is happening physically to their body as they allow that feeling of fear to envelop them.

Attach the first sheet of paper headed 'Fear' on the wall. Ask participants to write down how their body felt physically when they experienced the emotion of fear.

Ask everybody to shake their bodies and breathe deeply to clear away those feelings.

Repeat the exercise with the feeling of excitement. Ask, 'How does it feel?' 'What is happening to your body?' 'What is the difference between the two emotions?'

Ask them to write their response on the second sheet of paper headed 'Excitement'.

Repeat with feelings of anger, suspicion and joy.

Ask them to articulate and write down the different physical feelings after each emotion.

### Review

Ask participants to come back and sit in the circle. Discuss what happens to our bodies as we experience different emotions. They will have recognised that when afraid, they close in and tense up whilst when they are excited they feel lighter, more energetic. Explain that when we are feeling positive our body feels light and opens up. If we experience negative emotions our body feels heavier and we use our energy differently.

When speaking to an audience, a presenter must be open. It is therefore important to be critically aware of your body language. For example, holding one's arms across one's body closes a person in and creates a barrier between the presenter and the audience. Fidgeting with objects whilst you are presenting is annoying and indicates that you are nervous. Speakers must stand calmly and openly in front of the audience and use eye contact to engage the audience members.

## WHAT IS IMPORTANT FOR YOU (30 minutes)

### Purpose

*To build confidence in the ability to speak out*

### Preparation

During the break, write, on the board, the list of questions on the following page and keep them covered until after the visualisation. Alternatively you can write them on a large sheet of paper that you attach to the wall at the appropriate time.

Explain that they will now do a relaxation exercise followed by a creative visualisation about giving a successful talk. This is again a personal exercise that each person will do alone. They can go wherever they want to with the exercise. Tell the group that if anybody wants to use their own technique to relax they can do so, and ignore the facilitator's vocal cues.

### Activity

Ask each person to sit comfortably. Guide participants slowly through this exercise.

'Close your eyes. You are now going to relax. (Pause) Allow every breath that you take to relax you more and more. Every time you exhale, relax. (Pause) Take your attention to your feet. Relax your feet as you breathe out. Wiggle your toes and relax. Relax the whole foot. (Pause) Start to work up through your body, relaxing each muscle as you visualise it. Your body is becoming very relaxed, but your mind is sharp. You can hear all the sounds around you and all that is being said. Move through the calf muscles and relax. (Pause) Relax the thighs, the buttocks. (Pause) Relax every time you exhale. (Pause) Be aware of the torso and all the tension you are holding in your body. (Pause) Relax the stomach, the chest. (Pause) Relax the lower back. (Pause) Now focus on your fingers. Relax them. (Pause) Relax the hands. (Pause) Move up, through the arms. Relax. (Pause) Be aware of the shoulder muscles. Relax. (Pause) Breathe out and relax. Now move up through the neck, relaxing. (Pause) Become aware of the face muscles. Relax the jaw, the mouth, the tongue and the lips. (Pause) Relax the brow and the top of the head. (Pause) Allow all the tension to release through the top of your head, leaving you completely relaxed. Your whole body is relaxed but your mind is very alert.

(Long Pause)

'You now find yourself in a beautiful garden. In one hour you will give your first talk. (Pause) You have arrived early and have an hour to spend in this garden to refresh yourself. (Pause) Look around. Flowers are everywhere. Walk along the path in front of you. It leads you to some water. (Pause) The water is beautiful and clear. It is warm and inviting. The sun is on your back. (Pause) You decide to bathe in the water. Nobody else is around. Take off your shoes and clothes and walk into the water. Feel the water touching your toes. Breathe in deeply with each step you take. Look at the water. It is inviting you. (Pause) Plunge headfirst into the water. Feel yourself swimming, like a fish. (Pause) You can breathe in the water. Glide through the water and look at everything about you. (Pause) The water is clear and fresh and you can see all around. Swim about and enjoy your newfound freedom ...

(Long Pause)

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‘When you have finished your swim, come back to the shore. Laid out on the ground is a beautiful set of clothes ready for you. Your body is dry from the sun’s rays. You feel refreshed.(Pause) Put on the new clothes. Now you realise it is time to go to the talk. Walk slowly back along the path.A person is waiting to greet you. (Pause) The person smiles, comes up to you and walks with you to the place where the audience awaits you. You breathe deeply and walk in. You are introduced. You stand before the audience. People are friendly. You smile. You begin to tell your story. You feel everybody’s keen interest. They listen to you intently. Some nod their heads in agreement. Some are shocked,some upset. Be aware of how you feel as you stand and deliver your talk.Sometimes the audience laughs as you tell your story. Check how that makes you feel.See yourself standing in front of the audience. (Pause) You come to the end of your story. People clap. They come up and thank you.The person who brought you to the venue gives you a gift. You open it. (Pause) You thank them. Your talk is over and now you can come back to this room. Take a deep breath.Move your fingers and toes. Begin to open your eyes and stretch out your arms and legs.Stretch your whole body and blink your eyes. You are back in the circle. Welcome’.

Display the following questions on the whiteboard or on paper. Before anybody speaks to anybody else,ask everybody to write down the answers to these questions.

Tell people not to worry if they cannot answer all the questions. Write down whatever answers they can.

- What clothes did you wear to the talk?
- What gift were you given?
- How did you feel about yourself?
- What qualities did you display?
- How did you respond to the audience?

## **Review**

Ask each person to share their experiences and responses within the group.

Explain that it is important to dress appropriately for an audience. ‘People often judge a book by its cover’. It is important to wear something that makes the speaker feel comfortable and also makes them feel good about themselves.

Explain that their gift is a token of acknowledgment and thanks.

Explain that we can create our own reality. If we visualise ourselves in a positive light, we will get positive results.This visualising of ourselves doing a successful talk is important work, and something we can come back to from time to time, to affirm to ourselves that we are competent presenters.It is a very useful exercise to do alone,the night before a talk.

## STRUCTURING TALKS (40 minutes)

### Purpose

*To develop a structured approach to storytelling*

Explain that speaking out openly about living with HIV pushes people's comfort zone.

In order to stretch people's comfort zone gently we need to make them want to hear our story. It is therefore important to work on the common points between the presenter and the audience rather than the differences. People remember stories they can relate to. If people relate to the speaker and see some similarity between that person and their own situation, they will be more interested in listening to what the speaker is saying.

### Beginnings

Explain that first impressions are very important.

People often remember, for example, the mood a person was in when they first met.

