

# Fact Sheets on HIV/AIDS for nurses and midwives

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**Welcome to the HIV/AIDS Fact Sheets**

We hope you will find these Fact Sheets a useful support in your daily work. They have been designed for

ease of use, depicting the major points in the subject areas. This document is also available in a loose-leaf binder (WHO document no.: WHO/EIP/OSD/2000.5) so that you can insert your own pages of relevant information: perhaps phone numbers for local clinics or pharmacies, maps, updated regimens for drugs and supportive care, notes for course presentation, and other information.

If you are a WHO Country representative or WHO member of staff or an international partner:

These materials are designed to be adapted for use at national or sub-regional level. In addition to being available through the WHO website, they are available in a loose-leaf binder and on CD-ROM. The Fact Sheets give general information and their target audiences are nurses and midwives. Nevertheless they will be useful for other health workers and for other professionals such as teachers, pharmacists and community workers.

Below are some notes to help users to adapt, disseminate and use the Fact Sheets. It would be of great help to have feedback on the value and use of the Fact Sheets, and whether the flexible process of dissemination is helpful. An Evaluation Sheet is included and we would be grateful if you could encourage users to evaluate the way the Fact Sheets are used, either with this form or from a design of their own. Please do not hesitate to contact Barbara Stilwell (contact details given below) for more help, including where to obtain printed versions of this document.

We hope these Fact Sheets will prove to be a useful tool in keeping health workers up to date in this important area of work.

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## How to use the Fact Sheets

For all document users:

1. There are thirteen Fact Sheets, covering major topics of importance on the care of people living with HIV/AIDS. The Fact Sheets are written so that they can be used individually or together. The target audience for the Fact Sheets is nurses and midwives, which means that, though they are written in a style which is easy to understand, they do contain detailed information about nursing care and some medical matters. They might therefore need some additional explanatory material if they are to be used with other health workers.
2. The Fact Sheets have been designed to be attractive and inviting to a reader, so contain photographs and other illustrations. These may not be culturally appropriate for you and we invite you to change the illustrations or text, wherever you feel this would be desirable. To make this easier the material is also available on a CD-ROM, which allows you to change the contents. However, we would suggest that you first save the document to your computer and then change it, keeping an original copy for yourself.
3. The software used to prepare this material is Adobe Pagemaker, version 6.5, which is available for both IBM-compatible computers and for the Apple Macintosh. The fonts used are Adobe Myriad and Zapf Dingbats. The material can be edited if you have Adobe Pagemaker 6.5 available on your computer. Your local computer centre (if there is one in your organisation) might be able to help with this, or a computer sciences centre at a local university. If you are stuck then contact Barbara Stilwell (address below) for more help.
4. If you feel confident to change the document - maybe with help from someone experienced in document preparation on a computer - then go ahead. If you would like help with this process, please contact Barbara Stilwell at WHO Geneva. Full contact details are given below.

5. WHO/OSD aims to be as flexible as possible in helping you to adapt and use this material. We can arrange for help for you with matters of design and production. We can suggest sources to you for photographs and other illustrations, and we might be able to help with identifying donors to support the production process. Please do not hesitate to get in touch.

6. The text is as generic as possible in the version of the Fact Sheets which you have. You may wish to include local figures and to adapt some of the text to reflect local practices. One way of deciding this is by asking a small group of local people with expertise in this field to advise and act as resources for preparation of the materials. You could also consider collaborating with your local school of nursing or university schools of health sciences.

7. We would appreciate your help in evaluating the adaptation, dissemination and use of these Fact Sheets. An evaluation form is enclosed. This can be copied or adapted.

8. Remember! These Fact Sheets provide basic information only. There is much more to know on each of the subjects covered. But if you feel we have omitted essential information, please let us know. Locally essential information can be added when you adapt the Fact Sheets for your country's use.

