

With

H O P E



and

H E L P



© KenDune

Manual for People with HIV/AIDS

For facilitators and positive people groups
To accompany the video "With Hope and Help"
manual provides information and positive advice
for People With HIV/AIDS

DIS-325

“With Hope and Help”

Manual For People with HIV/AIDS

This manual was compiled by the Education and Counselling specialist staff from the Albion Street Centre, Sydney in conjunction with the Counselling Staff of Bamrasnaradura Hospital, Nonthaburi with assistance from the UNICEF Regional Office for East Asia and the Pacific.

**To accompany the
video “With Hope
and Help”**

**This manual provides
information and advice
for people with
HIV/AIDS on a wide
range of issues that
have proved to be of
great concern for HIV
positive people. As
well, the manual
includes individual and
group activities which
explore strategies for
living well with HIV.**



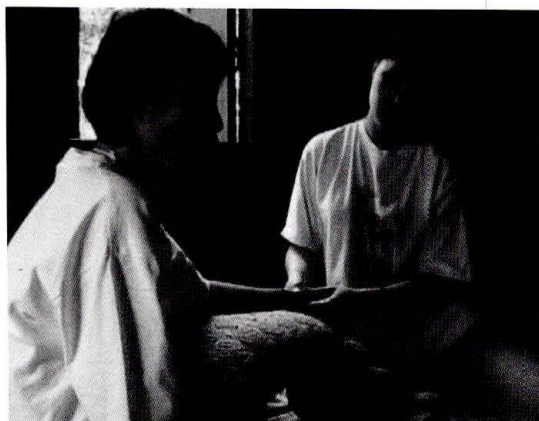
“With Hope and Help”

Foreword.....	3
About this vidio.....	4
How to get the most out of this manual.....	6
How to get the most out of this video.....	7
Finding Out.....	12
Keeping Well.....	13
Being Sick.....	17
Mental Health.....	18
Nutrition.....	20
Herbal Medicine.....	24
Employment.....	26
Love, Sex and Intimacy.....	29
Families.....	38
Disclosure.....	40
Facing Prejudice.....	45
Transmission.....	47

Acknowledgments

A great many people and many organisations contributed to the process of developing these materials. We would like to thank the people living with HIV/AIDS, the school children and students, the young people in workplaces and communities, members of various communities who sacrificed their time to discuss the video with our production team. We would also like to thank the participating organisations, both those who were represented on the project committee and contributed to the brainstorm process and those who organised meetings with various target audiences:

AIDS Project of the European Union
Asian Development Bank
Association for the Advancement of Children
Banglamung Hospital
Duang Prateep Foundation
Candlelight Club
CARE International, Thailand
Clear Skies Project
Family Health International
Foundation for Increasing Capability of Populace
Gillette, Thailand, Limited
Hyatt Erawan Hotel
Jardine Mathieson, Thailand Limited
Living Films
Minprasart School
Nawamintrachuthit Secondary School
NGO Coalition On AIDS
Nestle, Thailand Limited
Panat Nikom Hospital
Pearl S. Buck Charitable Foundation
Regent Hotel
San Pa Tong Hospital
Thai Business Coalition on AIDS
Thai Red Cross AIDS Program
Thai Spectacles Factory
Wednesday Friends Club
White Dove Association
YMCA



DIS-325
16037

Foreword

None of us deserves to be excluded from society because we have an illness or even just the germ of an illness in our bodies. This is the kind of exclusion people with HIV and AIDS are now experiencing. Those who imagine that they themselves are far removed from such a plight are the very ones busy excluding and discriminating against people with HIV and AIDS. Such people lack true understanding.

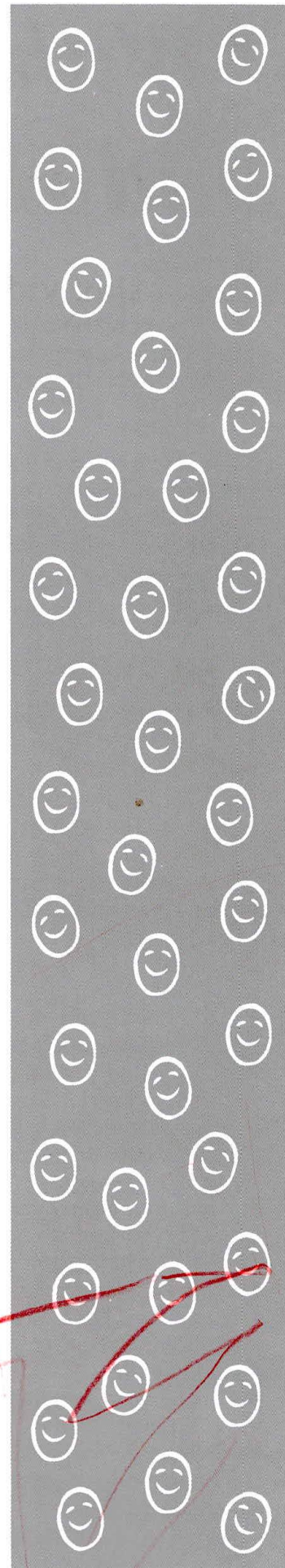
True understanding is the best cure society can provide to solve the very worst of problems. Everyone fears pain and suffering. We all fear death even more. But, most of all, people fear the living death which is caused when a person is excluded from the society in which they have lived their life.

This manual which accompanies the "With Hope and Help" video has been designed to give group leaders ideas and direction to run activities and discussions. The manual addresses misconceptions about people who have HIV and those sick with AIDS. The manual will be used with groups of leaders in society and with communities so that they can gain a true understanding of what it really means to have HIV. This is the sort of understanding that will open the gates of loving kindness and will be followed by the best help and support possible.

If you have HIV, the manual will help build your self-awareness and increase your understanding of your situation, which will lead to better care of your physical and mental health. It will encourage you to help out friends who are in the same situation. Being independent and caring for yourself is tremendously empowering. If you are able to help your friends and society as well, this can give you life-giving hope and strength.

What the world needs now is understanding. We all need to understand ourselves, our fellow human beings, and our society. From this, loving kindness will proceed. If we can do this, the world will certainly become a happier, more peaceful place.

Dr Chaowalit Natpratan
Director,
Communicable Disease Control Office, Region 10



“With Hope and Help”

About this video...

“With Hope and Help” is a 35 minutes video about HIV and AIDS. This inspiring video features intimate interviews with long term survivors confronting the epidemic throughout Thailand.

The aim of this video is to promote community support and acceptance of people with HIV/AIDS. The HIV positive people in the video can show communities that people with HIV/AIDS are ordinary people struggling to maintain their health and well-being, despite having a serious health problem.

What audiences wanted to know about the video

● **Is it true?**

This video is a documentary. The people in this video are not actors. They are not reading from scripts, either. They are real people, who have been brave enough to stand up and talk to us about living with HIV/AIDS. The film maker interviewed a total of forty people with HIV/AIDS for this video, but not all of their stories were used. (You can see the faces of all forty people during the credits at the end).

● **Does everyone on the video have HIV/AIDS?**

There are a few people talking on the video who don't have the virus. These include a monk, a nurse, a doctor, a herbalist, a nutritionist and a traditional medicine doctor, who are all involved in helping people with HIV/AIDS and working with communities to understand their needs.

● **How come they are all from the North?**

The HIV positive men and women in this video are from all parts of Thailand: from cities, towns and villages in the countryside. You may see places you recognise in the backgrounds. There are also a number of people in the video from the North of Thailand. This is because the North was the first region in Thailand to be seriously affected by HIV/AIDS. Now, there are more and more people in the North East and Central and Southern Regions who are also affected by HIV/AIDS. The people in this video hope that people everywhere will be able to learn from their experience.



This documentary was made possible through generous grants from : Care International Thailand; The Australian Government through AusAID; The European Union (ECAIDS) through Mahidol University's Asian Institute for Health Development and UN Thailand Theme Group on AIDS (UNICEF, UNDP, UNFPA, UNESCO, WHO, World Bank).

● **How come they don't look sick?**

The people with HIV/AIDS in the video are healthy and happy now. But as you will see and hear, they have all been through difficult times. Some of them have been seriously ill. Because HIV weakens people's immune systems, people with the virus can get a great many infections (called opportunistic infections). Many of these opportunistic infections can be treated. That is why the people in the video who were sick, look so healthy now, because they have received treatment of various kinds. Positive people need to take good care of their health and in this video, you will find some ideas for doing just that.

● **How come they don't seem to have problems like other people with HIV/AIDS you hear about?**

At first, the people with HIV/AIDS in the video all had a lot of problems. Sometimes families and communities rejected people with HIV/AIDS and treated them badly. They were scared to go near a person with HIV/AIDS. But, as time went on, more people understood that AIDS doesn't jump from person to person like a flea and that they could still eat with people with the virus and care for them if they were sick. Now, the people with HIV/AIDS in the video are able to lead full and happy lives as productive members of society, thanks to the support received from friends, relatives and community members, as well as their own determination.