Consequently, beginnings are important. This is when you build rapport with the audience, make connections with them and establish the benefit of the talk for the listener.

### Activity

Ask participants to sit alone for a moment and think about what they might say at the beginning of their talk. How will members of the audience relate to you? What do you have in common with them? It could be your similar educational backgrounds or upbringing or you might remind them of a neighbour or relative. How will you introduce yourself? What mood will you establish? Will you disclose your status immediately? Where will you begin? Ask them to write down their thoughts in point form.

As a group, share ideas about how to begin a talk.

### Body of the Talk

Explain that their presentation may cover many different aspects of their life. How much they decide to disclose is up to them. It is important only to talk about what feels safe.

### Activity

Create a list of the major issues that they may wish to include in their story, such as:

- Reasons for going for an HIV-antibody test
- Mode of infection
- Coping with an HIV diagnosis
- Telling friends or family
- Level of health and wellbeing
- Dietary requirements
- Impact on social life
- Impact on employment / income / housing
- Access to treatment and care
- Choosing a doctor
- Emotional and physical support
- Community attitudes
- Discrimination
- Grief and loss

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Explain that it is wise to try and focus on three major points in their story.

Ask everybody to write down three major aspects of their story that they want to share.

Ask them to think about why they made these choices.

Suggest that it is a good idea to group similar ideas together. For example, when highlighting discrimination issues, talk about all the experiences together, rather than moving away from and back to the same concepts.

### **Endings**

Explain that before one begins a talk one must decide where the story is going to end. There is little use in continuing to talk for the sake of filling in time.

Once a speaker has discussed the major issues that s/he planned to talk about before arriving at the venue, then it is best to stop and leave time for questions from the floor.

The ending should bring together elements of the talk and examine a way forward. For example, the speaker might revisit a major point, such as the help they got from HIV-positive peers, and then provide information about support groups or services available. The speaker may be able to provide different types of information including details of local contacts.

### **Activity**

Ask everybody to write down the concluding points of their talk.

### **Review**

In pairs, ask participants to spend five minutes or so reviewing their overall basic structure and the content of their talk and give each other feedback.

## **HANDLING DIFFICULT SITUATIONS (10 minutes)**

### **Purpose**

*To provide ways to handle difficult audience situations*

### **Activity**

Brainstorm some examples of difficult or awkward situations that speakers may occasionally face with an audience member.

These will include times when people are:

- not paying attention
- talking amongst themselves
- being abusive
- asking provocative questions.

Brainstorm reasons for these situations:

- the audience members are tired
- they are preoccupied with their own concerns
- they harbour prejudices due to the speaker's race, social status, religion, etc.

Brainstorm ways to overcome some of these barriers:

- change the focus or pace
- ask questions such as, 'Do you know the difference between HIV and AIDS?' or 'How many of you have previously met another HIV-positive person?' or 'What were you expecting before I arrived?'
- always mention any common points with the audience and affirm these.

## ENCOURAGING QUESTIONS (20 minutes)

### Purpose

*To develop techniques to encourage questions from the audience*

Explain the need to show the audience that the speaker is open and willing to talk about issues. If, however, a question is raised that a speaker feels uncomfortable with or to which they do not know the answer, then it is best to say so. The audience will respect the speaker more if they are open and honest than if they avoid a question or lie to them.

A person might choose to answer a particular question in one setting but not in another. For example, when talking to your peers, you may feel they could become infected in the same way that you did, and you may tell them so they can protect themselves.

Sample answers to some common questions are given on the following two pages.

### Activity

Ask participants why it might be important for the audience to have an opportunity to ask questions at the end of a talk. Questions can:

- indicate the audience's interests
- indicate the level of understanding of issues
- enable the audience to direct the discussion
- clarify misunderstandings
- keep people alert.

Discuss ways to encourage questions:

- Hand out pieces of paper and ask people to write down questions anonymously.
- Say, 'If you want to ask questions about any aspect of my story, please feel free to do so and I will try and answer as best I can. Try not to be too shy about asking questions because I am only here today to provide answers'.

Brainstorm examples of sensitive questions the audience might ask:

- How did you get HIV?
- Do you have sexual relations now?
- Do you have children?

Ask why some people may not wish to discuss such questions:

- They may be embarrassed or afraid of the associated stigma.
- It may be a sensitive issue, such as the loss of a child or the ability to have children.
- They are not yet emotionally prepared to discuss the issue.

One speaker may answer a question that another may choose not to. The reason is not important. If a speaker is uncomfortable with a question they do not have to respond. Tell participants that the golden rule is:

*Only tell people if it is comfortable for you and it is of value to the audience.*

Each speaker must decide which questions s/he is willing to answer.

Discuss techniques to respond to unwanted questions.



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## COMMON QUESTIONS AND SAMPLE ANSWERS

### 1. What is the difference between HIV and AIDS?

HIV stands for the Human Immuno-deficiency Virus. When a person is infected with HIV, the virus attacks the immune system. Over several years, HIV depletes the immune system. At this point, the person may contract opportunistic infections such as pneumonia, meningitis, tuberculosis. The person is then said to have AIDS or Acquired Immune Deficiency Syndrome.

### 2. Can I get it from touching people with HIV?

No. Air, skin or saliva cannot transmit HIV. For an adult to contract HIV, there must be blood to blood contact (from injecting equipment, a blood transfusion or blood products) or sexual contact.

### 3. Can you get HIV from mosquitoes?

No. A mosquito sucks blood into one part of its stomach and injects saliva from another part into the skin. If people could contract HIV from mosquitoes, infection rates would be distributed across all age groups in society, which is not the case. HIV infection is found predominantly in young sexually active adults, injecting drug users and babies who contract it directly from their mother.

### 4. Are men and women at equal risk of contracting HIV from sex?

Globally, most people contract HIV through sexual intercourse. In countries where the epidemic is most prevalent, approximately equal numbers of men and women are living with HIV. However, women usually contract HIV at a younger age. This is because young women have the least socio-economic power within society and the least negotiating power within relationships and they are physiologically more vulnerable to infection. During sexual transmission, the virus passes into the blood stream of the sexual partner via the vaginal wall, the penis, the anus, or the mouth. Transmission rates increase when there are microscopic breaks in the thin skin lining the penis or the vagina. This happens when there is rubbing or injury due to coerced sex or infection.