For more information about evaluation and information about local WHO staff who could help you, please contact:

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## Fact Sheet 1 HIV/AIDS: the infection

- **Introduction: What is HIV/AIDS?**
- **HIV transmission**
- **Natural history of HIV infection**

Acute HIV infection  
HIV infection before the onset of symptoms  
Progression of HIV

- **Testing for HIV antibodies**
- **Informed consent and confidentiality**
- **Questions for reflection and discussion**

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### • **Introduction: What is HIV/AIDS?**

In 1983 the virus that caused AIDS was discovered by scientists in France and the routes of transmission were confirmed. The virus eventually became known as the human immunodeficiency virus (HIV). There are 2 different types of HIV:

**HIV-1** the most common type found worldwide, and  
**HIV-2** found mostly in West Africa.

HIV infection affects the immune system. The immune system is the body's defense against infections by microorganisms (such as very small bacteria or viruses) that get past the skin and mucous membranes and cause disease. The immune system produces special cells called antibodies to fight off or kill these microorganisms. A special weakness of the immune system is called an immunodeficiency. Human immunodeficiency virus (HIV) infects, and eventually



destroys, special cells in the immune system called lymphocytes and monocytes.

*Nurses and midwives in Ghana participate in HIV/AIDS Awareness Days by developing key messages for the public. (Credit: JHU/CCP)*

These cells carry the CD4 antigen on their surface (CD4+ lymphocytes). HIV recognizes the CD4 antigen and enters and infects CD4+ lymphocytes. The result is the killing of many CD4+ lymphocytes. This slowly leads to a persistent, progressive and profound impairment of the immune system, making an individual susceptible to infections and conditions such as cancer. HIV is the beginning stage of infection and can be detected by a blood test (described in this Fact Sheet). When the immune system becomes very affected, the illness progresses to AIDS. Blood tests (described in this Fact Sheet), or the appearance of certain infections (see Fact Sheets 4 & 5), indicate that the infection has progressed to AIDS.

## • HIV transmission

### **HIV can be transmitted by:**

Sexual intercourse (vaginal, anal and oral) or through contact with infected blood, semen, or cervical and vaginal fluids. This is the most frequent mode of transmission of HIV world wide, and can be transmitted from any infected person to his or her sexual partner (man to woman, woman to man, man to man and, but less likely, woman to woman). The presence of other sexually transmitted diseases (STDs) (especially those causing genital ulcers) increase the risk of HIV transmission because more mucous membrane is exposed to the virus (See Fact Sheet 12).

Blood transfusion or transfusion of blood products (eg. obtained from donor blood infected by HIV) (see Fact Sheet 12).

Injecting equipment such as needles or syringes, or skin-piercing equipment, contaminated with HIV (see Fact Sheet 11).

Mother to infant transmission of HIV/AIDS can occur during pregnancy, labour, and delivery or as a result of breast feeding (see Fact Sheet 10).

### **HIV can NOT be transmitted by:**

*Coughing or sneezing  
Insect bites  
Touching or hugging  
Water or food  
Kissing  
Public baths*

*Handshakes  
Work or school contact  
Using telephones  
Swimming pools  
Sharing cups, glasses, plates, and other utensils*

## • Natural history of HIV infection

## Acute HIV infection

Most people infected with HIV do not know that they have become infected. HIV infected persons develop antibodies to HIV antigens usually 6 weeks to 3 months after being infected. In some individuals, the test for the presence of these antigens may not be positive until 6 months or longer (although this would be considered unusual). This time -- during which people can be highly infectious and yet unaware of their condition -- is known as the "the window period" (see Fact Sheet 12).

Seroconversion is when a person recently infected with HIV first tests sero-positive for HIV antibodies. Some people have a "glandular fever" like illness (fever, rash, joint pains and enlarged lymph nodes) at the time of seroconversion. Occasionally acute infections of the nervous system (eg. aseptic meningitis, peripheral neuropathies, encephalitis and myelitis) may occur.

## HIV infection before the onset of symptoms

In adults, there is often a long, silent period of HIV infection before the disease progresses to "full blown" AIDS. A person infected with HIV may have no symptoms for up to 10 years or more. The vast majority of HIV-infected children are infected in the peri-natal period, that is, during pregnancy and childbirth (see Fact Sheets 5 & 10 ). The period without symptoms is shorter in children, with only a few infants becoming ill in the first few weeks of life. Most children start to become ill before 2 years; however, a few remain well for several years (see Fact Sheet 5).