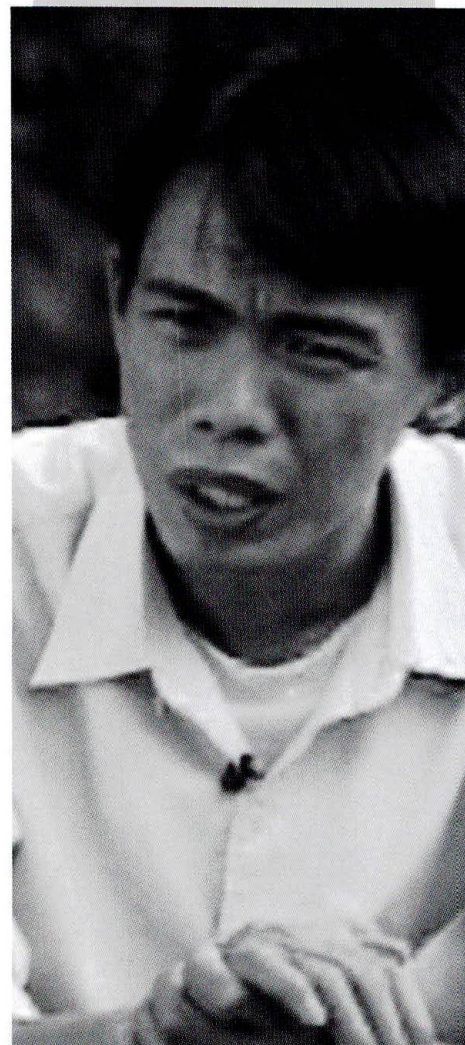
● **What can we do to help?**

We can support our friends, neighbours, workmates and family members with HIV/AIDS. We can give them encouragement and we can try to make sure everyone knows what HIV is really like. There are still some people who don't understand about the virus and who have trouble accepting people with HIV/AIDS. This can lead to people with the virus being treated unfairly, or with hostility, in their homes, in their work or in their communities. We can try to inform communities so that they change their attitude.

In the kit that follows: "With Hope and Help: For people with HIV/AIDS", you will find additional information and learning activities to enhance the message of the video for use with HIV positive people. The materials in the "With Hope and Help" series are:

- With Hope and Help, Manual For Communities
- With Hope and Help, Manual For People With HIV/AIDS
- With Hope and Help, Manual on Self-Care, For People With HIV/AIDS and their Carers.

All materials in this series are available in Thai and English. Please contact UNICEF EAPRO for distribution details on 2805931, extension HIV/AIDS Unit.



"AIDS is not something that should divide and isolate us, one from another, but something that should bring us together."

Prasert Dechaboon

How to get the most out of this manual

About this manual...

This manual was designed to promote the effective dissemination of the message of the documentary film "With Hope and Help" to a wide ranging population. The content, activities and advice that have been collected in this volume are intended to give people with HIV/AIDS alternatives and to inspire them to live with hope. The video was also designed to enable people in society, whether they be young people or the general population, or people providing services to people living with HIV/AIDS, to better understand the feelings and needs of people with HIV/AIDS.

One part of the process we used in designing this manual was to run discussion groups to find out what points interested our audiences, what questions they had, and what experiences and advice about living with HIV/AIDS they wished to share. We used this feedback to select additional information and develop activities. We hope this manual will assist people to have a positive and realistic approach to problem solving, as well as learning to live with the HIV virus on a day to day level. The manual was focus tested in a draft form with the range of target groups. We even developed some advice on how to best use this manual to promote discussion and to engage participants in active learning through activities.

Who can use this manual?

This manual is especially aimed at group leaders or facilitators to use with groups of people with HIV/AIDS. The group leader or facilitator may be an HIV positive peer educator, a teacher, a health worker, a volunteer or an interested HIV positive member of the group.

Viewers will get the most out of this video if it is followed by discussion and activities which explore viewers' reactions to the messages in the video. It is easier to conduct discussion and activities if the video is presented by a group leader or facilitator.

IN THIS MANUAL...

Topics with background information and activities:

- **Finding Out**
- **Keeping Well**
- **Being Sick**
- **Mental Health**
- **Nutrition**
- **Herbal medicine**
- **Employment**
- **Love, Sex and Intimacy**
- **Families**
- **Disclosure**
- **Facing Prejudice**
- **Transmission**

If you have limited time to spend with the group, we recommend asking the group to prioritise the discussion/activity topics. EG: Choices could be conducting the activity "Disclosure" which covers a number of significant issues, followed by "Facing Prejudice" or "Love, Sex and Intimacy" or "Keeping Well", depending on the needs and interests of the group.

How to get the most out of this video

Before viewers arrive to see the video...

Time and Place

If you're showing the video during the day, try and pick a spot that is as dark and shady as possible. Indoors is best, but if that is not possible, spend a little time finding the least reflective position for the screen. Videos often look their best at night, when the picture and colour stand out more.

Caution

Don't operate during thunderstorms as equipment may be damaged.

Distractions

If your viewers are busy senior executives in their offices or children during their playtime you may find that the executives want to keep on working and the children want to keep on playing!

Unless viewers are very, very interested in the topic they will be distracted if the video is shown somewhere where there are frequent interruptions or people coming and going. Try to find somewhere quiet where people can concentrate on the video.

Planning

Plan what you will do when the video is over.

In the following pages we give suggestions as to activities you might like to do with the group. However, the group may have its own ideas on what topic they are interested in pursuing. Get them to arrange the list of topics in order of priority. Background information sheets are provided for each topic. Where appropriate we have designed activities to encourage group participation. Use the activity sheets to get the group started with discussions.

TOOLS:

Videos need electricity or a generator, to operate. Check that the place you want to show the video has power and a VCR and TV in working order.

Before viewers arrive, make sure equipment is working, that the video is tuned, connected correctly to the TV etc.

When you start the video, check that people at the back can see and hear.

Before you show the video...

Preparing yourself

Make sure you know who will be viewing the video, how old viewers will be, what level of education they have, how much experience they have of HIV/AIDS.

Community Groups:

It is increasingly likely that general community groups will include either positive people who chose not to disclose their status or relatives of people who have HIV or are sick or have died. Group leaders may try and remember to include these perspectives in their presentation. Some terms that were used in Government campaigns early in the epidemic can offend people with HIV/AIDS or make them upset. Avoid phrases like "Only promiscuous people get AIDS". Emphasising the difference between "innocent victims" like wives and children and "guilty" people who may have acquired HIV through drug use or sex outside marriage, can make people feel rejected and excluded.

You need to:

- have seen the video;
- have a good idea what issues your group will be interested in and what issues you want to highlight;
- know how long each activity takes. There are many activities in this manual and you will not be able to do them all in one session;
- have ideas on how you will conduct the session: how you will move from viewing to discussion; whether you will break up into small groups after the video etc.;
- have any handouts ready to give out after the session (if you give these out before the session people will spend first five minutes of the video reading handout);
- know who the relevant contacts are in your area. You can use these contacts to refer people to, if they need further support or information;
- prepare participants by telling them the questions you will be asking them after they have viewed the video. For instance...

"After you've watched the video I want you to tell me who your favourite person was."

Preparing your audience

On a practical level:

Viewers need to know the video takes 35 minutes and how long you want them to stay afterwards, as well as what the video is about and where it comes from. Go through page4-5 "About this video", beforehand.

People are more likely to be interested in the video if they feel it is relevant to them. To make it relevant, introduce the video with a story about a local incident, or ask participants if they know any stories about people with HIV/AIDS or give the local statistics on HIV.

On an emotional level:

Group members are likely to experience a range of different feelings and thoughts as they watch the video and in the discussions that follow. It's helpful if you, the facilitator, can prepare the group for this.

- Inform the group that previous experience has shown that some people may become distressed as they watch the video and compare their own situations to those people sharing their stories in the video.
- Inform the group that they can debrief about the different feelings and thoughts they experience following the viewing of the video.

During the video...

Problems can occur!

- Viewers can ignore the video completely.
In this case it may be better to switch it off and talk about the topic instead.
- Some viewers may watch and others not.
In this case you may ask the group whether they want to keep watching or come to an arrangement that allows those who want to continue and take part in discussion to do so, while others can leave or find something else to do.
- Pay attention to the body language of participants.
You may notice participants who are moved or upset by the material, or they may quietly leave.
HIV/AIDS raises lots of sensitive issues. Sometimes, as the facilitator, it's hard to know what to do when people react strongly to the video. That's why we have included some suggestions for ways you can help follow-up participant's needs in the sections entitled "De-briefing" below.
- Some people may feel they need to discuss taking a test for HIV antibodies.
You should have contacts they need and be prepared to refer them to an appropriate testing place , where pre and post test counselling is available.

After the video...

Before you carry on with discussion or other activities you may give the group time to explore the feelings and thoughts raised by the video. Many group members may have not had previous opportunities to explore these feelings and thoughts. Some people may feel sad or angry. It is important not to joke about people's reactions or try to force them to feel better. Instead allow them to experience these feelings and thoughts in a supportive environment that can assist them to cope with their reactions in a productive manner.

Exploring Feelings

Ask the group to spend some quiet time considering their feelings.

- **Let group members express their feelings:**

You may choose to go around the group and ask each member to give one or two words that best describes their reaction to the video.

- **Acknowledge the feelings expressed:**

"So it seems there is a range of feelings in the group after watching the video..."

"It seems that while there are a **range** of feelings in the group, **many** people are feeling"

"I can see some group members are (upset, sad)"

- **Normalise these reactions:**

Let the viewers know that you understand why someone might feel that way. For instance:

"These feelings are understandable given the stories we have heard and the many issues related to HIV."

"These feelings are a normal reaction to HIV issues."

- **Viewers who don't want to talk about feelings:**

Viewers may also not demonstrate any signs of being upset or affected by the video, especially in a larger group. You may describe some responses that other people have had and acknowledge that in a large group it's hard to talk about feelings. For instance:

"Some people watching the video felt sad when they saw K. Pimjai and her family, because they felt that their family wasn't like that..."

You may then move on to the activities.

WHAT TO DO WHEN...

- **Only one or two people are upset:**

Ask the person if they would like to discuss their feelings within the group or whether they would prefer to talk with you individually after the group or in a break;

OR

Approach the person after the group or in the break, express your concern about them and ask if they would like to spend some time talking with you.

- **No-one is particularly upset:**

Move on to discussion, or start one of the activities we suggest, on the topic that the group is most interested in...

- **More than two people are still upset:**

Continue with the debriefing techniques on the next page.

You can also come back to the debriefing section at any time. It's often a good idea to run through it right at the end of the session to make sure everyone is ok to go home.

After the video... de-briefing

Strategies for Feeling Better

Ask the group to consider what strategies or 'plan of action' can help them deal with some of the uncomfortable feelings they may have experienced.

