

# Stigma & Discrimination

*Live and Let Live!*

Global Campaign 2002 - 2003



## World AIDS Day 2002 Advocacy Kit

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## Message From The Regional Director



We often look towards science to solve medical problems. AIDS has not been an exception to that rule. Since its discovery in 1981, we have hoped for a cure and a decline in one of the most feared diseases in modern history. Today, we have an effective treatment and are heading closer towards a vaccine.

Yet AIDS is nowhere near entering the history books. The disease will kill more people this decade than all the wars and natural disasters in the past 50 years. Today, more than 40 million are living with the virus and the pandemic is still growing. Why is this?

AIDS is a biological phenomenon, caused by a virus, but it is not just about science and medicine. It is also a social phenomenon. The shape and response to the epidemic is determined by governments, communities and individuals. Dealing with the social problems related to HIV/AIDS is just as much a public health issue as drugs or vaccines.

This is an important point to understand, given the current debate about access to drugs. Consider a recent study on wealthy patients receiving anti-retroviral therapy in a clinic in Kampala, Uganda. The study found that the stigma around HIV/AIDS kept some clients from continuing treatment. They said they feared discrimination and loss of confidentiality. Thus, access to therapy is important, but it is no panacea to the crisis. Even a miracle drug may not overcome the stigma and address some of the most painful parts of HIV infection – prejudice, rejection, hurt, ostracism.

The stigma around the disease could be attributed to cultural or religious beliefs or a lack of education. Another ingredient is the need to blame. But by blaming individuals, communities and governments may fail to take responsibility and action. This can lead to denial. Governments may refuse to reveal the full extent of the epidemic in their country. People living with the virus may not admit it. Denying the existence of the epidemic is dangerous - it fuels the spread of the virus.

The lesson for public health from AIDS is to think beyond medicine. We need to address the related social problems to strengthen care for those infected and prevent infection for those vulnerable. This may involve taking a pragmatic, honest appraisal of drug abuse, prostitution and sex outside marriage. And for this to succeed, we need to remove the hostile climate around HIV/AIDS.

Defusing the stigma and discrimination around HIV/AIDS is as much a part of the solution as condoms and clean needles. That is why the theme chosen for 2002 – 2003 for World AIDS Day is “stigma and discrimination: **live and let live.**”

**Dr Shigeru Omi**  
Regional Director  
WHO Western Pacific Region

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## Executive Summary

Throughout human history, many diseases have carried some stigma, including plague, leprosy, and tuberculosis. People with these diseases were often shunned, isolated and even mistreated. A lack of knowledge and beliefs that the disease was ill-fated or divine punishment fuelled the prejudice.

**Fight AIDS - not people with AIDS**



*Last year, more than half a million children were born with HIV because their mothers did not get tested or go for treatment*

Today, people with HIV/AIDS are regularly ostracised and rejected by their own communities – and sometimes even by loved ones. Often, they are blamed for their illness. The disease is considered a deserving punishment for “immoral” or “bad” behaviour such as drug use or sex outside marriage. Sometimes, discrimination is sanctioned by the state.

Making moral judgments serves little purpose, however. It does not help the sick get better, prevent infection or stop people from taking drugs. In fact, it does the *reverse*. It increases the negative impact of the epidemic, presenting obstacles to fighting and treating the disease.

Stigma generally makes the disease more difficult to discuss and harder to deal with. It can spread infection through misunderstanding. It can make people hide their HIV status, amid fear of rejection from loved ones and the possibility of a divorce or eviction. Some people living with HIV go for years without telling a soul.

Due to discrimination, those infected may be denied treatment by health care services, have difficulty getting jobs or housing or be refused entry into a foreign country. Stigma and discrimination can thus become the hardest part of living with the disease, creating a climate that is a private hell for those infected and affected.

This has a wider impact. Last year, more than half a million children were born with HIV, although the means to prevent infection are available. The reason? Many pregnant women, fearing discrimination, do not get tested or get the necessary treatment.

“People with HIV may be seen as bad people or even a ghost or monster. People will keep away from him or her” - health care professional in China.