### 5. Can a woman who is HIV-positive have a healthy baby?

Yes. About three out of every four babies born to HIV-positive mothers do not become infected with HIV. The probability of an HIV-positive mother transmitting the virus is reduced to less than one in ten if she takes a course of anti-retroviral drugs before delivery, has a Caesarean delivery and does not breastfeed her baby. Most women do not have access to anti-retroviral drugs or Caesarean section and issues around breastfeeding are complex. A baby who is not breastfed is at greatly increased risk of death from diarrhoeal disease because of the lack of protection from breast milk. Infant formulas are often unaffordable and, for some, clean water is unavailable. And in many cultures it is socially very unacceptable not to breastfeed. Currently WHO recommends exclusive breastfeeding for the first six months of all newborn babies lives then immediate weaning to solids. Mixed feeding increases the baby's vulnerability to HIV. Good nutrition for the mother, including multi-vitamin supplements, reduces the risk of transmission.

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## **6. Is there any treatment?**

There is no cure for HIV and a vaccine is still many years away. Over recent years, triple combination therapies, which include three different anti-retroviral drugs, have reduced the incidence of AIDS-related deaths in developed countries. For people living in developing countries, treatments are unavailable or very expensive, even drugs for opportunistic infections.

## **7. How can I live longer?**

An important factor in living longer with HIV is having a positive attitude and having support from other positive people, family and friends. If you do not have a positive people's support group in your area, consider starting one. Eating a variety of nutritious foods and reducing stress are both extremely important in long-term survival. With a balanced diet, a reduced workload, good support and a positive outlook, it is possible to live healthily with HIV for many, many years without progressing to AIDS. When opportunistic infections do occur, it is very important to receive treatment as soon as possible.

## **8. How did you get it?**

In most cases, a person contracts HIV through an intimate exchange with a person they trust. It is therefore important, particularly for young people, to examine the basis on which they trust their partners and their ability to be assertive about the choices they make.

Whether you disclose how you contracted HIV may depend on your audience. For example, if they have a similar background to you, it could be advantageous to tell them how, so that they readily identify with you. The method of contracting HIV is no protection against the stigma and discrimination a person living with HIV may face. It is more important to know how a person lives with HIV than how the person got it.

## **9. Why focus on HIV/AIDS when other diseases kill many more people?**

Globally AIDS-related illness is now the fourth leading cause of mortality and the leading cause due to infectious disease. HIV-infection rates continue to rise and have had a significant impact on average life expectancy in many countries. Unlike other leading causes of mortality, HIV selectively affects young adults, the most productive members of society. The effects of illness and death amongst these individuals are amplified because of their dependants. Effort and money expended early in promoting HIV prevention is most cost effective and can potentially completely arrest HIV infection.

## **10. Does sex education make young people more sexually active?**

Most people become sexually active in their mid-teens, irrespective of culture or religion. Studies show that providing sex education to children before they become sexually active delays the onset of first intercourse, and encourage safer sexual practices and/or monogamy. In countries where infection rates have decreased, the greatest reductions occurred in young people, indicating that it is easier to influence people's behaviour before they become sexually active, than to change established behaviour patterns.

## USING OVERHEADS (OPTIONAL - 20 minutes)

### Purpose

*To provide guidelines on the use of overhead projectors*

### Preparation

Prepare two overheads before this session. The first will be a copy of this page. It has 36 single-spaced lines in 12-point type. It includes all the directions on the use of overheads but cannot be easily read. You are using it to demonstrate this.

Overhead 2 is provided on the following page.

Explain that some people have very visual minds and as speakers become more confident they may wish to include visual aids such as posters or overheads. Explain that you are now going to give some tips on how to best utilise overhead projectors.

Suggest that, if they are going to use any equipment, they try it out before the talk.

Make sure the projector is in working order.

Position the projection most effectively so that no light falls directly onto the screen.

### Activity

Place the first overhead on the projector. Ask what the problem is with this overhead. Replies will include too many lines, typeface too small.

Demonstrate how to change from one overhead to another. Have a piece of paper on top of Overhead 2. Place it on top of the overhead that has just been used. Slide the first overhead away from underneath. Cover this second overhead, which contains the major points below, in large, bold font, with a piece of paper and slide it down the page as you address each point. Do not let participants see the whole overhead at once.

- Make sure the overhead is in focus. (Demonstrate how to do this.)
- Use large type, few lines, dot points.
- To ensure that people are not reading ahead, cover the material and work down the page, only revealing each point as you reach it.
- Make sure everybody can see the projection screen.
- Ensure the overhead is correctly placed on the glass. Look up and check the alignment on the actual screen.
- Point to items on the projector glass, not on the projection screen.
- Face the audience when addressing overheads.
- Switch off the machine when not in use.

Switch the machine off. Ask people why you have done so. If participants do not say, mention that it is very distracting both visually and aurally. Switching the machine off when it is not being used cuts out distraction. It gives you quiet, changes the pace and enables you to focus your attention.

- **Make sure the overhead is in focus**
- **Use large type, few lines, dot points**
- **Cover material and work down, only revealing each point as you reach it**
- **Make sure everybody can see the projection screen**
- **Ensure the overhead is correctly placed on the glass (Look and check)**
- **Point to items on the projector glass, not on the projection screen**
- **Face the audience when addressing overheads**
- **Switch off machine when not in use**

## CONTRACTS (10 minutes)

### Purpose

*To emphasise the importance of signing a contract*

Handout copies of the sample contract below (from Page 55 of the speakers' manual). Brainstorm why it is important to sign a contract when doing a talk. Include the following:

- It is a safeguard against non-payment.
- It gives clear guidelines about the time and place of the talk.
- It enables you to gather information about the audience.
- It places value on the speaker.
- It gives the impression of professionalism.

## POSITIVE SPEAKERS' BUREAU BOOKING FORM

Please complete this form and return to:

Contact Name: \_\_\_\_\_

Organisation: \_\_\_\_\_

Postal Address: \_\_\_\_\_

Phone: \_\_\_\_\_

Fax: \_\_\_\_\_

Date of Talk(s): \_\_\_\_\_

Starting Time: \_\_\_\_\_

Length of Talk: \_\_\_\_\_

Venue Address: \_\_\_\_\_

Number of Participants: \_\_\_\_\_

Age Range: \_\_\_\_\_

If the group is mixed, indicate the number of males and females: Male \_\_\_\_\_

Female \_\_\_\_\_

To your knowledge is there anybody in the group who may have had or has a friend or relative who has been affected by HIV/AIDS? \_\_\_\_\_

Describe group's general knowledge and level of understanding of HIV/AIDS issues: \_\_\_\_\_

### Please tick the issues to be discussed:

Personal Experiences	( )	Death, grief, loss	( )
Community Attitudes / Discrimination	( )	Treatments	( )
Experience with Health Care Workers	( )	Transmission	( )
Support from Family, Friends	( )	Sexuality	( )
Other (specify) _____		Pregnancy	( )

Have you used the Positive Speakers' Bureau before? Yes ( ) No ( )

How did you hear about the Positive Speakers' Bureau? \_\_\_\_\_

The fee for a 1-hr presentation (including questions) is \_\_\_\_\_ per speaker

Plus Travel Costs of: \_\_\_\_\_ per/km

Accommodation, food and expenses are subject to negotiation. (The Positive Speakers' Bureau is dedicated to addressing the widest audience possible. Fees are negotiable if financial constraints limit access to the service.)