- You may choose to again go around the group asking each member to share a 'strategy' or course of action or activity they find useful for them when they are upset, angry, worried, etc.
- As the facilitator, you may need to add some strategies to those generated by the group if they are having difficulty, like: talking to someone, phoning a friend, reading, exercising, eating or drinking something nice, watching television, listening to music, doing something they enjoy.
- You may just open this issue for group discussion.
- You may decide to ask them to break into pairs or small groups to discuss this.

Are participants ready and able to go home?

De-briefing/exploring feelings

Reassess how people are feeling – you may again choose to go around the group and ask each group member to use one or two words to express their current feelings.

If group members continue to show distress you will need to discuss whether they are able to return home safely.

- ★ Check how group members intend getting home.
- ★ Alternative arrangements may need to be made to ensure people's safety, eg. people may be too distressed to ride motorbikes or drive.
- ★ For some people it may be helpful to delay their return home – have a cup of tea, go for a walk.
- ★ You can also use the contact list to suggest places to go for help.

CONTACTS

It is essential that you have a list of available contacts in your area so you can refer group members for further assistance and professional support as required.

Finding Out

For many people finding out they have the virus is a big shock.

Like any serious health problem, it takes a while for a person to adjust to the news that they have the virus.

Immediately after hearing the news some people don't take in information and advice. They need time for the message to sink in. Others can't believe that they have such a virus.

For a long time people didn't understand about the virus and how it affects the body. In the early days of the HIV/AIDS epidemic, many people were confused and thought that if you contracted the virus, you had to get sick and die instantly.

People can remember all these messages when they are told they have contracted the virus and this can be a very anxious time for them.

In fact, it is not true that people with HIV become sick or die a short time after contracting the virus. In this video you have just seen, there are many people, men and women, old and young who have had the virus for years and years. The man who has had the virus for longest in the video has had it twelve years. Others have known they have been infected for eight and nine years.

As one woman said

“I’ve been positive for 8 years now, its not just one or 2 days you know.”

In America there is a long term survivors group for people with HIV who’ve lived up to 20 years without even getting sick.

QUIZ QUESTION

What’s the greatest number of years that someone in the video has lived knowing that they had the virus???

“When the doctor told me I was infected, I just laughed! How could I be infected, I’m young and healthy...”

HIV positive woman

“Whether you’re men or women, young or old, you’re not going to die tomorrow! It all depends on your attitude and state of mind. You can live for decades, look at me! I have been infected for 9 years now.”

HIV positive woman

“I’ve fallen down, but I’ve picked myself up every time. It has taught me so well so that if I’m down, I won’t be down forever. Why? Because of my state of mind.”

HIV positive artist

Keeping Well

In the video, Prasert, the leader of the Association of People with HIV/AIDS in the North looks pretty healthy. As he tells us, he has not always been so well...

“Actually, I’ve been sick before, in fact I’ve been hospitalised 3 times, the last time it looked like I was at the point of no return. People who saw me thought I was surely going to die.”

Like many people with the virus Prasert has been vulnerable to ‘opportunistic infections’. An opportunistic infection is any disease or germ that gets an opportunity to infect people when their immune system is not working well.

There are many viruses and germs which live in healthy bodies or which we are exposed to regularly in daily life. A healthy immune system keeps these viruses and germs from making us sick, but because HIV weakens the immune system, it gives some viruses and germs an opportunity to make people sick.

The kinds of opportunistic infections a person with HIV can contract vary according to the germs they have been exposed to in the past and any new germs or diseases they come into contact with.

Very common opportunistic infections that people with HIV/AIDS get include: lung diseases like pneumonia and TB, and fungal infections from thrush to cryptococcal meningitis. Some of these are mild and easily treated. Others require more intensive treatment.

Prasert was seeing a doctor regularly so that his illnesses were detected early and were able to be treated.

“I am a pretty strong person, I’m not easy to scare. But we can’t fight this disease with our minds alone. We have to take care of our bodies as well.”

Young HIV positive man, Northern Thailand

“With the encouragement of one person and then another their health slowly improves.”

**Nurse Siriporn
Aksornsophapun**

Keeping Well

Many people with HIV may go for years without any symptoms. During this time you won't need a lot of medical attention. However, you should still have regular health check-ups, usually every three to four months. During these regular health check-ups your doctor will be able to measure your general health and to look for any effects HIV may be having on your health.

That's why health check ups are a good idea for people with HIV, even when they feel quite well. All healthy people get occasional minor illnesses like colds and headaches. If you see a doctor regularly, you can also be reassured about symptoms like these that are unrelated to HIV.

The way health check-ups are conducted varies from place to place according to the facilities, equipment available and medical staff available. During a check-up the doctor or health care worker should take your history and give you a physical examination. While the doctor or health care worker is "taking your history" you can tell them about any symptoms you may have. During the physical examination, the doctor or health care worker will be looking to detect any early signs of the disease and treat them.

In some places laboratory testing facilities are available and you may have a blood test or a sputum test or a chest X-ray if the person performing the examination considers these necessary. In other places you will be referred elsewhere for laboratory testing.

You may need to try different health care centres or clinics to get the best treatment. You can ask the doctor or health worker questions. Sometimes you need to write down questions so you don't forget them when you are actually having your check-up.

Often people who know they are HIV positive and are well, take steps to improve their general health through exercising regularly, eating healthy food, and reducing alcohol and tobacco consumption and/or using traditional therapies in preventing disease, reducing stress and boosting their immune system. (We discuss these therapies on Page 24).

REGULAR HEALTH CHECK-UPS can include:

- ★ **History taking**
- ★ **Physical examination and**
- ★ **Laboratory tests**

Physical Examination

Often includes some of the following:

- ★ **Weight**
- ★ **Temperature**
- ★ **Blood pressure**
- ★ **Mouth examination**
- ★ **Head and neck examination**
- ★ **Lymph nodes**
- ★ **Chest examination**
- ★ **Abdominal examination**

Keeping Well

Activity Sheet



Preparation

Photocopy the page and cut out case studies. If you are going to be using them again you could glue them onto cardboard or cover them with plastic.

Activity

Break up group into smaller groups of 3-5 and give copies of the case study cards to the groups. Ask them to spend ten minutes discussing the question and then return to the larger group to summarise the discussion and answers to the questions.

After obtaining responses from the group on each question, the facilitator should refer to the suggestions in the following activity sheet to make sure all aspects of the questions have been discussed, adding to participants comments on each question, if necessary.

ANUSORN

Anusorn found out he was HIV positive some years ago. He didn't visit the doctor for many years. After putting up with a persistent cough for some time he went to OPD at the local hospital. After a couple of days Anusorn was diagnosed with a serious lung infection called PCP.

- **Could Anusorn have done anything to help prevent this situation?**
- **Why do you think Anusorn didn't go to the doctor?**

TUPTIM

Tuptim had HIV but didn't monitor her health by visiting the doctor for regular check-ups. Each time she got a headache she thought it might be cryptococcal meningitis. The worry caused her more headaches. When she finally did visit the doctor, Tuptim found that she did not have crypto, but some problems with her posture at work. He gave her some exercises to do, she changed the way she sat in her chair at work and she had traditional massage. After a few days her headaches disappeared.

- **Why did Tuptim think her headaches were Cryptococcal Meningitis?**
- **What could have helped Tuptim?**

Keeping Well

Activity Sheet

Case Study 1: Anusorn

Anusorn found out he was HIV positive some years ago. He didn't visit the doctor for many years. After putting up with a persistent cough for some time he went to OPD at the local hospital. After a couple of days Anusorn was diagnosed with a serious lung infection called PCP.

Q: Could Anusorn have done anything to help prevent this situation?

Hopefully group will come up with the suggestions below: A) that he could have been diagnosed and treated earlier or B) could have been given a preventative medicine to stop it developing.

Facilitator's Remarks should include the following.

If Anusorn had been regularly visiting a doctor to monitor his health, he could have been given preventative medicines for PCP which may have prevented this episode. If any infection had developed it would have been picked up earlier and better treated.

Q: Why do you think Anusorn didn't go to the doctor?

The group may come up with several answers, such as: he thought if he wasn't sick, there was no point in going; he didn't have enough money; he feared that doctors would discriminate against him or be rude to him; he was too scared to go in case it was bad news.

Facilitator's Remarks should include the following:

There are many reasons why HIV positive people do not want to go to the doctor's. We have heard some of them. One is that Anusorn didn't understand the value of visiting the doctor. The others are reasons to do with the health service. Not all health services are equally good. Some doctors may still discriminate against people with HIV. Some people with HIV say that doctors do not want to give them a physical examination. Sometimes it is worth going to different health services until you find one that suits your needs.

Case History 2: Tuptim

Tuptim had HIV but didn't monitor her health by visiting the doctor for regular check-ups. Each time she got a headache she thought it might be cryptococcal meningitis. The worry caused her more headaches. When she finally did visit the doctor, Tuptim found that she did not have crypto, but some problems with her posture at work. He referred her to a physiotherapist who gave her some exercises to do, she changed the way she sat in her chair at work and she had traditional massage. After a few days, her headaches disappeared.

Q: Why did Tuptim think her headaches were Cryptococcal Meningitis?

Group may come up with any of the following points. If they do not, facilitator may mention these:

- It is true that headaches are a symptom of Cryptococcal Meningitis, particularly, when they persist over a number of days, and should be checked out by a doctor.
- Tuptim may not have known that most people with HIV remain well for years after they have got the virus. It is normal to get minor illnesses like colds or headaches or muscle strain.
- People with HIV often think that any symptom they get is a sign of a serious illness or related to their HIV infection. In fact, people with HIV may still get other common health problems like anybody else.

Q: What could have helped Tuptim?

- If Tuptim had been visiting the doctor regularly she may have been more confident that she was in good health and able to consider other reasons for her headaches.
- She may have been over-anxious and stressed because of her HIV status. As well as visiting the doctor Tuptim could try other ways to reduce stress in her life.