**Ask Yourself:**  
Is there a climate of hostility to those infected with HIV/AIDS in your community?

Part of the stigma around AIDS has emerged out of long-standing stigmas predating the disease. For example, drug users have long been social outcasts, often facing the toughest arm of the law. Sex workers also have long been marginalized while homosexual behaviour is not acknowledged in many societies. Such groups have long been denied services and treatment. Such stigma poses barriers to HIV prevention, and as long as they remain, the epidemic will continue to grow.

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## LIVING WITH THE REALITY *of stigma & discrimination*

Despite 20 years since the discovery of AIDS and the scientific advances gained, there is still much denial, discrimination, fear and stigma all over the world – even in countries where large numbers of people are infected. For example, in some African countries, only a small number of people have declared their status – although as many as a quarter of adults are infected. Similarly in Cambodia, which has the highest HIV prevalence in Asia, rejection by the family is common.

Some societies are openly unwilling to accept people with HIV/AIDS. An extreme case was that of South African Gugu Dhlamini, who was stoned and beaten to death by neighbours in Durban after she spoke publicly about being HIV-positive in 1998.

### *Ask Yourself:*

How easy would it be for someone with HIV/AIDS in your community? Would they be blamed for their disease and face rejection?

In the Western Pacific Region, people with HIV/AIDS have been thrown out of their homes, rejected by families, turned away from jobs and had their children expelled of school. They often face barriers at various levels and are denied certain rights. For example, people with HIV have been barred from using swimming pools in some areas.

Discrimination is most apparent within health care systems. Hospital staff in many countries frequently refuse or withhold treatment, do not attend to people with HIV/AIDS or give them poorer care.

In many countries in the Region, most people with HIV/AIDS get very little or no treatment and only a small handful are on anti-retroviral therapy (ART). For example, in China, it has been estimated that less than 1% receive treatment and less than 100 people are on ART, according to the National AIDS Centre. In Cambodia, access to care is limited, particularly in rural areas. Some international organizations offer care and are giving ART to some 300 people.

ART is costly and difficult to administer. But many drugs for opportunistic infections are affordable, effective and simple to administer. They can lengthen life and ease pain and suffering considerably. Yet many countries do not even offer such drugs. As a result, many people suffer unnecessarily.



*Testing is often done without counselling*

A few years ago, one patient arrived at Kuala Lumpur hospital clutching a large, sopping wet bath towel. He was drooling and unable to swallow because of a fungal infection called candidiasis. He thought he was dying. He did not know that cheap drugs could cure his condition.

HIV testing is another area where discrimination is evident. Voluntary HIV tests and counselling is often limited, not well known, inaccessible or only in urban areas. People may also be deterred from getting tested because of laws that restrict an individual's confidentiality.

Instead, within the Region, HIV tests are often done without consent or counselling on individuals and some groups, such as drug users and sex workers. In some areas, couples wishing to get married have had to get HIV tests. In Cambodia, couples getting married are often pushed by relatives to go for HIV tests, despite a law preventing mandatory testing.

In a stigmatised climate towards HIV, open discussion may be more difficult. And people have less incentive to get tested or protect others from infection. In Thailand, the establishment of anonymous clinics increased the numbers of people seeking HIV testing.

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## DRIVING FACTORS *behind stigma & discrimination*

As a fatal, new disease linked to taboo behaviours such as extra-marital sex and drug use, HIV/AIDS would inevitably be seen as shameful. The disease reinforces existing social stereotypes and prejudices. For example, when a drug user gets infected with HIV, the community may see it as a fitting “punishment” for what is seen as immoral or perverse behaviour.

### *Ask Yourself:*

What groups of people are considered to be the “worst” in your society? Why?



*The status of women is linked to the spread of HIV*

In Viet Nam, drug use and sex work have been described as “social evils” and people with HIV/AIDS are often blamed for contracting the disease. In Malaysia, drug users have been called “sampah masyarakat” (trash of society).

But blaming people does not help stop the disease from spreading. In fact, it usually causes the disease to spread further because stigmatized groups tend to become more hidden and opportunities for giving them information and treatment are lost.

### *Ask Yourself:*

How much do the people around you know about HIV/AIDS? What can be done to raise awareness?