I, \_\_\_\_\_ request the Positive Speakers' Bureau to provide \_\_\_\_\_ talk(s) at the fee of \_\_\_\_\_ on the date(s) stated above. Method of Payment: Cash ( ) Cheque ( )

Signed \_\_\_\_\_

Date \_\_\_\_\_

## DEBRIEFING (20 minutes)

### Purpose

*To examine the role of debriefing*

### Activity

Brainstorm the reasons why it is important (and at times invaluable) to debrief after talks. Write all the responses on the whiteboard, including:

- to discuss one's emotional response to a talk
- to work out how to deal with difficult situations
- to gain more confidence
- to evaluate and acknowledge one's accomplishments.

Go around the circle and ask each person how she or he feels after today.

### Planning

Tell the group that they now have the skills to do a talk. All they need is practice. Tomorrow, therefore, they will present part of their talk to the rest of the group. The talk should be about 15 minutes long, depending on how comfortable they feel.

Tell them to review their opening, the major focal points and their ending overnight, so that they are prepared to speak out tomorrow.

Ask them not to write out their speech but to note down the main points on prompt cards.

Suggest that, if they have the opportunity, they can talk into an audiocassette player to check the quality and length of their talk.

Thank all the participants for their input.

**END OF DAY ONE**

## WELCOME (15 minutes)

### Purpose

*To check on how people are feeling and to develop focus and concentration*

### Preparation

If somebody is absent remove that chair from the circle.

Ask each person in the circle how he or she is feeling before their presentation today.

Explain that today will be very interactive and they will be doing much of the work themselves. Most of the session will concentrate on personal presentations and they will give feedback to each other on the work they do.

Suggest that they try to be creative in their feedback. Ask them to focus on what does work, rather than on the negatives. Of course, if there is something that is particularly distracting, people must try not to be shy because constructive comments will help the speaker in the long run.

After today's presentation it will be easier to talk to other groups because it is usually much more frightening to present to peers than to strangers.

Before participants begin their talks, explain that they are going to spend a few moments focussing their mind. This can be done through controlled breathing.

### Activity

Ask everybody to sit comfortably.

Go through the following 'Alternate Nostril Breathing' exercise.

'Using one hand, place your thumb on one nostril and a finger on the other. Press the right nostril closed and inhale a full deep breath through the left nostril. Now close the left nostril and release the right. Breathe out through the right nostril. Now inhale a full deep breath through the right nostril. Close it. Release the left nostril and breathe out.'

Repeat this exercise six times.

### Review

Ask participants how they feel. Most will recognise an immediate effect on controlling their emotions and focussing their mind.

Suggest that they try this exercise before they give a talk.

## VOICE WORK (15 minutes)

### Purpose

*To realise the need to exercise our voices to become more effective speakers*

Explain that speakers need to strengthen their voices to develop good tone, clear articulation and the volume to project their voices effectively. Doing vocal exercises before a talk ensures that our voices do not get strained and it helps to calm the mind and focus on the talk.

Go through the following voice exercises.

### Tone and Volume Exercise

Stand straight up, with your feet placed evenly and comfortably apart. Relax your shoulders. Drop your chin a little towards your chest. Imagine there is a fine string attached to the top of your head and it is pulling you up gently. Relax your lips gently together and start to hum, making a continuous 'Mmmmm...' sound.

Take another few breaths and continue to hum. Try to find the deepest, lowest note with which you feel comfortable to hum. Relax the throat.

On the next breath begin to open the mouth slowly as you are humming, so that you make a 'Mmmaaaaaaa' sound. Repeat a couple of times.

Now, start to project the sound across the room, reaching further across with each breath. Make sure that you are not straining your neck muscles. Repeat.

### Articulation Exercise

Loosen the tongue by writing your full name on the roof of your mouth with the tip of your tongue. Stretch the tongue right across the whole surface.

If the tongue muscles are not yet aching, repeat the exercise.

Now push and squeeze your lips into every strange shape you can make, really stretching your mouth muscles.

Repeat a tongue twister such as 'red leather, yellow leather' over and over again. Start off slowly and increase the speed, retaining clear articulation.

### Review

Suggest that participants try these exercises from time to time when they are alone.

If they have access to an audiocassette recorder, they can record parts of their talk before and after these exercises to compare the difference in the vocal clarity and tone.



## STYLE OF TALKS (60 minutes)

### Purpose

*To give participants experience in developing the style and quality of their presentations*

Explain that each person will now present her or his sample talk. After each talk there will be about 10 minutes to give feedback on what works and what does not.

Discuss the need to stand squarely in front of the audience, to use eye contact as they speak, to speak slowly and clearly and to change the tone and pace from time to time. Ask them not to have any barrier between themselves and the audience or to hold any item with which they may fiddle and thus distract the audience.

Unless the group is small, in order to ensure that everybody has an opportunity to give their presentation and not be overwhelmed by too many personal stories, the group must be divided into two, with one facilitator working with each group. (You can start with one large group and split up after the break.) Explain where each group will work.

### Activity

Ask participants to split into two groups (or allocate participants to each group).

Once everybody is settled, ask the first person to begin.

When participants are delivering their talk, tell them when 10 minutes is up, then 15 minutes and if they are still talking at 20 minutes, politely cut them off, reminding them how important it is to keep track of the time and to pace of their talk.

As each person presents, ask the others to take notes on the following:

- Body language and eye contact
- Volume, tone, speed, clarity
- Structure and content

### Review

After each talk, ask the presenter to give their critical comment first. This can be stimulated by asking questions such as, 'How did you feel it went? How could you have improved your body language?'

Invite others to give positive criticism of each other.

Give your feedback to the speaker. Remember to mention the positive elements first. For example: 'That was a great start. You appeared to be very relaxed and in control'.