Being Sick

When people who haven't previously had any symptoms become sick, it can be a great shock. Some people have said that becoming ill can be as great an adjustment as getting a positive blood test. In addition to the worries and anxieties being sick can raise, the person also has to cope with their physical symptoms, such as feeling ill or tired, having eating problems, diarrhoea, coughing, fevers or pain.

For a lot of people with HIV, physical health problems are made worse by anxiety about issues like disclosure. Some physical symptoms, like skin diseases, have become very strongly associated with AIDS. Positive people can be very upset when these symptoms appear, because they are then exposed to the fear and prejudice of people around them.

Early AIDS campaigns in many countries presented an alarming picture of AIDS symptoms. Posters showing severe cases of oral thrush, herpes, wasting and tuberculosis conveyed the message that having any one of these symptoms meant that you were in 'final stage' AIDS and would die very soon. However, this is not necessarily the case. As you have seen from the video, Prasert and the man in the striped shirt had severe illnesses but made good recoveries.

In particular skin diseases that are common in people with HIV are generally not serious and often clear up quickly. Even blisters or sores that look awful at first, can dry up in a week or two. Doctors can provide the appropriate creams and ointments to help healing.

Another disease that can be upsetting to HIV positive people is Tuberculosis or TB. This is because, unlike, HIV/AIDS, TB can be transmitted by prolonged close contact with a person with TB. This is worrying for people with HIV who may be concerned about family and friends. However, what many people don't realise is that, with effective treatment for TB, a person may be no longer infectious. Further, most people in Thailand have been exposed to TB already. For a person with a healthy immune system, TB is not easy to catch. The most important thing for HIV positive people is to get treatment quickly for TB. It is also possible to get preventative treatment- that is to take medicine which prevents you getting sick with TB.

"I may get sores, my health may deteriorate, but keeping my will power is the most important.

I have been able to pull myself together because of my morale and my friends. Because of these things I'm here speaking to you now."

**HIV positive artist,
Northern Thailand**

Mental HEALTH

Mental health means “having a life that is happy as a result of your way of thinking, your view of the world and your view of yourself”¹. This is very important for all people, and with the social and economic stress of modern times, it’s becoming harder to achieve. This is what an HIV positive man living in Bangkok has to say about stress:

“People ask me how I can live here in Bangkok, with the congestion and the traffic and the cost of living as high as it is. The truth is about 90% of people, living in Bangkok suffer from stress. They are stressed by the traffic and by the chaos of travelling to and from work. If you ask me how I’ve been able to survive with all that stress on top of having HIV, well, I was stressed before I found out that I was infected. But I’ve realised that stress makes only my condition worse. I get fevers and herpes, my body deteriorates and I can’t sleep, food loses all its taste. So I ask myself, what’s the point of getting stressed?”

STRESS

There are lots of ways of dealing with stress. Phra Kru Sophon makes a few suggestions in the video. He says:

“If you know you have HIV you should try and take care of your health... get plenty of exercise and plenty of sleep, make peace with yourself and know you still have a chance to live a long time.”

Phra Kru Sophon from Wat Doi Saket

On the right and on the next page you will find suggestions for sleeping, exercising, meditation and what to do if you feel sad.

¹ Dr. Prawate Tantipipatanaskul, Suan Prung Hospital, Chiangmai

EXERCISING

Exercise at the right level is good for your muscles, your joints, your heart and lungs, your circulation and respiratory system. It can reduce stress and help you sleep.

Health professionals generally recommend that you exercise at least 3 times a week for 15-30 minutes at a time.

Exercise should be conducted in 3 stages:

- Warm-up
- Exercise and
- Rest and relax

If you’re new to exercise take it easy at first. Do gentle exercise to begin with like walking, yoga or swimming.

Make sure exercise is appropriate to your age and physical state.

EXERCISE should be:

- Easy
- Fun
- Convenient
- Something you choose to do

SLEEP

Sleep is a great way for the body to rest and relax. However, many people find it hardest to sleep at times when they need it most, when they are stressed or facing a lot of problems. Some people get into a pattern of not being able to sleep, perhaps not being able to get to sleep at night or oversleeping.

Some simple things that may help you sleep better include:

- Get up at the same time every day.
- Avoid sleeping during the day.
- Reduce tea and coffee intake and other caffeine drinks like 'Coke' or 'Krating Dang'.
- Do not lie awake for more than 30 minutes, get up and find a relaxing activity.
- Try relaxation exercises.

MEDITATION

Many people in the video also espouse the practice of meditation. Meditation is beneficial on many levels, physiologically, spiritually and mentally. Many temples today run lay meditation courses. Some are particularly focused on the needs of people with HIV. If you have never seriously practiced meditation it might be best to attend a course first, whether it's a general one or one particularly for people with HIV. Some people find that the peaceful atmosphere at temples and meditation centres is a good antidote to the stress of modern living. Many people with HIV find that their appetite improves and that they gain weight after attending courses.

FEELING SAD

Some people do not have a problem with stress but often experience feeling sad, low or even "down". These feelings are normal and are felt by many people during different stages of the disease.

Sometimes people need a period of time to understand their problems, to come to terms with them and to think of ways of coping with them.

If possible, talk about these feelings with a good listener, someone who is supportive who can help you understand what is happening to you. You may be able to talk these through with a good friend, family member or counsellor.

KEEPING BUSY

There are mental health benefits to keeping busy or being active:

- **Activity distracts people from problems and negative thoughts.**
- **Activity can motivate people: the more they do, the more they feel like doing.**
- **Activity can help people think more clearly.**
- **Family and friends can help you plan useful or enjoyable and affordable activities: like cooking, gardening, going to market, exercising, visiting friends and relatives.**

"Try to be optimistic and create a positive environment in which to live. Don't despair and don't sit around doing nothing. Don't think about your situation too much. Do whatever it takes to keep busy."

HIV positive woman

Nutrition

One way that a lot of the people in the video have chosen to maintain their health is through healthy eating. As Dr. Maitreya Suiythajit says on the video:

“Food is medicine... Try to find food that even in small portions contains a lot of nutrition.”

People’s nutritional needs vary a lot, especially those of people with HIV. Vitamin pills or tonics are no substitute for healthy eating.

Well people

In the non-symptomatic years people with HIV benefit from a nutritious or balanced diet . This means eating a variety of foods each day to supply the body with the nutrients it needs. Nutrients are the components of food and include: proteins, carbohydrates, fats, minerals, dietary fibre and water. No one food contains all the nutrients you need. Certain types of foods contain similar nutrients and can be grouped into 5 main groups called “The Five Food Groups”. You should have something from each group each day, although more from some groups than others. An easier way of thinking about it is the “Healthy Diet Pyramid”: You need to:

Eat MOST: fruit, vegetables, cereals like rice and flour foods like noodles

Eat MODERATELY: fish, lean meat, poultry, legumes, nuts

Eat LEAST: oil, butter, sugar, coconut cream

Eating a good range of foods makes expensive vitamin supplements unnecessary.

Some common ingredients in foods are also used as herbal medicines. Your favourite dish could be a great source of nutrition and a traditional medicine! Herbal medicines used in cooking include lemon grass, galangal, basil and ginger.

Traditional diets

Some traditional therapies advise particular diets and stipulate foods to avoid. If you are on one of these diets you should make sure that what you eat still

provides you with all the nutrients your body needs. For instance, if you can’t eat seafood, then make sure you eat fresh water fish and pork, eggs and soy beans and tofu to keep up your protein. If you are on a vegetarian diet then you need to pay particular attention to protein and calcium. Soy beans, bean curd, soy bean milk, cow’s milk and yoghurt are good sources of protein. Cow’s milk contains calcium and so do dark green leafy vegetables.

Sometimes people with symptomatic HIV develop specific nutritional problems. These need to be addressed on a case by case basis. Different opportunistic infections may lead to particular eating problems.

Common ones are chewing and swallowing difficulties due to throat and mouth infections, loss of appetite, diarrhoea and weight loss. See the next page for some suggestions to help with these.

“Just like me when I eat these days I also eat for the virus in my body. I eat so this virus and I can live in harmony.”

HIV positive man, Bangkok

Nutrition

Activity Sheet

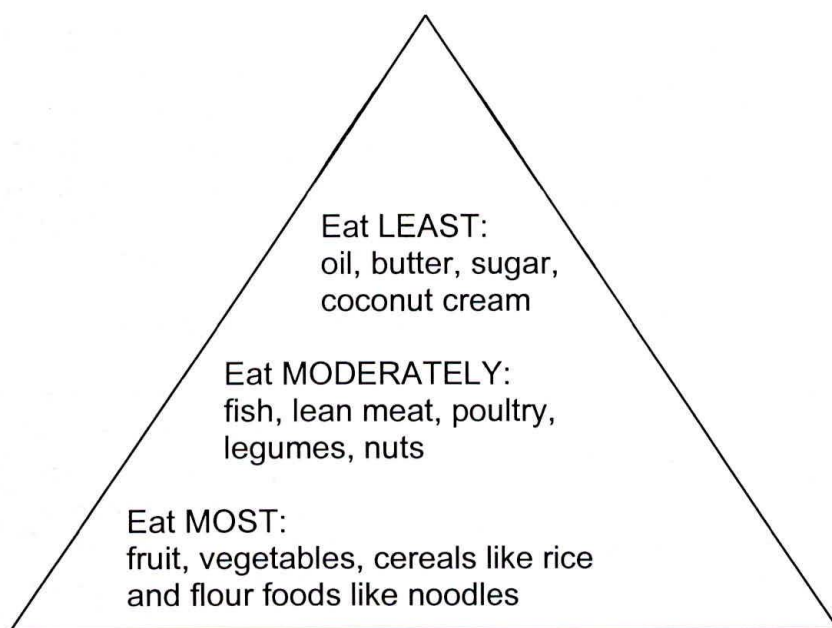
Facilitator

Is what you eat healthy?