Blaming certain groups also allows societies to avoid the responsibility of dealing with the epidemic. This denial can be dangerous. Governments may hide cases, fail to gather accurate data or not care for people with HIV/AIDS. Officials may use figures of *detected* cases rather than estimated cases to downplay the magnitude of the epidemic in their country. People at risk may also be in denial. They may assume a false sense of security by believing only “outsiders” or marginalized groups can become infected.



*Poverty is interlinked with HIV*

Ultimately, HIV is tied to complex social patterns and behaviours, such as drug addiction, that cannot be readily explained. People with HIV/AIDS require understanding rather than intolerance.

On a wider scale, the dynamics of the HIV epidemic are often related to inequality, poverty, discrimination and the poor status of women. For example, the poor are usually less well-informed, less able to afford condoms and less able to get treatment for sexually transmitted infections, which greatly increase the likelihood of HIV infection. Further, poverty can force women into prostitution. Migration, urbanization and rapid cultural modernization have also exacerbated the epidemic.

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## STRATEGIES TO STOP *stigma & discrimination*

### 1. Information and awareness campaigns

Ignorance about the disease and how the virus is transmitted can generate fear and prejudice towards those who are infected. There is still a significant lack of knowledge and misunderstanding about the disease in this Region. Information and awareness campaigns have an important role to play in changing this situation.

Studies show that there is a strong linkage between what young people know and how they act. Ideally, the information in campaigns should be relevant and aimed at a specific audience. A variety of strategies can be used – talks, lectures, peer education, leaflets or workshops. More on this subject is given later.

### 2. Involving people with HIV/AIDS

Personal contact with someone affected by or infected with HIV can help dispel myths about the disease, and generate empathy and understanding. Hearing someone's personal story, either by a lecture or in a face-to-face conversation can be a powerful experience. It helps "normalize" the experience of the disease. Studies in the United States have shown that direct contact can help reduce stigma.

People with HIV/AIDS (PHA) can play a key role in fighting the epidemic. They can be advocates for change and contribute to their communities' development by giving talks to religious leaders, workplaces, health workers and vulnerable groups.

Delegating such responsibilities to PHA can be very empowering. In some countries, PHA involvement has led to activism, for example the Wednesday Friends' Club and Access in Thailand. In Viet Nam, the Friend-to-Friend club has provided peer support. In China, the first HIV-positive organization, Mangrove, offers training and support.

Celebrities with HIV can make a particularly significant impact in changing perceptions and attitudes towards HIV. One such example is Earvin "Magic" Johnson, the American basketball player who publicly declared his HIV status.

### 3. Care, counselling and support services

Support systems for those infected and affected by HIV/AIDS, particularly those that build skills and capacity, can help create an enabling environment to increase the participation of PHA. In HIV testing, quality counselling and care can provide an incentive for people to reveal their HIV status. For example, in Cambodia, there is a reluctance to get tested due to a lack of follow-up care. Good counselling can play a critical role in how a person responds to a HIV+ test result, and can contribute towards the person taking precautions to prevent others getting infected.



*Care can provide an incentive to get tested and reveal HIV status*

Care is not just about treatment. It also helps those who are infected to deal with the disease and plan for the future. Also, it helps to reduce the isolation of stigmatized individuals and can help shed stigma. Home-based care programmes in both Cambodia and Thailand have helped to raise awareness about the disease, dispel myths and misinformation, and reach out to isolated individuals.

For marginalized groups such as drug users, outreach care may be the first line in prevention work. When offering simple treatments for injection wounds, drug users can be given HIV prevention messages as well as motivated to care for themselves.

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## STRATEGIES TO STOP *stigma & discrimination* (continued)

### 4. Training of health workers

Health workers need to be sensitized and aware of how to respond to the disease. Many have strong fears about catching the disease, but the chance of infection, even from needle-stick injuries, remains very small. At the very least, health workers should have a thorough understanding of how HIV is transmitted, familiarity with universal precautions, knowledge of available care, and an awareness of the importance of confidentiality. Ideally, they should also have a basic grounding in counselling and support skills, and should be able to refer PHA to available services. In New Delhi, India, one nongovernmental organization, Horizons, has been working to create “HIV patient-friendly hospitals.”