Do not be rigid with what people say in their stories. The personal narrative is the important, if not the essential element of HIV-positive educators. The audience must connect with them on an emotional level.

## CONTINUE SAMPLE TALKS (90 minutes)

Continue through each person's presentation. Ask how their talks might be improved. Various comments will arise as you go through the talks. Make sure they are all written up on the board.

Discuss the need for eye contact. Try the following exercise at an appropriate point.

### Activity

Ask a volunteer to address the group for 60 seconds without looking at anybody.

Discuss how it feels to be in the audience but have no eye contact with the speaker.

Ask another person to repeat the exercise but to focus on one person and keep unbroken eye contact with them.

Discuss how it feels to be singled out for eye contact.

Explain that eye contact means catching the eyes of the listeners without focussing for too long on any particular person but moving their eyes around the room catching the attention of any person looking at them.

### Review

Ensure that the following points are covered during the feedback from the presentations:

- ✓ Speak slowly and clearly
- ✓ Speak loudly enough for the people at the back to hear
- ✓ Avoid saying 'umm', 'err', etc too frequently - breathe instead
- ✓ Relax
- ✓ Vary the tone and pace
- ✓ Shift eye contact and briefly engage with different audience members
- ✓ Remain still; do not continually move from foot to foot
- ✓ Avoid fidgeting and other distracting habits
- ✓ Do not cross your arms; remain open and welcoming
- ✓ Stand rather than sit
- ✓ Remember to smile
- ✓ Use appropriate language
- ✓ Talk about your own experiences, not other people's
- ✓ Do not read your talk as it becomes monotonous; use prompt cards
- ✓ Tell your story as if it is the first time you have ever told it
- ✓ Always speak from the heart

## **SUMMARY OF LESSONS LEARNT (40 minutes)**

### **Purpose**

*To develop a checklist of what is needed to ensure a successful presentation*

If necessary, allow time for the last presentations.

After everybody has finished, bring both groups back together.

Tell them that they now know how to present and all they need is to try it out in the field.

Explain that they are now going to review the important issues raised during the training.

### **Activity**

Ask each person to find a partner from the other group. In pairs, spend up to 15 minutes devising a checklist of things they need to do before, during, and after a presentation.

Bring the group together and taking one idea from each pair in turn, create a collective checklist on the board.

#### **Before**

- Check the time and place of the talk
- Find out any background material about the audience
- Try out the talk with an audiocassette recorder
- Prepare prompt cards indicating the major points to discuss
- Prepare smart, comfortable clothes

#### **On the Day**

- Arrive with plenty of time to spare
- Ensure the room is laid out to its best advantage
- Have no barrier between you and the audience
- Rearrange the seating if necessary
- Check that any equipment is working properly
- Have a glass of water on hand before you start
- Focus your mind
- Loosen the voice and tongue

#### **After the Talk**

- Do something relaxing
- Arrange to meet somebody
- Debrief
- Congratulate yourself

## GOAL SETTING (20 minutes)

### Purpose

*To enable participants to set realistic, achievable goals*

Take a look at the list of learning goals that were developed at the beginning of day one. Ask participants whether they feel they have achieved their goals.

Ask them to sit alone for a few moments and think of three new SMART goals to set for themselves. Write the word SMART on the board, vertically.

Explain that it means that their goals must be:

**S**pecific

**M**easurable

**A**chievable

**R**ealistic

**T**ime-framed

### Activity

Ask everybody to write down their three new goals:

1. Short-term goal - they will work towards over the next day or so
2. Medium-term goal - to be achieved over the next week or so
3. Long-term goal - to achieve over the next few months.

Explain that writing down one's goals helps us to focus on them. Ask participants to review their new goals from time to time and to continually set new ones.

## DEBRIEFING & EVALUATION (30 minutes)

### Purpose

*To monitor how people feel at the end of the workshop and discover what aspects of the training worked best*

### Preparation

Photocopy the evaluation form over the page, or design your own and copy.

Ask participants to whom they will go to debrief after their first talk. Stress the importance of strategically planning this.

Suggest that people try and find a buddy to go along with them to their first talk. This should be somebody with whom they can discuss issues freely and whose criticism they feel okay to listen to.

### Activity

Explain that it is now time to debrief from the training.

Firstly go back to the goals that people had on the first day of the course.

Examine the list. Ask if there is a consensus on whether we have reached the goals.

Go around the circle and ask people to discuss how they feel, what they have gained from the course and what new goals they have set for themselves.

*Thank all participants for their contributions over the past two days.*

Hand out the evaluation forms and ask everybody to complete one before they leave.

**END OF TRAINING**

# POSITIVE SPEAKERS' TRAINING

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## EVALUATION FORM

Please complete this course evaluation to help us improve this training.

CIRCLE the appropriate numbers in questions 1 and 2.

### 1. What is your assessment of the speakers' training course?

Unenjoyable	1	2	3	4	Very Enjoyable
Poor Quality	1	2	3	4	High Quality
Expectations Not Met	1	2	3	4	Met My Expectations
Content Too Familiar	1	2	3	4	Much New Material
A Waste of Time	1	2	3	4	Highly Worthwhile

### 2. How would you rate the facilitators' overall style?

Poor	1	2	3	4	Excellent
Inappropriate	1	2	3	4	Appropriate
Gave Confusing Directions	1	2	3	4	Gave Clear Directions

### 3. How could either facilitator improve their performance?

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### 4. What was the most valuable aspect of the training for you?

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### 5. What were the strengths and/or weaknesses of the course?

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### 6. Is there anything you intend to do differently when you do a talk as a result of this course? If yes - what? If no - why?

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### 7. Any other constructive comments about the course and/or facilitators?

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*Thank you very much*

# LIFTING THE BURDEN OF SECRECY

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## Part B - PARTICIPANTS' GUIDE

The following pages are an abridged version of 'Lifting the Burden of Secrecy - A Manual for HIV-Positive People Who Want to Speak Out in Public'. The manual was produced by APN+ in 1999 and has since been reprinted and translated into French, Spanish and several Asian languages. Copies of the complete manual and this accompanying training module are available from the HIV Focal Point in most UNDP Country Offices in Asia or by contacting the Asia-Pacific Regional Project Office via [benjamin.brown@undp.org](mailto:benjamin.brown@undp.org) or [angeline.ackermans@undp.org](mailto:angeline.ackermans@undp.org), or from APN+ via [apn@pacific.net.sg](mailto:apn@pacific.net.sg).