Ask everyone in the group to remember what they ate over the last 24 hours and to write it down.

Then ask them to go through the foods and see if they can work out what category the food fits into.

- Did you eat something from each of the three food groups shown in the "Healthy Diet Pyramid"?
- Which of the three groups did you eat most of?



- Which of the three groups did you eat least of?

When illness affects eating...

Weight Loss

There are three food groups you should concentrate on to build up your weight. Increase each in turn:

- ★ Protein
- ★ Energy foods (Starch and Sugar)
- ★ Fats and oils

Step 1.

First try and add more protein to your diet: Fish, pork, chicken, beef, eggs, beans, tofu, soy bean milk and cow's milk all contain protein.

Step 2:

Then add energy foods, foods with starch and sugar like rice, noodles, bread or cakes and fruit.

Then lastly add fats and oils, like milk, coconut milk, coconut custards, deep fried foods.

Try and eat only food and drinks that are nutritious. Don't fill up on water, drink milk or fruit juice or coconut juice.

Try and keep snack food and a milk drink (cows milk, soy milk or yoghurt drinks) by you at all times.

Step 3. Add extra protein to food you already eat, such as adding egg to everything possible, adding extra dried skim milk powder to Ovaltine or Milo.

Loss of appetite

Here are some suggestions to help you eat more.

- ★ If you don't feel hungry, try and eat a little, often.
- ★ Choose food that's high in calories to give you energy, like fried bananas, peanuts or fruit juice.
- ★ Avoid food or drink that's filling but low in calories, like water or Diet Coke.
- ★ Check and see that it's not your medicine that's making you feel sick.
- ★ Try and make mealtimes enjoyable: play music, eat with friends, try and make your food look pretty.

Chewing and swallowing difficulties

- ★ Try to eat only soft, smooth foods like eggs, steamed fish, Ho Mok, tofu, blended fruits, banana puddings and coconut custards, icecream.
- ★ Cut up food very finely before cooking to reduce time taken to chew.
- ★ With noodle soup, cut up glass noodles or other noodles in one or two inch lengths to prevent choking.
- ★ Thicken sauces to make them viscous and easy to swallow. You can even add a little agar-agar powder to soups to make them slippery like jelly.
- ★ Avoid hard crunchy food.

What to eat when you have ... Diarrhoea

Diarrhoea means that you produce runny stools more than three times a day. You may have vomiting and stomach ache as well.

Dehydration

Dehydration which is caused by diarrhoea can be very dangerous. You must replace the water and salts that your body loses in diarrhoea by drinking water with salt in it, broth, coconut juice, weak cordial or oral rehydration mixture. You can make this yourself by adding ½ teaspoon of salt, and 2 tablespoons of sugar to 750cc of boiled water.

Minerals

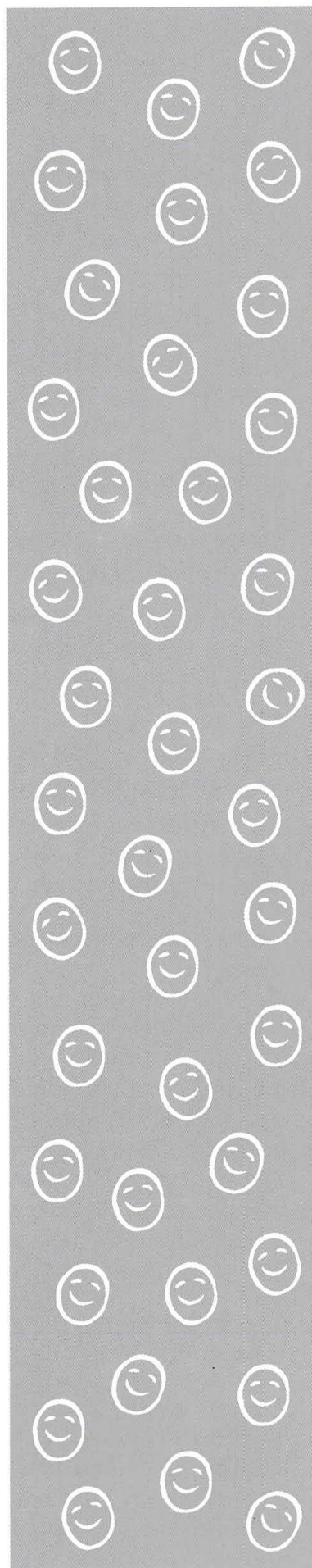
Your body loses a lot of minerals as well, in particular, potassium, which is found in bananas, tomatoes, oranges, coconut juice and fruit juice. You should try and eat some of these foods everyday.

If you have severe diarrhoea you should avoid:

- ★ Fatty foods - your body will not be able to absorb fats and oils.
- ★ Milk - lactose can cause diarrhoea.
- ★ Fibrous foods - these may make diarrhoea worse.
- ★ Alcohol and caffeine – these make diarrhoea worse.

If you have diarrhoea for more than 2-3 days you should see a doctor or a nutritionist to ask for treatment or nutrition supplements.

When your symptoms clear up you should be able to eat normally again within the week.



Herbal MEDICINE

Traditional herbal medicines can be a valuable resource for people with HIV. The ingredients in traditional medicine are often cheap and some can be easily prepared. Today many people choose to combine traditional treatment with modern, they may take herbal medicines but they also see a modern doctor at the same time...

“Our hospital’s basic approach to healing combines emotional encouragement with the introduction of herbal medicines as tonics. Presently we’re using medicinal herbs as tonics... They increase the patient’s appetite and activate the immune system. They stimulate resistance enabling the patient to fight disease. Modern medicines are used to attack and kill the virus. Here we treat patients with a combination of methods.”

Dr. Thara Onchomchant MD, Phaya Meng Rai Hospital

Modern doctors and pharmacists are now researching and refining many traditional medicines. People with HIV will find that a number of books have been written about herbal medicines and HIV/AIDS. As well, magazines like "Folk Doctor" also provide up-to-date information on the latest advances in herbal medicine, with a particular focus on HIV. Newsletters of positive associations like Naam Chiwit and others also contain information on herbal medicines and HIV/AIDS. We do not have room to give detailed information on the range of herbal medicines (See box for the traditional use of the three medicines named in the video).

Don’t forget to inform your doctor if you are taking herbal medicines! They sometimes cause side effects or may interfere with other medications. Let the doctor know how they are helping you. With herbal medicines, as with any other medicine, you need to be well informed and choose them carefully. (See Exercise: Using Complementary Therapies p.25)

Here is some information that the Communicable Disease Control Office in Chiangmai has published on three of the herbal medicines mentioned in the video.

Five roots medicine

The traditional formula for “Benjalokwichien “ or Five Roots is used for fevers where patient has headache and aching joints. It is made up of Chingchee, Kontana, Ya Nang, Tao Yai Mom and Madeuh Choompon (in rainy season, use bark or wood of plant , in dry season use roots), *Take equal quantities of all five herbs, wash and cover with water, boil over low flame until reduced by two thirds. Drink a glass of liquid remaining 4 times a day, before meals and before bed.*

Bo-ra-pet

Traditionally, Borapet can be used for loss of appetite, where the patient cannot eat at all or eats very little, and is losing weight ... It can be chopped up, dried and ground to a powder, then mixed with honey to form pellets, one is taken before meals.

Fa-talai-joan

Traditionally used for chronic fever (often combined with upset stomach and headache). Infuse one or two fresh plant tips in warm water as a drink. High in potassium.

Herbal medicine must be prescribed by a Licensed Traditional Practitioner.

*Ref: Holistic Self Health Care
CDC 10, Chiangmai MOPH
1997*

Herbal

MEDICINE

Activity Sheet

Herbal Medicine is still medicine. We need to be sure that all medicines we use are safe and do not contain harmful substances. We also need to be sure that people are not making false promises about particular medicines and are not tricking us into paying a lot of money for ineffective treatment.

Write a list of all the herbal treatments the group knows of on a big sheet of paper. Then ask the group to answer the following questions in turn about each one:

Has this therapy stood the test of time?

- ★ Has it been used over a long period with no ill effects?

Have there been any experiments done on the therapies to show they work?

- ★ Increasingly, there is scientific research into the properties of traditional herbal medicines, often conducted by Government bodies and University Pharmacy faculties.
- ★ You should try and find firm evidence that the medicine is safe to take and contains no harmful substances or additives, like steroids. These substances are sometimes added without being on the label.

Does this therapy work for people with HIV or for people who have a weaker immune system?

- ★ If you know a number of people with HIV who have taken it consult them, ask around. Making a decision to take any medicine based on the experience of just one or two other people is not very reliable. Ask about side effects. See if it has worked well on people in your condition.

Facilitator

Has it been hygienically prepared?

Hygiene is very important for people with impaired immune systems. Cooked or boiled herbal preparations should not be left unrefrigerated for too long. Herbs can go mouldy or have been picked from unhygienic places too!

How much does the therapy cost?

- ★ Very expensive therapies are more often sold to help the seller get rich than because they contain rare or precious ingredients. (More expensive does not necessarily mean better.)

Is it prescribed by a licensed traditional doctor?

The licensing of traditional doctors is a way of protecting the public against fraud and quackery. Traditional Doctors also have to pass exams.

Employment

Many viewers have told us that their favourite person on the video was the old ironsmith, a man of 60. Viewers, young and old, admired his determination and his dedication to his heavy manual work. In fact, in the video the old ironsmith's son tells us the one thing which makes his father sick is stopping work.

Should I work?

If you are healthy and able to work then give serious consideration to continuing to work. Many people misunderstand the nature of HIV/AIDS and think that they need to protect their health by resting and not working. While this is certainly true for people who have serious opportunistic infections, it is usually unnecessary for people who are well to stop working.

Should I tell anyone at work that I have HIV?