*Health workers need AIDS training*

### 5. Setting policy guidelines & confidentiality

Policies on discrimination, access to prevention and care, confidentiality of care, and individual's rights can make a significant impact. In some settings, individuals have a restricted right to anonymity and confidentiality on the basis that the disease forms a public health risk. But notification of the disease can be done while maintaining confidentiality.

Confidentiality can affect whether people get tested or not. People may not want to get tested for fear of negative repercussions – a HIV+ test result could mean isolation, loss of a job or partner and discrimination. In Thailand, such fears were reduced with the establishment of anonymous clinics. The numbers of people wanting tests also rose.

### 6. Strengthening the legal framework & mandatory testing

Supportive laws can help challenge discrimination and provide a supportive environment for PHA. Cambodia recently passed a new law that aims to end discrimination. For laws to be effective, PHA must know their rights. Also, there must be mechanisms for enforcement and monitoring discrimination.

Laws that result in inequality, marginalization and social exclusion of groups vulnerable to HIV infection can help spread the virus. Some laws directly block prevention efforts, such as laws prohibiting condom promotion. In many countries in the Region, it is difficult to conduct prevention programmes for drug users. Laws and police practices need to be reviewed to ensure that they support rather than hinder HIV prevention.

Some countries have laws allowing mandatory HIV testing of certain groups, such as drug users or sex workers. This is not in the interest of public health. It is ineffective, expensive and can drive vulnerable groups away from treatment or prevention activities. Very often, mandatory testing is given without counselling, which further increases the negative impact of such testing.

### 7. Encouraging political, community and religious leaders to provide leadership

Leaders can spearhead and lead public campaigns, or at least, add a strong voice to them. National leaders can set the tone for a campaign. Political leaders in Thailand have demonstrated that action from the top can filter down to all levels. Celebrities can also create a strong impact - as did the late Princess Diana when she hugged someone with AIDS. Efforts can be made to encourage leaders to participate. In Cambodia, home-care teams have worked with traditional healers, schools, local politicians and religious leaders to promote awareness.

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## FIGHT FEAR WITH FACTS *on stigmatised groups*

Information is the first step in HIV prevention. And it helps combat fear, prejudice and myths. But knowledge of HIV/AIDS is poor - as is knowledge on health issues generally in some areas. Sex and drug use may also be considered culturally out of bounds.



*In some rural areas, little is known about AIDS*

A recent United Nations study found the vast majority of the world's young people have no idea how HIV/AIDS is transmitted or prevented. A study on several thousand Chinese found the "vast majority" did not know about the cause and transmission methods of HIV/AIDS. A quarter of farmers – the most common occupation in China – had never even heard of the disease, found the study by China's State Family Planning Commission and the US Centers for Disease Control and Prevention. About three-quarters did not know condoms could prevent HIV infection.

In Cambodia, a survey of urban young people aged 11 to 20 years found that 80% believed that it would not be possible for them to contract HIV. Only one in three had ever talked to anyone about AIDS and about half thought HIV could be transmitted by coughing and mosquitoes.

Clearly, more AIDS information campaigns are needed, even in countries where generally there is awareness. Earlier this year, a Thai village refused to allow children with HIV into a local school. The villagers feared that the HIV+ children could infect their own children through physical contact or mosquito bites.

Information and awareness campaigns should explain the basics about the disease. But campaigns need to go further and raise the prevention strategies that conflict with social mores, such as using condoms. To help shed the myths, it is important to know the issues. Below is some information on specific stigmatized groups.



*The right to go to school is not always guaranteed, as was the case for some HIV+ children in Thailand recently*

### 1. People with HIV/AIDS (PHA)

PHA can live vigorous and productive lives for several years after infection if given appropriate information, treatment and support. There is still much misunderstanding about how the virus is transmitted, which affects how PHA are treated. HIV is not a strong virus. It only survives for a short time outside the body and *only* in human blood, sexual fluids and breast milk. It cannot be transmitted through tears, urine, nasal secretions, sweat or saliva.

### 2. Injecting drug users

Drug injection is a global phenomenon that cuts across cultures. It has been closely tied to the spread of the epidemic, particularly in this Region. The sharing of contaminated needles is a highly efficient means of spreading HIV. There have been explosive epidemics among injecting drug users (IDUs) in many countries.