### THE POWER OF POSITIVE SPEAKERS

Almost universally, our earliest messages about AIDS imply that people who are infected with HIV are morally blameful. This stigmatisation of AIDS makes people deny that HIV can affect them. After an HIV diagnosis, most people lead a double life, unable to disclose their secret for fear of discrimination.

HIV-positive people who put a human face to AIDS challenge societal attitudes. They show their communities that anybody is vulnerable to HIV infection and that people living with HIV can lead productive lives for many years. People who speak out openly about the reality of living with HIV come from all backgrounds. Some have not finished their primary education whilst others have university degrees. Some are inspired to speak out after listening to their peers whilst a few have never met another positive person before they go public.

Meeting positive people breaks down fear, decreases discrimination and prejudice and creates an atmosphere in which people can discuss AIDS openly and begin to treat positive people with respect. As AIDS-related stigma decreases and community norms are challenged, people change their perceptions about their vulnerability and take greater responsibility for HIV prevention.

*I encountered a lot of discrimination before I came out in public. There were lots of rumours that I was HIV-positive. One day I just decided, 'This is enough. I do not want this to happen to another person. I'm safe here in the support group. Nobody can touch me'. I think it was better if I'd come out earlier. The discrimination against me is now less because people know I am HIV-positive.*

*(Marites, Philippines)*

The power of HIV-positive people speaking out publicly is in lifting the burden of secrecy. No positive person, however, should publicly disclose their HIV status unless they are ready. Very few people disclose their status on national television, radio or newspapers. Most talk to relatively small groups of people with whom they feel safe. Many carry out public AIDS education without disclosing their status to people in their neighbourhood. Some do not inform their immediate family, although most do.

The following pages outline the support needed before taking this brave step and some techniques to develop effective presentations.

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## BENEFITS TO THE SPEAKER

Often a positive diagnosis shatters one's self esteem. Most HIV-positive people face huge issues of loss, disempowerment, isolation and social ostracism. The vast majority hide their status for fear of negative repercussions. They live with a carefully guarded secret, which masks the face of AIDS.

HIV-positive people who do publicly disclose are usually passionately motivated. Some are propelled by the desire not to see other people in their situation. They want to arrest the spread of HIV. Many speak out to show they have the same rights as others to housing, employment, care and support, access to treatment, privacy, freedom of movement or freedom from violence.

*I was married when I was 18 and I was so faithful to my husband. To be told that I have HIV was very painful. I thought of how many women in these marriages die of things that they don't know. That's what made me talk about it. I talk to women who think they are not at risk of HIV because they are married.*

*(Jane, Zambia)*

Coming out openly and discussing one's status not only challenges the status quo and breaks the silence surrounding AIDS. The vast majority of positive speakers also find it to be an extremely rewarding experience.

- Public speakers feel they are making a worthwhile contribution to society.
- Audience responses instil self-respect.
- HIV disclosure is accompanied by enormous feelings of relief that one is lifting the burden of secrecy that has weighed heavily since diagnosis.
- Releasing this stress has a positive impact on the speaker's health.

The overall impact of speaking out and publicly disclosing is that it enables people to take back some control over their lives. It re-establishes personal dignity, builds self-esteem and improves overall wellbeing. Most HIV-positive speakers say the benefits far outweigh any negative consequences.

*Everything was tight inside me... I opened the door to my health. Everything is helped. Life is better from the day that I was open about my status. I am happy I have come out.*

*(Joseph, Tanzania)*

*The most difficult thing about living with HIV is putting on a mask. Now, I no longer have to live in a shell with a split personality. I'm no longer afraid.*

*(Paul, Singapore)*

*Keeping quiet kills. It really kills. If you talk to someone you feel so relieved. It's not an easy step to talk openly but it helps. Before, I was so scared. But talking openly about my HIV status made me very, very strong.*

*(Helen, Botswana)*

*I'm valuable. I'm important. I have a part. I haven't lost my worth as a person.*

*(Suzana, Indonesia)*



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## SUPPORT NEEDED

Disclosing one's status is confronting. Taking that first step and speaking out openly to strangers can be terrifying, even if you are strongly motivated and have previous public speaking experience. People need time to come to terms with their diagnosis before they can publicly disclose their status. Usually it is necessary to talk through the decision with other people living with HIV or with a counsellor.

Before you go public about living with HIV, you need good support; sympathetic, trustworthy people with whom you can discuss issues that arise after a talk. For the majority of positive speakers, their greatest support is peers and/or their family.

### Positive Peers

- Other positive people know what it is like to face the fear of living with HIV.
- Ask other positive educators if you can accompany them to a talk.
- Try to answer some questions at the end of their talk.
- When you give your first talk, ask your buddy to accompany you and discuss it with you afterwards.

### Family

- It is extremely frightening to talk to your family about your status.
- Family members are often much more supportive than people expect.
- In practically all situations, few negative repercussions have come about because of telling family members.
- In most instances the outcome of family disclosure is closer, more supportive family relationships.
- When disclosing to your family, start with a family member to whom you can most easily share your thoughts and feelings. In many cases this will be a sibling.
- If family disclosure is very difficult, ask for help from a counsellor or a health worker

*My family was very, very afraid of other people's reactions. I was thrown out and not allowed at home. I spoke to my HIV-positive friends about the importance of representing others. I wanted society to understand people with HIV in order that my family and my village might understand.*

*(Oom, Thailand)*

Some people go public without telling their family or revealing their status to their local community by carefully selecting to they speak, only giving talks in areas far from their residence or by adopting a pseudonym, a name they use when publicly disclosing their HIV status.

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## LEGAL ISSUES

Nobody should harm you physically or mentally because you are infected with HIV. Before you speak out in public, talk to somebody with a legal background and find out what rights you have. Most people face little, if any, social stigma after going public. It is, nevertheless, important to think through the possible consequences and consider how you would deal with them.

- If somebody threatens or harms you, what recourse do you have?
- How sympathetic are the police towards people living with HIV?
- What protection can they provide?
- What happens if you lose your job because you go public?
- Do you have the right to challenge this in court?
- Would you be willing to go to court?
- If your child's education is threatened, what recourse do you have?
- How would your child cope with discrimination at school?