## Progression from HIV infection to HIV-related disease and AIDS

Almost all (if not all) HIV-infected people will ultimately develop HIV-related disease and AIDS. This progression depends on the type and strain of the virus and certain host characteristics. Factors that may cause faster progression include age less than 5 years, or over 40 years, other infections, and possibly genetic (hereditary) factors. HIV infects both the central and the peripheral nervous system early in the course of infection. This causes a variety of neurological and neuropsychiatric conditions. As HIV infection progresses and immunity declines, people become more susceptible to opportunistic infections.

## These include:

*Tuberculosis (see Fact Sheet 13)*  
*Other sexually transmitted diseases*  
*Septicaemia*  
*Pneumonia (usually pneumocystis carinii)*  
*Recurrent fungal infections of the skin, mouth and throat*  
*Unexplained fever*  
*Meningitis*

### **Other Conditions:**

*Other skin diseases*  
*Chronic diarrhoea with weight loss (often known as "slim disease")*  
*Other diseases such as cancers (eg. Kaposi sarcoma)*

Any blood test used to detect HIV infection must have a high degree of sensitivity (the probability that the test will be positive if the patient is infected) and specificity (the probability that the test will be negative if the patient is uninfected). Unfortunately, no antibody test is ever 100 % sensitive and specific. Therefore, if available, all positive test results should be confirmed by retesting, preferably by a different test method. HIV antibody tests usually become positive within 3 months of the individual being infected with the virus (the window period). In some individuals, the test may not be positive until 6 months or longer (considered unusual). In some countries, home testing kits are available. These tests are not very reliable, and support

such as pre and post test counselling (Fact Sheet 7) is not available.

## • Testing for HIV antibodies

Tests for HIV detect the presence of antibodies to HIV, not the virus itself. Although these tests are very sensitive, there is a "window period." This is the period between the onset of infection with HIV and the appearance of detectable antibodies to the virus. In the case of the most sensitive anti-HIV tests currently recommended, the window period is about three weeks. This period may be longer if less sensitive tests are used.

### **The three main objectives for which HIV antibody testing is performed are:**

- *screening of donated blood (see Fact Sheet 12)*
- *epidemiological surveillance of HIV prevalence (see Fact Sheet 2)*
- *diagnosis of infection in individuals (see Fact Sheets 4 & 5)*

Screening of donated blood accounts for the majority of HIV tests performed worldwide. It is a highly cost effective preventive intervention as the transmission of HIV through infected blood is at least 95%.

At the beginning of the HIV epidemic, HIV testing was used mostly for clinical confirmation of suspected HIV disease. More recently, people have been encouraged to attend voluntary counselling and testing (VCT) services to find out their HIV status (see Fact Sheet 7). It is hoped that if people know their HIV status and are seronegative, they will adopt preventive measures to prevent future infection (see Fact Sheet 12). If the person is seropositive, it is hoped that they will learn to live positively, accessing care and support at an earlier stage (Fact Sheet 3), learning to prevent transmission to sexual partners (Fact Sheet 12) and planning for their own and their family's future (Fact Sheet 8).

### **Antibody tests**

Traditionally, HIV testing has been done using ELISA (Enzyme Linked ImmunoSorbent Assay). However, there are various essential requirements for ELISAs to be performed accurately:

- *Laboratory equipment (eg. pipettes, microtiter trays, incubators, washers, and ELISA readers) must be available*
- *Constant supply of electricity, and regular maintenance of equipment*
- *Skilled technicians*
- *Accurate storage and testing temperatures*

Recent advances in technology have lead to various simple rapid tests being developed. Most of these tests come in a kit and require no reagent, equipment, training, or specified temperature controls, and tests can be performed at any time. These tests are as accurate as ELISA and results can be obtained within hours. In some countries, over 50% of people do not return for their test results. With these rapid tests, people can wait for their results. Although the costs of these simple rapid tests are higher than ELISA they will be useful in STD clinics, antenatal clinics, and counselling centres, because of the ease of use. In

some countries, home testing kits are also available. These tests are not very reliable, and support such as pre and post test counselling (Fact Sheet 7) is not available.