But HIV epidemics among IDUs can be stopped. Australia has demonstrated that "harm reduction" strategies, which aim to reduce the possible harm from injecting drugs, can be very effective. The HIV infection rate among Australian drug users has remained low.

Harm reduction strategies include giving IDUs:

- information on how they can prevent HIV infection;
- outreach services in their own communities;
- access to sterile injecting equipment (for example, from pharmacies); and
- drug detoxification and treatment programmes, such as methadone.

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## FIGHT FEAR WITH FACTS *on stigmatised groups (continued)*

A variety of widely accessible options should be given to drug users, as they have a wide profile, with different backgrounds and different levels of addiction. Drug users living on the margins of society may be best reached by outreach services. Working professionals though, are probably better served with methadone substitution, which can allow them to lead relatively “normal” lives, working and living with their families.

Many countries deal with addiction through punitive treatment. China, Malaysia, Myanmar, Singapore and Viet Nam all have compulsory drug rehabilitation centres with strict discipline – some almost military-like – and terms ranging up to two years. Yet relapse rates are at least 70%. Aside from being very costly, such methods are simply ineffective, as they usually fail to treat the root cause of the problem.

Addiction is a symptom, not the essence of the disorder. It has a psychological basis. Treating addiction often requires building self-esteem, coping skills and emotional stability. It may involve sorting out basic needs – housing, family ties and managing money. Only a limited number of programmes in the Region are doing this effectively.

### 3. Sex workers

The response to prostitution by many countries is often similar to that of drug use. The state may seek to wipe out or punish the business through the arm of the law. Yet no society has ever been able to wipe out the “oldest profession in the world.”

Often, it is the sex workers, like the drug users, who are at the receiving end of the law. When clubs or bars are raided, the sex workers – the ones who pay the highest cost of all involved in the business – usually get picked up rather than the bar owners, pimps and clients. It often makes no difference whether the women were victims of exploitation, abuse, or coercion. Decriminalization can get around this – it protects the women but upholds that prostitution is still a crime. By doing so, the criminal focus can be directed towards the pimps and profiteers. The women can be offered options to train for other opportunities rather than face a jail term. Some sex workers have drug problems or were victims of rape or incest and may need psychological support.

Condoms should be made available in outlets or areas where sex work continues. Implementing a “100% condom use programme” in commercial sex outlets has been shown to have a tremendous impact in bringing down new HIV infections. Both Thailand and Cambodia have managed to contain their epidemics, preventing millions of new infections, through such programmes.



*Sex work outlets must supply condoms*

### 4. Men who have sex with men (MSM)

In all societies around the world, MSM are believed to comprise about 5% to 10% of all sexually active males. However, MSM do not fit a regular profile and represent a diverse group. They may be married, “bisexual” or “homosexual”. Some may engage in sex with other men frequently, others only occasionally. In some all-male institutions, such as the military and prisons, male-to-male sex can be common.

MSM represent a group vulnerable to HIV infection. Unprotected anal sex carries a high risk of HIV infection for the receptive partner. In many developed countries, sex between men accounts for the bulk of HIV infections.

MSM are not a well-defined group in most countries in the Region. There is often little knowledge about the structure and patterns of MSM groups. There should be an awareness that such practices continue. Very often, governments and societies deny that MSM exist in their countries and thus refuse to support appropriate prevention work.

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## FACING HIV BRAVELY AT 10 YEARS

(From Lao People's Democratic Republic)

Pia is only 10 years old, but already has her own business. She is the best marbles player in her village in Lao People's Democratic Republic and when she wins enough, she sells a bag of 10 marbles for 500 kip. She carries her marbles and money in a rice basket slung over her shoulder. Her aunt Manikone says that she is also a talented student, achieving the second best place in class. This lively, inquisitive and highly intelligent young girl is also HIV-positive.

Last year, she spent three months at home when she had open and inflamed sores on her skin. Manikone did not want to let Pia leave the house for fear of infection. Several times at night, she would wake her niece up to take medication.

The sores, which left Pia's skin pockmarked, were extremely uncomfortable. These were tough times, but Pia told her aunt that she was not afraid of dying. "If I die, I don't have to suffer," her aunt recalls her saying. "But despite all this she has never failed a single subject," Manikone says proudly. "I organized a private tutor for her at home."