*The elite feels that HIV is only for the wretched people in society, not for them. They live in the greatest denial. It was terrible for them to hear me, a university graduate. I have made people appreciate that people living with HIV are not stupid, dirty people who cannot talk. They see me looking clean, arguing sensibly and I've demystified the fears and misconceptions. We are now involved in the design and implementation of programs, in making things move. These are great advantages and I believe very strongly that if I had kept my HIV status secret, this would not have happened ... When I first got diagnosed I was silent for some time. I had just come out of university and I needed a job. I knew if I came out into the open immediately, it would not be easy for me. Also, I was in a rented house. I was not independent. When I got a job in an AIDS organisation I had an understanding boss so I was protected. Then my father gave me a place to stay, so my landlord could not throw me out. I haven't faced discrimination because I gauged the stage at which I should go public.*

*(Beatrice, Uganda)*

### Signing a Contract

As experts in what it is like to live with HIV, positive speakers should be reimbursed for time and expenses incurred in giving a talk. If your presentation is informal, you should be given an honorarium to cover costs such as transport and meals. Once you gain respect and legitimacy and establish yourself as an AIDS educator, you should request a fee. It is always advisable to sign a contract with the person who books you to talk.

By signing a contract,

- You avoid embarrassment if anything goes wrong.
- It is a safeguard against non-payment of expenses and/or fees.
- It gives clear guidelines about the time and place of the talk.
- It enables the speaker to gather background information about the audience.
- It gives the impression of professionalism.

The contract should state who is booking the talk, the date, time and place, the size of the audience and the expenses or fees to be paid. It can also indicate the audience age range, and levels of HIV knowledge/awareness, which can help you to shape your presentation for that particular audience.

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## TELLING YOUR STORY

### *Only tell as much of your personal story as feels comfortable*

The art of good storytelling is to speak from the heart. It is important that your talk is a personal perspective, your own story. Because your life is constantly changing, so also will your story. The value of speaking face-to-face with an audience is that, if you are true to yourself you allow the audience to empathise with and relate to you on a human level. This makes them realise that people living with HIV are a cross-section of society and not very different from themselves. You are able to break down prejudicial attitudes and get people talking about AIDS.

- You do not have to reveal everything about yourself.
- Do not tell people anything that makes you feel uncomfortable.
- Speaking out should not be a confession or testimonial.
- There is nothing wrong with having HIV.
- Telling your personal story is not about giving a purely factual lecture but about describing how HIV has affected your life.

### **Structuring the Talk**

A good story has a beginning, middle and an end. Before you start you must structure your talk and decide where you will begin, what are the major points on which you want to focus with that particular audience and where your story will end. Once you have done this, do not write out your talk as a speech; it will sound monotonous and the audience will switch off. Instead, use prompt cards (small pieces of paper indicating the key points you want to cover).

Your opening is when you create the audience's interest and desire to hear your story. Begin by introducing yourself. Tell the audience something about yourself that they can relate to. If it is a group of young people, you might say where you went to school and what you did after that. If it is a group of mothers and you have children, mention that. Focus on the common points between you and the audience.

The body of the talk can cover many aspects of your life with HIV. Choose the major points and write them down. Some of these may be:

- the impact HIV has had on your lifestyle
- telling friends and family
- any discrimination that you have faced
- how your health has been affected
- treatments you have tried
- how you have remained well, if that is the case
- any impact HIV has had on your earning capacity
- how you have maintained your emotional and psychological well-being in face of a life-threatening condition which is surrounded by so much stigma and taboo
- what support is available

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*I feel very good.I feel relief. In seven years I've never been sick,never admitted to hospital.*

*(Paisan,Thailand)*

## **Soliciting Questions**

The most successful talks are those that involve the audience and get them asking questions.Once you have discussed the major issues that you had planned to, stop and leave time for questions.Speaking for the purpose of filling in time will turn off the audience's interest. As you become more confident in handling questions, reduce the length of your introductory talk and encourage questions from the audience.

- Tell people that you will welcome questions.
- If it is a group of self-conscious young people,hand out pieces of paper before the talk and ask them to write down anonymous personal questions.
- If you do not know an answer, say so. People will respect you for it.
- You do not have to answer anything you do not want to.

If something is too personal, you can decline to answer in a way that makes people feel welcome to ask more questions. Try, 'I prefer not to discuss that,as it is a very sensitive topic for me at the moment but perhaps you would like to know more about ...how my family or friends responded,or the difference between HIV and AIDS?'

## **IMMEDIATELY BEFORE A TALK - CHECKLIST**

- ✓ Contact the organiser and find out any background material about the audience.
- ✓ Prepare prompt cards indicating major points to discuss.
- ✓ Try your presentation on a cassette recorder.
- ✓ Check time and place of the talk.
- ✓ Have contact details for any support services that audience members may want,such as support groups, care services, testing sites and treatment information.
- ✓ Prepare smart, comfortable clothes.
- ✓ Arrange to do something relaxing afterwards and to meet somebody to debrief.

### **Creative Visualisation**

We all create our own reality. If you can visualise yourself doing a successful talk, you will get positive results.The night before a talk,as you go to sleep, try this exercise. Go through the body, part by part,and relax with every outward breath.Then imagine you are walking to the place where you are to give your talk. Your journey takes you along a beautiful garden path to a body of crystal clear water. You have plenty of time so take time out to have a swim in the water. When you have finished,dried and dressed,picture yourself arriving at the venue and being warmly greeted by the audience. See yourself delivering a successful talk.Imagine yourself delivering your words calmly and clearly. Check that you are not tense. See yourself smile. As you fall asleep, check where you are holding tension in your body. Every time you breathe out, release the tension from a different part of the body.

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## ON THE DAY OF THE TALK - CHECKLIST

- ✓ Give yourself time to eat and rest before you depart.
- ✓ Arrive at the venue with plenty of time to spare and locate the organiser.
- ✓ Consider the layout of the room and decide where you will stand.
- ✓ Do not stand in front of a window. It strains the audience's eyes and puts you in silhouette. Place yourself in the lightest part of the room.
- ✓ If the chairs are moveable, rearrange the seats if necessary. (If the audience is large, stand up in front of them; if it is small, sit everybody in a semi-circle.)
- ✓ Make sure everybody can see you and there is no furniture immediately in front of you that will act as a barrier between you and the audience. The more intimate you make the environment, the more engrossed the audience will be and the more easily they will relate to you.
- ✓ Have a table or desk behind or beside you on which to place a glass of water, your bag, any handouts you plan to give out.
- ✓ Check that any equipment is working properly.
- ✓ Focus your mind and loosen up your voice and tongue.

### WARM UP EXERCISES

Regular breathing exercises lead to increased lung capacity. Voice exercises reduce stress on your vocal chords and improve the clarity of your speech. Try out these.