You do not need to inform anyone of your HIV status in the normal course of events.

Unless you are quite sure that there will be no repercussions and that you will not receive prejudiced treatment, it is unwise to disclose HIV status in your workplace.

What if I get sick?

Being ill may mean you have to take sick leave on occasion. People in the work place may also ask you about your health. If you recover and can continue in your work and your employer is happy for you to continue then by all means: Continue Working! Many people find it helpful to lead as normal a life as you can when you are well. Work keeps you busy and active as well as earning an income.

“If you ask dad to stop working he says no. If he doesn’t work he gets sick. If he stops for 3 or 4 days, he loses his strength completely. If he keeps working he stays strong and healthy. It’s hard to believe but it’s true.”

Ironsmith’s son

“I am HIV positive, but I’m still perfectly healthy, so, of course I can still work. But if I don’t work, and have nothing to do, I get stressed out. When I have work to do, I lose myself in my job, and I feel much better.”

Young HIV positive woman

Employment

“If you have work to do, it doesn’t matter what your co-workers say about you. Don’t pay attention to that at all. If your boss is willing to keep you on, then by all means, keep working.”

HIV positive artist

Under Pressure?

You may feel under pressure to resign because you are taking so much sick leave or because other workers are gossiping about you. If you have a supportive personnel manager or a boss you can trust, then it is well worth talking to the personnel manager or your boss in confidence at this point. Your employer may be happy to change your job or your shift in a way that makes it easier for you to continue working. Knowing that you have your employers support will make it easier to deal with gossip. It is also part of a manager’s responsibility to address problems of this kind in the workplace. Managers can organise training on HIV/AIDS or educate staff in other ways.

Brainstorm

Before you consider the discussion points on these pages, or, as part of the next activity, you may like to ask the group these questions:

- Whether members wish to work or not?
- Whether they would like to continue working if they are symptomatic?
- What problems or obstacles they might face in each case?
- What possible solutions are there?
- Where they could turn for help?



Employment

Activity Sheet

Divide participants into small groups. Give out copies of the case histories, one to each group. Ask them to read aloud the histories and discuss the questions. Then ask them to present their conclusions to the whole group.

Case History 1: Chalerm

Chalerm, a very competent worker at a prestigious Hotel, had a number of HIV related illnesses. He had not disclosed to anyone that he was HIV positive. He began taking more and more sick leave. His friends at work noticed that he was often sick and kept asking him what was wrong. Chalerm began to feel ashamed and guilty, so he gave notice. He told the personnel manager he was going back to the country to be with his parents and work the farm.

What do you think of Chalerm's actions?

Did he have any alternatives?

What would you do if it were you?

How could his friends at work have helped him?

Could his personnel manager have helped him in any way?

Case History 2: Somchart

Somchart was an older man in the civil service. He began to have symptoms which his colleagues thought were HIV related, possibly because they had all heard stories about his lifestyle and how he liked to go out partying with his friends. Somchart began spending a lot of time at the doctors. He told his colleagues he had a lung condition. He was also losing weight. His colleagues, who were convinced he had AIDS, kept asking him about his health, and suggesting that he should take time off. Each time, Somchart would say that he was fine and able to keep working. Finally, a colleague asked him to his face if he had AIDS. Somchart looked him in the eye and said "I don't have AIDS. I am able to work." He kept on working until he became seriously ill and died.

What do you think of Somchart's actions?

Did he have any alternatives?

What would you do if it were you?

Were his colleagues really trying to help him?



Love, Sex and Intimacy

“In my opinion re-marriage is a good thing, because love is a good thing.”

HIV positive young man

Having HIV does not change people's need for love and intimacy in sexual relationships. In this video we hear from two couples who talk about their relationships. One couple is made up of two HIV positive people who met and got married, each knowing the other person was HIV positive. Prasert and Lamai feel the fact that they were both positive has meant that they are better able to understand each other than most couples.

The other couple to talk about their relationship are the artist and his partner. She is HIV negative and he is HIV positive, yet they continue to have a relationship which is mutually supportive.

For both couples these relationships have been an important source of comfort and strength, have helped them feel more positive about life and helped them maintain their health.

Some people think that HIV positive people should not form relationships or get married after they know they are HIV positive because their lives will become harder, instead of easier, if they have to care for a partner as well as themselves. This may or may not be the case but the decision here should be left to the participants in the relationship to decide.

“I'm thinking back to when we met, 3 or 4 years ago. At that time, people didn't really understand us. But we kept struggling until they did. All along I believe we had to prove that people with HIV have the right to live like everybody else... If people aren't ready they shouldn't get married. But if they are going to get married, they must learn to understand each other, to see into each other's hearts and to learn to share their lives together.”

But the thing that makes me most proud is that we are one of the first couples with HIV to marry, and we let everyone around us know that we are positive. It's a good feeling not to have to keep any secrets from anyone.”

Prasert Dechaboon

Love, Sex and Intimacy

Another question that many people are troubled by is whether HIV positive people should have babies. The situation for HIV positive women who are pregnant or wish to get pregnant has changed dramatically in the last few years. New treatments, such as the use of AZT by pregnant women, are available to reduce the risk of transmission from mother to child.

When we were preparing this manual we found that most people we spoke to were confused about transmission from mother to child. People thought that **every** child born to an HIV positive mother would have HIV.

In fact, even without the new treatments only about a third of babies born to HIV positive mothers will be positive. When breast feeding is withheld, drug treatments can reduce this number by between 50 – 67%, depending on the drug therapy used. When drug is used in combination with other treatments like caesarian section, the transmission rate will be lower and could go down to 0%.

However, this question is just one of a number of issues for women with HIV who are pregnant or wish to become pregnant to think about.

Talking to a counsellor, doctor, or to other positive women may help them clarify these issues.



Love, Sex and Intimacy

HOW HIV CAN BE SPREAD

We all think we know the three ways HIV Transmission can occur:

- Through Sex : unprotected sexual intercourse, (which can be *penis/vagina sex*; *penis/anus sex*) or oral sex.
- Sharing needles or syringes which carry the blood of an infected person into the blood stream of another.
- From mother with HIV to baby during pregnancy, birth or breast feeding.

Some people may think that because we have HIV our sexual needs automatically cease. This is not true, most people with HIV continue to experience sexual needs and feelings in the same way as other people. Although, sometimes worry and stress can have an impact on people's sexual feelings.

PROTECTION

What is really very important for us as positive people to know is how to protect ourselves and others, through SAFE SEX and SAFE INJECTING.

It is also important to know how we can prevent the virus being passed on TO OUR CHILDREN THROUGH PREGNANCY, BIRTH and BREAST-FEEDING. We cover these issues in this section.

Safe Sex:

- Safe Sex prevents us transmitting the virus to others.
- Safe Sex prevents us from being re-infected with a different strain of the virus.
- Safe Sex prevents other sexually transmitted diseases.

WHAT IS SAFE SEX?

Safe sex can stop a body fluid that contains HIV from entering your body or from leaving your body and entering another person's body.

This kind of sex can be a lot of fun!

Here are some ways you can have safe sex:

Rubbing together

Kissing and hugging

Massage and touching

Mutual Masturbation

Using a condom with water based lubricant every time you have sexual intercourse. Condoms need to be used properly (See below).

- Open the packet carefully to avoid damaging the condom.
- Squeeze the air out of the top of the condom before rolling it on (bubbles of air can make it break).
- If uncircumcised pull the foreskin back before fitting the condom.
- Use water based lubricant on the outside of the condom.
- Hold the condom at the base while withdrawing penis after ejaculation.

Love, Sex and Intimacy

SAFE BEHAVIOURS

There have been a lot of education campaigns about condoms. One advertisement people often remember compares an apple skin, a car tarpaulin and a condom, because they all protect things, skin protects the apple, tarpaulin protects the car and condom protects the person. But using condoms isn't always easy.

People complain about loss of sensation. This can be reduced if you make putting on the condom fun and sexy and if a sexual partner continues to touch or lick the condom-covered penis before penetration.

Another common problem is not having one handy. It's good to keep condoms in the rooms where you make love or carry one on your person. If you don't have a condom, oral sex is safer than intercourse or you can try another form of non-penetrative sex.

SAFE INJECTING

Again, people may think that because we are HIV positive we will never feel the need to use drugs again. Some people will continue to use drugs. The most important thing in these circumstances is to make sure we protect ourselves and others.

Getting someone else's blood into your bloodstream is the most efficient way of getting HIV. Sharing needles and syringes can pass on HIV, Hepatitis and other infections.

So how can you use drugs safely?

- It's not what you use it's **how** you use it

Heroin can be safe, if you smoke it or snort it.

Even prescribed drugs from a doctor can be dangerous if injected with shared needles.

SAFE USING

Means ALWAYS using a new needle and syringe.

If you can't get a clean needle and syringe then and ONLY then, clean a used one thoroughly.

Cleaning is not 100% safe but it's better to clean than not to.

CLEANING SYRINGES

- Fill the syringe with clean cold water. Shake to remove all blood. Then squirt down the drain. Do this twice.
- Completely fill the syringe with bleach. Shake for 30 seconds to clean it. Then squirt down the drain. Do this twice (use fresh high strength bleach).
- Fill the equipment with clean, cold water again to rinse away the bleach. Do this twice. After injecting, rinse your syringe with clean cold water immediately.

Love, Sex and Intimacy

Activity Sheet



The safe sex game

Draw up a chart like this:

Body Fluids		

Ask the group:

- **What are all the body fluids you have ever heard of?**

Write down all suggestions: sweat, spit, semen, mucous, urine, vaginal fluids etc.

In the next column write "entry points or holes".

Body Fluids	Entry points or Holes	

Ask the group:

- **What are all the entry points or holes you have ever heard of?**

Write down all suggestions: anus, vagina, puncture due to needle injection, mouth, cuts, penis, eyes, ears, nose.