After a long course of treatment organized by the Care and Support project team, Pia's health improved. She is now back in school. Her aunt says she is back to normal, describing her as an energetic child always "coming home with grazed knees!"

Pia was either born with HIV or contracted it through breastfeeding. She had lost both parents to the virus by the time she was four years old. Manikone explains that her brother – Pia's father – and his wife often went to work in Thailand. When Pia was just 11 months old, her mother went back to Thailand, leaving Manikone to bring Pia up.



Millions of children have lost their parents to HIV

After a couple of years, Pia's father also went to Thailand, where he met up with his wife. She was very thin and sick with tuberculosis. He decided to bring her back home. An AIDS test was carried out and she was found HIV-positive. She died shortly after.

Care and Support project staff tracked down Pia because hospital records showed that both parents had died of AIDS. Three years ago she had a HIV test and the result was positive. "I didn't know what to say when they told me. I've raised her since she was 11 months old, as my own daughter," Manikone says.

Some boys in the village initially gave Pia a hard time, shouting to her friends that they should be careful of getting infected. But the Care and Support staff spoke to teachers at Pia's school, who then spoke to parents. Pia is now treated normally again.

Manikone attends meetings with others who are affected with HIV/AIDS. "It's fun going to the meetings," she says. "It's a chance to exchange ideas. It makes me realize that it's not only my niece who is infected."

Pia understands everything that is said at the meetings – afterwards, she talks about what has been said with her aunt. After one meeting, she read through a booklet given to her aunt and explained to her aunt how she should be looked after.

Manikone admits that her niece's future is uncertain. But Pia remains optimistic. She has promised that when she wins the lottery she will buy a motorbike for her aunt.

(Story courtesy of UNICEF, Lao People's Democratic Republic)

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## FEATURE STORY

**POSITIVE - AND STILL POSITIVE****(From Lao People's Democratic Republic)**

For a whole year, Thor's husband was ill with constant diarrhoea and sores on his hand. Thor and her husband both had blood tests done at a hospital. She was extremely surprised at the results. "Both tests came up positive," says Thor, age 28. "I would never have guessed that his symptoms meant that he had AIDS."

Thor and her husband did not tell neighbours in the village in Savannaket province that they were HIV-positive. But somehow, they found out. "People would tell their friends, 'Be careful if you touch something they've touched, you might catch AIDS'. When I heard this, I didn't want to go anywhere, I just wanted to die," she recalls.

"When my husband died, I didn't really understand what being HIV-positive meant," she says. "I had no symptoms myself at that time. I heard what the doctors were saying but didn't really listen. When I saw him die, I thought that I would soon share his fate, that I should start counting the days."

Shortly after he died, Thor received a note from Dr Khamphang of the Care and Support project team. "You should not be alone. There is a self-help group you can join. There are other people who are HIV-positive, you should come and meet them," it read.

"Every month is a sharing experience," she explains. "The group gives me encouragement. It makes me realize that there are still many things which I can do."

Thor has become involved in the income-generation scheme run by the Care and Support staff. "I have just started weaving cotton," she says. She weaves and dyes cotton, which is then used to make traditional blue farmer's shirts. The money will supplement her income from farming and will ensure that she has enough to eat.

The scheme has also renewed confidence. "Several of us from the self-help group are thinking about setting up a weaving business together," she says.

Thor's health varies from month to month but she is upbeat. "I feel like I lead a normal life at home. I think more optimistically these days. I have fun with my friends and sometimes I can forget that I am living with HIV."

The Care and Support staff have sent a team to the village to educate people about HIV/AIDS and the situation with Thor's neighbours has now returned to normal.

Thor seems happiest when she talks about her seven-year-old daughter, whose blood tests have all proved HIV-negative. "I was so relieved when I found out. It was like having a weight lifted from my shoulders."

Thor says that the self-help group has given her the will to live again. "I no longer feel like I will die easily," she says. "We have been given back our faith in ourselves."