#### Alternate Nostril Breathing

Sit comfortably. Using one hand, place your thumb on one nostril and a finger on the other. Press the right nostril closed and inhale a full deep breath through the left nostril. Close the left nostril and release the right. Breathe out through the right. Inhale a full deep breath through the right nostril. Close it. Release the left nostril and breathe out. Repeat six times. The effect on controlling emotions and focussing the mind is instant.

#### Releasing the Voice

Stand up straight with your feet placed evenly apart and shoulders relaxed. Drop the chin towards the chest. Hum softly and deeply with your lips gently closed. See how deeply you can hum. Relax your throat. Repeat several times. Now start with lips gently closed, then open the lips and make a 'Mmmaaaaaaaaaa' sound. Repeat several times. Imagine the sound travelling far across a great hall.

#### Loosening the Lips and Tongue

Squeeze and stretch the lips into every possible strange shape. Write your name with the tip of your tongue on the roof of your mouth. Repeat. (You can do this exercise in front of people and they will not know you are doing it.)

#### Improving Articulation

Say a tongue twister, such as: 'red leather, yellow leather'. Repeat it over and over. Start very slowly and increase your speed without 'twisting' your tongue.

#### Deep Breathing

Breathe deeply several times. Feel the bottom of the lungs expand with each inward breath. As you breathe out, expel all the air from your lungs. Let go of tension each time you exhale.

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## DELIVERING YOUR TALK

Bigger does not mean better. Your first talk should be in a safe environment to a small supportive group such as health workers, members of a religious group, or workplace employees. This will give you the opportunity to feel the ground and weigh up how much more public you want to go.

- Before you begin your story, imagine it is the first time you have ever told it. This enables you to retain a fresh perspective each time that you do so.
- Keep a check on the time, and pace yourself so that you cover your major points
- Mark the most important points and note those you can omit if you run out of time.
- Allow time for questions.
- If you become overwhelmed by emotions, relax, take a deep breath and don't worry; the audience will understand.
- Make sure the audience can hear you. Ask if the people at the back can hear you.
- Vary your rhythm, tone and pace to capture the audience's attention.
- Make eye contact with the people you address. Do not focus too long on any one person, as it makes them uncomfortable, but catch the eyes of different individuals in different parts of the room for a few seconds each so that everybody feels involved.
- Use appropriate language and do not feel shy to ask the audience if they understand what you are saying.
- Be aware of your non-verbal body language. If you appear open, relaxed, smiling and in control, the audience will be more at ease and ready to listen. Try to remain still and do not cross your arms.
- Do not hold anything in your hands as you will fiddle with it and distract attention.
- Talk about your own experiences, not other people's.
- Always speak from the heart

The first time people do a talk they are usually very nervous and speak far too quickly. The quicker you speak, the higher your voice rises and the greater strain you place on it. Realise that the audience is probably adjusting to your voice, what you are saying and to the shock of somebody telling them that they are living with HIV. Many thoughts might be going through their minds. Do not rush anything. Before you talk, take a sip of water, breathe in and out calmly and smile.

### Using Overheads

- Ensure your transparency is in focus and properly aligned. Check on the screen.
- Have only a few major points on each transparency.
- Use large type, few lines, dot points.
- Limit the number of lines per overhead.
- Make sure the lighting is good.
- Work down an overhead point by point, uncovering each point as you get to it. This ensures that people are listening to you, not reading ahead.
- Make sure everybody can see the projection.
- Point to items on the projector, not on the projection.
- Face the audience when talking to overheads.
- Switch off the machine when not in the use.

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## DEALING WITH THE MEDIA

*Nobody* should go public in the media unless they have a great deal of support and it is their decision to do so. Doing an interview with the media is *very* different to speaking out live. The live experience allows people the opportunity to relate intimately on a personal level to the speaker. The possible negative consequences of media exposure are potentially far greater than speaking personally, face-to-face, with an audience.

The experience of Gugu Dlamini provides a solemn warning to those who dare to speak out and break down the wall of silence surrounding AIDS. On World AIDS Day, 1998, Gugu went public in the local media. She lived in a South African province where approximately 30% of adults are HIV-positive, one of the highest infection rates in the world. Yet Gugu's neighbours threatened her because she had supposedly given her community a bad reputation and brought shame on them. Three weeks later they attacked and killed her.

- Choose your medium (radio, television, print) carefully.
- Be very clear on your conditions.
- Decide whether you are going to use your real name or a pseudonym.
- Decide whether you are willing to be photographed or filmed.
- Only give an interview if you are confident the interviewer has sympathetic views.
- Check that the policies or style of the publication or station will allow an accurate presentation of you.
- Do not give an interview to media that sensationalise AIDS or depict HIV-positive people as 'victims' or 'sufferers', or place blame on them.
- When you first discuss the interview, ask what sort of questions you will be asked.
- Beforehand, write down three major issues that you wish to address.
- If the journalist asks you surprise or difficult questions, say, 'I prefer not to discuss that' and immediately move on and talk about an issue that is important to you.

*Everyone was shocked that I was diagnosed, and I didn't think it could happen to me, and I know there's a million people out there in the same boat. And hopefully by my standing up in front of them, it might help them think twice. I consider I'm saving lives.*

*(Shelly, Australia)*

Nothing will guarantee against surprise, trick questions being inserted by an unscrupulous interviewer. Take control of the interview from the start. It is your choice to do it so decide what you want to say. If you wish to stop the interview at any point, you can. *You have every right to refuse to give an interview* if you are not one hundred per cent comfortable with what the outcome may be.

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## AVOIDING BURNOUT

You will feel mixed emotions after your first talk. The experience may be draining but it becomes less so as you speak out more. There may be parts of the talk you want to change for next time. Do not worry. The overall response is likely to be very positive. With time you will improve and gain more confidence.

As you become more active it is likely that you will have difficulties coping with the competing demands of responding to further requests for your expertise, maintaining your health and catering to the demands of your family. Burnout is a real issue for many positive people, particularly if they are the only one doing advocacy work in the region.

Be very careful not to overdo it. It benefits nobody if your work exhausts you to the point that you become ill. Do not over commit yourself. If you are the only person who can do the job, you cannot do everything at once. It is okay to say no. The opportunity will arise again. Take time out regularly to look after your own needs of good food, rest and relaxation. Reflect and congratulate yourself on all that you have achieved.

*I've challenged a lot of misconceptions in my country... People have come to accept that there is no danger in associating with people with AIDS. And it has helped me to grow a lot and to adjust much faster than if I had not come out. It has been very healthy for me.*

*(Joe, Kenya)*