In the next column write "Sexual activities".

Body Fluids	Entry points or Holes	Sexual activities

Ask the group:

- **What are all the sexual activities you have ever heard of?**

Write down all suggestions: masturbation, receptive vaginal intercourse, receptive anal intercourse, insertive vaginal intercourse, insertive anal intercourse, licking, kissing, etc.

- Now, go through the list in column one and ask **What are high risk body fluids that carry HIV in sufficient quantities to transmit the virus?**

You can assess and correct their answers according to this information:

HIV is present in sufficient quantities to transmit the virus in semen and blood and vaginal fluids and breast milk. HIV is not present in sufficient quantities to transmit the virus in saliva, sweat, vomit, tears, urine, faeces, mucous.

Mark on the board which fluids are low risk, no risk, high risk.

Then ask:

- **What holes can HIV get in?**

Use this information to assess the answers:

To transmit the virus, body fluid containing sufficient quantities of the virus to infect must enter the blood stream through a hole like a needle puncture or through mucous membranes in the lining of the vagina, rectum or urethra (pee-hole in a man's penis).

Then ask the group to assess the sexual activities listed as: "no risk", "some risk" and "high risk".

Families

Family support is valued by a great many people. People need their families especially when they are unwell or having hard times. HIV/AIDS presents some challenges to families.

One step at a time

Usually families need time to adjust to the news that a family member has HIV, just as the person who has the virus does. Some peoples' families are warm and supportive right from the word go. But more commonly, families go through a period of adjusting. This does not usually happen overnight and can take a long time. This can be a very difficult time for positive people.

Building acceptance

In the video it looks like everybody's mothers and fathers have been supportive all along. But in most cases, families take time to find out about AIDS. At first they may not understand about transmission. Sure, they know the facts about transmission, but deep down they might still feel doubtful about whether they can catch AIDS through casual contact. Families need to understand what Pimjai's mother says. HIV is not like a flea, it doesn't jump out at people, or jump from one person to another.

This manual has included a detailed section on how HIV is transmitted for families and communities to read. Give it to your family and friends.

Another thing that can really help is learning by example. If your family can see someone else who is behaving normally towards a positive friend or family member, it may help reassure them, that their fears are just that: fears, like a child's fear of the dark, not based on fact.

Perhaps you can ask another person, a parent of another positive person, or a doctor or counsellor, whom your family members trust to talk to them.



Families

Families who don't understand HIV

Today, there are many people who still don't understand about HIV. There are people who firmly believe that it is very contagious or that only bad people can get HIV. Families may feel ashamed or embarrassed that someone in their family has HIV. They may be worried about what other people will say. Some people with HIV have been rejected by their families for these reasons. Being rejected is very painful. People often feel isolated at these times. Others experience acceptance from the start and yet others experience rejection at first, but over time (and this can take weeks, months or years) their families come to accept family members with HIV.

Families of choice

Not everybody is close to their families. Today people often move away from families to work or study. Some people might have a lifestyle that's different from their family's.

Workmates or friends can come to take the place of family. Gay and lesbian people often think of their gay and lesbian friends as their families. The support of these chosen families is important too.

For people with HIV who don't have family support, peer support groups can be very important. In these groups people with HIV can get together to talk with people who are facing the same problems.

"There's a sense of community here that's not easy to find. If I wasn't infected I don't know if I ever would have found true friends."

"When we get together in a group like this, there are 200, sometimes 500 of us. We sing, we eat together and we hold hands. We help each other any way we can."

Girl in white shirt

"I've been infected for about 5 years. My health is good right now. I'm doing fine. We are not alone in this world. There are lots of others ready to open their arms to us. Nowadays I feel a lot of warmth. There are a lot of people standing by to help me."

HIV positive young woman, Northern Thailand

Disclosure

A lot of people do not really understand about HIV/AIDS. Although there has been a lot of education and advertising about HIV over the years, people still have misunderstandings about the nature of the virus. In some cases, they can repeat the facts from the television ads but they don't really believe them. In other cases the education campaigns have even confused people further. This means that there is still a lot of ignorance and prejudice about HIV.

Society in general has often been very judgemental about people with HIV, not realising that people with HIV are just ordinary people, like anybody else going through hard times and dealing with a serious health problem. That's one of the main reasons disclosing their HIV status is such a big issue for people who are HIV positive.

But it is also very hard to live with a serious health problem and try to keep it a secret. That's also very stressful for positive people. It can often be a huge relief to tell someone, especially someone who can be trusted.

Whether or not to disclose is a difficult and personal decision. People generally do not want to risk their status becoming known to people they don't trust or know. This is because, they may experience rejection or discrimination as a result. Some people may choose to become a member of an association of positive people but not tell their parents or to tell their family but not their workmates.

Sometimes in disclosing, a positive person can get support that they would not otherwise receive. This can be support from family members or individuals, from professionals, from government (like social welfare support) or from friends or peers in the same situation.

"I'm completely open about my condition in my community. I talk with the villagers. I visit friends in the village who are sick. I also help with rural development work, like finding work in the village for people who are infected, eg. we teach them to breed ducks and chicken. That way, the villagers can see that people with HIV can still benefit their communities, that they still can work and that they can help others. That makes a big difference in the way villagers think of people with HIV."

Lamai Dechaboon

Disclosure

Educating communities

In the video you will see people who have decided to tell not just one or two people but to be completely public and open about having HIV.

Many of these people had support from family and friends, which has enabled them to have the strength to go public. Others have chosen to be open about their condition in order to help educate their community. This is very helpful in reducing ignorance and prejudice for communities. Then, they can see for themselves that people with HIV are just ordinary people. Like the man in the striped shirt says in the video: "I don't have scales or horns, I'm no different than other people".

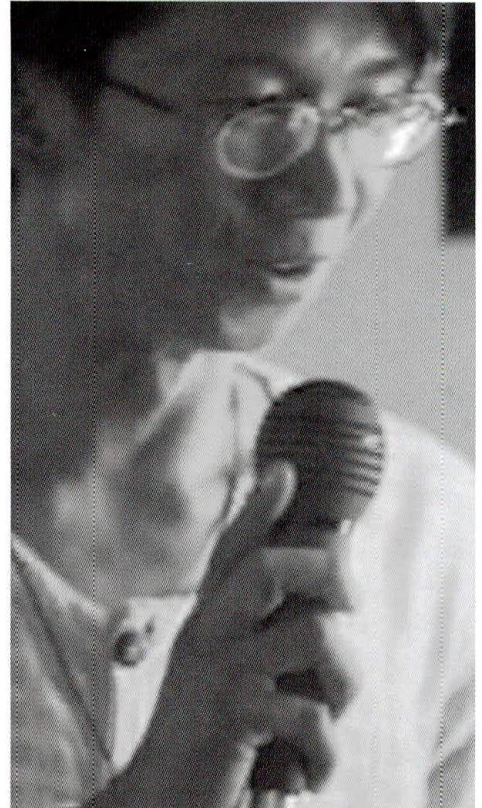
Relationships

Telling your current partner or an ex-partner that you are HIV positive is probably, one of the hardest situations HIV positive people face. Another challenging situation is telling someone you would like to become your sexual partner, that you are HIV positive.

However, there are many people who have disclosed under these conditions. There are people who've had to face rejection in this situation. There are also people who have met and fallen in love and disclosed their status and gone on to become sexual partners or get married. In the video there is one couple, Prasert and Lamai who met and married knowing they were both HIV positive.

Another couple, the artist and his wife are still married and living together, even though they found out, after they were married, that one of them was HIV positive and one was HIV negative. There have also been many other couples where both partners knew that one was positive and one negative but got married.

Clearly, there is a huge range of possible outcomes when a person with HIV discloses their HIV status. The exercises and activities on the following pages may help you explore some of the issues around disclosure.



Disclosure

Activity Sheet

WHO, WHEN, HOW & WHAT TO TELL (1 hour)

Exercise 1: (20-30 minutes)

The pictures that tell a story



Disclosure

Activity Sheet



WHO, WHEN, HOW & WHAT TO TELL (1 hour)

Exercise 1: (20-30 minutes)

The pictures that tell a story

Brainstorm what "disclosure" means to the group.

Show participants the picture page and ask them to spend a few minutes looking at the pictures. Ask each person to choose the image that best expresses what "disclosure" means to them.

Go round the group and ask them which picture they chose and why. This can take about five to ten minutes per person.

At this stage the pictures may trigger discussion and participants may naturally begin to discuss the questions below. In this case the facilitator simply has to keep the discussion on the subject and check that all questions below have been addressed, (perhaps by asking the group one of the questions if they go off the topic). The facilitator should also ensure that everyone has seen the pictures and had the chance to speak.

If the discussion does not flow naturally at this point, try returning to the exercises below.

Exercise 2.

Who?

(10 minutes)

Ask group to help think of all the kinds of people they could possibly disclose to: From family to relevant health professionals including people they might not want to disclose to like members of the public, shopkeepers, hairdressers and media.

Write the list up on a sheet of paper.

Disclosure

Activity Sheet

Exercise 3 (15-20 minutes)

Why Disclose?

“If you are not open, if your condition is still secret, you should ask yourself why your status must be hidden. If you cannot find a good reason, then by all means open up. There’s so little to lose and so much to gain.”

Nurse Siriporn Aksornsopapun

“We should have a reason for wanting to open up, you should not open up if you’re not ready to. If, in your heart, you’re not ready to come out, it’s alright to keep it a secret until you are. That way, you can really help other people when you do tell them, but you should really know your reasons before you do.”

Young HIV positive man with glasses

Discussion Questions

In the video these two people presented some different ideas on disclosure. From your experience,

- Whose advice would you take? Why?
- What are some reasons for disclosing?
- What are some reasons for not disclosing?
- Ideas for good ways to disclose?
- Can other people help you disclose?
- From the list in exercise 2, who would it benefit you to disclose to?