**(Story courtesy of UNICEF, Lao People's Democratic Republic)**

*Thor was surprised at the blood test*

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## TRUCK DRIVER TURNS AIDS ACTIVIST

(From Viet Nam)

Minh (not his real name) is gratified seeing the growing number of information materials on HIV/AIDS in Viet Nam in recent years. There is just one thing that makes him a little sad. It came too late for him.

"I wish that the HIV education was popular [a few years ago], as it is today. Then I would not have been infected with HIV," explains the former truck driver from Le Chan district, Haiphong city.

Minh, 30, said he had limited access to HIV information when he was a driver. "I sometimes read about HIV in newspapers or heard about it on the radio, but I thought it was only warnings." The real threat of the disease somehow did not sink in and he did not take precautions against HIV.

He tested HIV-positive in 1999. He told the district health department he wanted to try to raise AIDS awareness, especially among drivers. He wanted to use his own experience to try to educate people about HIV/AIDS. He wanted them to be aware of the risks and the methods to stay safe from HIV.

During the implementation of an AIDS prevention project for the mobile population in Hai Phong city, Minh was invited by World Vision International, a non-governmental organization, to talk about HIV prevention to truck drivers as well as people in the community.

Minh is now head of the Friend-to-Friend club, a peer support group. Minh tries to encourage people with HIV to join the club, saying that it can help them live better. Members of the club are able to share their difficulties, their discrimination by communities and the suffering of the disease with each other.

Together with his friends, Minh has organized campaigns to discuss HIV/AIDS and distribute information materials at truck stations. He feels by doing such activities, it allows him to contribute towards his society and city.



*There is a need for more awareness campaigns in many areas of the Region*

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## FIGHTING FOR HOPE FOR DRUG USERS

(From Malaysia)

Ben is an impressive 49-year-old Malaysian who works with HIV and drug use. Six-foot-tall, well-built and articulate, he appears strong and confident. He does not look his age, aside from the lines around his eyes, and is enthusiastic about his job in training recovering addicts and giving them coping skills.

"I really want to make a difference [to addiction]. I have a sense of commitment," he says, with a warm smile. He hopes to make a difference internationally, too, and has already worked abroad as a consultant with the United Nations on drug use.

The glow on his face reveals little about his limited future or his past – he has lived for 10 years with HIV and is not on combination therapy. For three decades, drugs directed his life. His resume as a hardcore addict is extensive – four prison convictions, house-breaking, stealing from his family, shoplifting, manipulating anyone and everyone for money, living on a piece of cardboard in the street, not bathing for months.

There is every reason why he should not be here, why he should have died on so many occasions. He once burst a major artery in his body. He lived on the street with a gaping wound half the size of his palm. He injected all kinds of filth in his body.

What made the difference in Ben's life was the right drug treatment programme. Ben spent years and years getting "treatment" in programmes that never really addressed his addiction – prison, a religious drug treatment centre and the Government's rehabilitation centre.



But from the day he entered Rumah Pengasih in July 1996, a drug treatment programme and halfway house in Kuala Lumpur, Malaysia, he has not touched drugs. "There's always hope. Every addict can go on to recovery," he says confidently. There are many others in Pengasih with similar stories – many who spent years, even decades, scrounging or stealing for their daily drug fix.

Unlike the government centres, Pengasih has no fences, no bullying and no military discipline. The programme used in the centre, known as therapeutic community, focuses on the root of addiction, and addresses basic needs for "whole person recovery", such as housing, family relations and money management.

"It wasn't always easy. I did a lot of hard work here. I cried and screamed sometimes," he says. It was his peers, former addicts themselves, who helped him through the process.

Ben says he will never go back to drugs. "With every step that I move forward, I move further away from who I was. But I have not forgotten that experience," he says.

Ben drifted into drugs in the early 1970s after his father's death, when flower power, hippies and drugs were in vogue. When he got hooked on morphine, he began to steal to support his habit. He wanted to stop, but did not know how. He began a cycle in and out of prison, drug detoxification centres and rehabilitation centres.

Every time he was out, he ended up on the streets taking drugs. He even tried a Christian treatment programme, but the transition required was too great. "For the junkie that I was, to make a 180 degree turn and face God, I couldn't do that. It didn't work for me," he says.