Exercise 4. (10 minutes)

How, When, Where

Ask the group to explore ways they think they might disclose to the people ticked on the list in exercise 3, from an unplanned casual conversation to appearing on TV to having to fill in forms...

Write up the list on a sheet of paper.



Exercise 5

(15-20 minutes)

Reactions

Most people will react strongly to news of someone close to them being positive. Their reactions may range from denial, shock, anger, disbelief, amusement to tears, or all of the above. At first they may be thinking about themselves, then they may turn to think about you.

Discussion Questions

- Ask what you might expect people close to you to feel?
- Ask how people who aren't so close might react? You can go back to the list of people you might tell, pick a couple and ask what the group thinks the hair-dresser's reaction will be or the doctor's or the mother's?
- Ask how the group thinks they could help the people to whom they've disclosed?

Facing Prejudice

“There’s no discrimination in our house. No one tries to separate me from anyone else because I’m infected.”

HIV positive artist

Prejudice is when you treat a group of people unjustly on the basis of some perceived difference, such as income, race, gender or HIV status.

People with HIV are ordinary people who happen to have contracted a virus and may need care or treatment if they become ill. The virus is not easily caught through everyday contact or being near someone who has it. They can work and live with other people.

However, many people do not understand this. They think people with HIV should not work or live with other people. In some cases, if employers find out that someone has HIV, they will be asked to leave work or be given the sack. Landlords may refuse to let houses to people who are HIV positive. Schools may refuse to take children with HIV. Neighbours and friends may stop visiting a house if they find out the people there are HIV positive. Doctors may refuse to touch people who are HIV positive. This is unfair treatment. The people who are doing these unfair things are prejudiced against people with HIV. They mistakenly believe that people with HIV are a danger to society.

Some people also believe that people with HIV must have done something bad or they would not have HIV. This is a complicated issue, but nobody deserves to get HIV. Of course, normally when we sell people a drink or rent them a room we do not ask about their sexual history or if they have ever used drugs, these are personal matters. But when it comes to people with HIV everyone wants to find out about their personal lives. That is not fair.

“My family lives normally and happily together... Our house is a meeting point, with all kinds of people coming and going. Everyone eats and drinks together. ...villagers, neighbours and friends understand me... and accept me as I am. They tell me: ‘You’re infected, ok. If you can take part in what we’re doing ...come and join us!’”

HIV positive artist

“In order to face the AIDS crisis, people everywhere should join hands. We must understand the situation of those who have AIDS. We should not scorn people. We should support them. We should not ridicule, blame or abandon each other. With compassion we will see our way through.”

Phra Kru Sophon, Doi Saket Temple

Facing Prejudice

“I don’t have scales or horns, I’m no different than other people. I have the same rights as anybody else.”

HIV positive man in striped shirt

Human rights are the rights of all people to be treated as equal in human worth and dignity. The parameters of these rights may be set by law, custom and social regulation. People with HIV /AIDS have no more rights than other people. However, all people, including people with HIV/AIDS, should *respect* each other’s human rights in the following ways:

- Encourage people to respect each other’s rights, and to treat others as they themselves would wish to be treated;
- Make sure that education and access to health care are available to everyone;
- Educate people to help them overcome the fears, ignorance and prejudices that lead them to abuse the rights of others.

We should *protect* each other’s human rights in the following ways:

- Support and defend people whose rights are threatened or abused;
- Remedy and compensate for abuses when they occur;
- Work to change the conditions of poverty, powerlessness and dependence that make people vulnerable to abuse of their rights.

The rights of people with HIV which are often abused include the following: the right to care and treatment equal to that received by people with other health conditions; the right to employment– not to be sacked or refused employment because of HIV status; to participate in community activity; to take out life insurance; to receive social welfare; to travel; to receive an education; to confidentiality as to HIV test results; to live.

Rights to Care and Treatment

In many countries laws have been changed or new laws introduced in response to AIDS. Laws can protect people from discrimination, although in some cases laws have been used to limit the human rights of people with HIV.

When there seems to have been an abuse of rights the thing to understand is what a person’s human rights are. An HIV positive person does not have special rights above others.

Seeking Solutions

When there is an abuse of rights, the law is not the only means of redress. The following means are also helpful.

- Trying to create understanding
- Education
- Negotiation
- Organising and lobbying.

International bodies working for the human rights of positive people:

- The United Nations,
- The International Federation of Red Cross and Red Crescent Societies,
- The Global Network of Positive People

National government and non-government agencies may also work on the rights of positive people. Find out who is taking action in this area in your country.

Transmission

“It’s not like an insect. It just doesn’t jump from one person to the next.”

Pimjai’s mother

“I’ve been doing this work for a long time now, I share my whole life with them. We eat together all the time. I’m not scared, because I know very well that you cannot catch it like that.”

Flower shop owner

There are only three ways HIV can be transmitted. These days every school child can tell you the three ways HIV/AIDS is transmitted and because people see them so often, they have become bored and no longer hear or see that information when they look at or listen to it.

Still, there are only 3 fluids that transmit HIV(See box).

Perhaps because this information is so widely known, it may help to think about the virus in different ways:

There are 4 principles to HIV transmission:

1. **EXIT** - the virus must exit the body of an infected person.
2. **SURVIVE** – the virus must be in conditions in which it can survive.
3. **ENTER** – the virus must enter the blood stream of another person.
4. **SUFFICIENT** –there must be sufficient quantities of the virus present to cause infection.

**ALL FOUR MUST BE PRESENT
FOR HIV TO BE TRANSMITTED!**

Sometimes, families or friends who care for people with HIV at home are worried about catching HIV from the sick person.

If you are worried about accidentally exposing others to HIV/AIDS you need to understand HIV transmission in detail. In the next page we give you some ways to assess what is a risk for HIV transmission and what is not.

How HIV can be spread

- Through Sex :
 - unprotected sexual intercourse, which can be *penis/vagina sex*;
penis/anus sex,
 - oral sex (although this is less risky)
The fluids that transmit HIV in this case are sexual secretions from vagina and penis.
- Sharing needles or syringes which carry the blood of an infected person into the blood stream of another.
The fluid that transmits HIV in this case is blood.
- From mother with HIV to baby during pregnancy, birth or breast feeding.
The fluids that transmit HIV in this case are blood and breast milk.

Fluids that transmit HIV:

- **Sexual secretions (semen and vaginal fluid)**
- **Blood**
- **Breast Milk**

Transmission

ASSESSING ACCIDENTAL EXPOSURE

What happens if someone accidentally gets blood on their skin?

An incident where blood from an HIV positive person, falls on to the unbroken skin of an HIV negative person is not regarded as dangerous. HIV cannot enter the blood stream of the uninfected person through their skin! Accidentally getting blood on skin is a good example of how you can use the four principles to assess whether something is risky:

1. Did the virus **exit** the body of the person with HIV?
Yes, in the form of blood.

2. Was the virus in **conditions** where it could survive for long?

No, the virus is fragile and could not survive for long on skin, also in this case, it would be quickly washed off.

3. Did the virus **enter** another person's body?

No, the unbroken skin did not allow the virus to get into the uninfected person's blood stream.

4. Was the virus in **sufficient** quantity to transmit?

Yes, blood contains HIV virus in sufficient quantity to transmit HIV, if it can get into a person's bloodstream.

ONLY TWO OF THE FOUR CONDITIONS ARE PRESENT THEREFORE THE INCIDENT COULD NOT TRANSMIT HIV.

In overseas countries, hospitals have very strict rules about infection control. In Australia, hospitals have a set of guidelines on how to assess an incident which could allow HIV to pass from one person to another. But, if a Nurse has an accident at work, for instance, if blood from a person with HIV splashes onto the Nurse's unbroken skin – all they have to do is - **wash it off with ordinary soap and water!** The Australian nurse gets no treatment in this case. That is because the medical authorities are so sure that blood on skin poses no risk to anyone. *However, because blood does contain HIV virus in sufficient quantities to transmit it, it is still wise to be careful around blood. (Nurses wear gloves for any procedure they expect will involve blood from anybody).*



QUESTIONNAIRE

May we request cooperation from facilitators who have used this manual with your target groups to answer the questionnaire. Your responses will be valuable to improve the manual. Please send the completed questionnaire to UNICEF EAPRO, HIV/AIDS Unit, 19 Phra Athit Rd., Bangkok 10200.

1. You are a (Please tick)

☐ Volunteer
☐ Community educator
☐ MOPH staff
☐ Peer educator

☐ Youth group leader
☐ Positive people group leader
☐ Teacher
☐ Others _____

2. You work with what group.

☐ Rural communities
☐ Slum dwellers
☐ Students
☐ Out-of-school youth
☐ Others _____

☐ MOPH staff
☐ Community leaders
☐ Employers
☐ Employees

3. Which part(s) of the manual did you read? List Contents (Please Tick)

☐ Accepting people with HIV/AIDS
☐ Finding Out
☐ Keeping Well
☐ Being Sick
☐ Mental Health
☐ Nutrition

☐ Herbal Medicine
☐ Employment
☐ Love, Sex & Intimacy
☐ Families
☐ Disclosure
☐ Transmission

4. Did you use the manual when you were showing the video to a group? ____ Yes ____ No

5. What particular group did you last show the video to/use the manual with?

☐ Rural communities
☐ Slum dwellers
☐ Students
☐ Out-of-school youth
☐ Others _____

☐ MOPH staff
☐ Community leaders
☐ Employers
☐ Employees

6. Which part of the manual did you and your target groups find most useful?

Useful to you _____

Useful to your target groups _____



7. Which part of the manual did you and your target groups find least useful?

Least useful to you

Least useful to your target groups

8. (Manual for Communities) Did using this manual assist your target group to better accept people with HIV/AIDS?

8. (Manual for Positive People) Did using the manual help your target group? If so, please say, from your observation, what they found helpful.

9. What other kinds of information or activities should be included in the manual?