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## FIGHTING FOR HOPE FOR DRUG USERS (continued)

(From Malaysia)

His lowest point came after he discovered that he was infected with HIV. He had a double burden – first the shame of drug addiction, then infection with a virus that made him feel like a social outcast. The members of the Christian drug rehabilitation centre where he was staying at the time eventually made it clear that they did not want him around. “People were saying that I should have separate plates and spoons,” he says. “It was 1990 then. There was still a lot of fear.”

Ben responded by giving up on life. If society gave up on him, he gave up on himself. He first moved to a dormitory, which turned out to be a “drug hell-hole” full of drug kingpins, pedallers and pushers. Then he ended up on the street again, scavenging to survive. He dug food out from dustbins, used water from the drain to mix his fix, did not bathe for six months and had ticks in his hair.

As the heroin he was buying was so weak, he injected about 20 to 25 shots a day. Eventually, he could only shoot in his femoral veins, major veins on his thighs, which quickly became swollen. “They bulged like goldfish eyes. I knew they were ready to explode, but I didn’t care. I still pumped that needle in them. I was trying to face death,” he recalls.

Eventually, one of the arteries exploded. “When I saw the blood shooting out in the air, I thought, ‘That’s it. My time has come.’ I was screaming hysterically,” he says. Instinctively, he tied up the wound with his filthy t-shirt. It immediately became soaked with blood.

Incredibly, he was taken to hospital in time and saved. After the surgeons removed the dead tissue around the wound, he was left with a gaping wound half the size of his palm.

Yet in just a couple of weeks, he was already injecting in his other leg – limping out of the hospital ward to score heroin. One of the surgeons found out, and begged him not to do it. “I was very moved when that doctor talked to me, someone who has thrown his whole life away. You can imagine what kind of heart he had. Other people would have given up on me,” Ben says.

But Ben did not give up drugs until many, many months later. After two months in hospital, he ended up back on the streets, but somehow still managed to dress and clean the wound every day.

One day, he walked into a drop-in centre run by Pengasih. “I asked them to help me. I didn’t know what to do any more. I had lost every resource,” he says. In his work with Pengasih, he has gone back to his old hangouts and met his old drug friends, who were stunned to see how he had transformed.

Ben believes that he is alive today because so many times in his life, someone chose to care, someone made that bit of an effort, such as that surgeon who saved his life. Sometimes, Ben goes to the hospital and gives a little food and care to the drug users there. “It doesn’t take a lot to care. And that little action of mine means so much to them. I know how lonely, how empty, how desperate they feel.”

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## FACTS AND FIGURES on HIV/AIDS

- An estimated 60 million people have been infected worldwide with the virus to date.
- Every year, three million people die of AIDS.
- In some countries, average life expectancy has fallen by more than a decade because of HIV/AIDS.
- Roughly one in five of all people living with HIV/AIDS are in Asia.



*AIDS is a problem that can no longer be ignored in many countries*

- Since 1996, HIV-positive patients in developed nations have had access to combinations of various drugs, known as antiretrovirals (ARVs), which can slow the progression of AIDS. These drugs have had dramatic results in some patients. But they do not cure AIDS. They are also expensive, do not always work and can have serious side effects. Recently, some developing countries are now producing ARVs at much cheaper prices.
- In 2001, more than one million people were newly infected with HIV in the Asia-Pacific Region and more than seven million were living with HIV/AIDS in the Region.
- Cambodia, Myanmar, Thailand and several Indian states have some of the highest levels of HIV infection among adults in Asia. Up to 3% of these populations are infected with HIV.
- In China, the government has estimated that about 850,000 Chinese were living with HIV in 2001. Experts have estimated that figure to be closer towards one million now.
- Commercial sex and injecting drug use have driven the epidemic in the Asian region, yet only a very small number of interventions address these problems.
- It is estimated that more than half of all injecting drug users have been infected with HIV in Myanmar, Nepal, Thailand, China's Yunnan Province and Manipur in India.
- In Viet Nam, Nepal, Malaysia and southern China, injecting drug use has been the main route of HIV transmission.
- In Ho Chi Minh City, Viet Nam, HIV infection levels among sex workers have been rising sharply in recent years. Some studies estimate that 20% of sex workers are infected.



*AIDS has even crept into very rural areas*

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