### **False positive result**

HIV tests have been developed to be especially sensitive and, consequently, a positive result will sometimes be obtained even when there are no HIV antibodies in the blood. This is known as a false positive, and because of this, all positive results must be confirmed by another test method. A confirmed positive result from the second test method means that the individual is infected with HIV.

### **False negative result**

A false negative result occurs when the blood tested gives a negative result for HIV antibodies when in fact the person is infected, and the result should have been positive. The likelihood of a false negative test result must be discussed with patients if their history suggests that they have engaged in behaviour which was likely to put them at risk of HIV infection. In this situation, repeated testing over time may be necessary before they can be reassured that they are not infected with HIV. The most frequent reason for a false negative test result is that the individual is newly infected (ie. the window period) and is not yet producing HIV antibodies. However, it is important to remember that someone who has tested negative because they are not infected with HIV can become infected the following day!

## **• Informed consent and confidentiality**

All people taking an HIV test must give informed consent prior to being tested. (Issues related to pre and post-test counselling and informed consent are covered in Fact Sheet 7.) The results of the test must be kept absolutely confidential. However, shared confidentiality is encouraged. Shared confidentiality refers to confidentiality that is shared with others. These others might include family members, loved ones, care givers, and trusted friends. This shared confidentiality is at the discretion of the person who will be tested. Although the result of the HIV test should be kept confidential, other professionals such as counsellors and health and social service workers, might also need to be aware of the person's HIV status in order to provide appropriate care.

### **Questions for Reflection and Discussion**

**Why is it important that nurses/midwives educate people about how HIV is and is not transmitted?**

**What role can nurses/midwives take in promoting HIV prevention?**

**Why is it important to understand the danger of HIV transmission during the "window period"?**

**Why is informed consent essential?**

**What role can nurses/midwives play in promoting shared confidentiality?**

**What are the dangers of receiving a false negative result? What should be done if a person's test is sero-negative?**



## References

World Health Organization (1993). HIV Prevention and Care: Teaching Modules for Nurses and Midwives. WHO/GPA/CNP/TMD/93.3

World Health Organization (1996). TB/HIV: A Clinical Manual. (WHO/TB/96.200)

World Health Organization (1997). Standard treatments and essential drugs for HIV-related conditions. Access to HIV-related drugs (DAP/97.9)

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## Fact Sheet 2 The global HIV/AIDS epidemic

- **Introduction**
- **The global estimates of HIV/AIDS (1999)**
- **The evolving picture of AIDS**
- **The spread of HIV**
- **Using epidemiology**
- **Questions for reflection and discussion**

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### • Introduction

The human immunodeficiency virus (HIV) continues to spread around the world, moving into communities previously little troubled by the epidemic and strengthening its grip on areas where AIDS is already the leading cause of death in adults (defined as people aged 15-49). Estimates by the Joint United Nations Programme on HIV/AIDS (UNAIDS) and the World Health Organization (WHO) indicate that by the end of 1999 over 30 million people were infected with HIV (27 million of whom did not know their HIV status), and that 12.7 million people around the world had already lost their lives to the disease. Unless a cure is found, or life-prolonging therapy can be made more widely available, the majority of those now living with HIV will die within a decade. The virus continues to spread causing nearly 16,000 new infections a day. Indeed, HIV/AIDS is among the top ten killers world wide, and given current levels of HIV infection, it may soon move into the top five (UNAIDS/WHO Report, 1999).



*Sex worker in a developed country undergoes examination to determine whether she is infected with HIV. (Credit: WHO)*

- **The global estimates of the HIV/AIDS epidemic as of the end of 1999 are:**

<b>People newly infected with HIV in 1999</b>	
Adults	5 million
Women	2.3 million
Children	570,000
<b>Total:</b>	<b>5.6 million</b>

<b>Number of people living with HIV/AIDS</b>	
Adults	32.4 million
Women	14.8 million
Children	1.2 million
<b>Total:</b>	<b>33.6 million</b>

<b>AIDS deaths in 1999</b>	
Adults	2.1 million
Women	1.1 million
Children	470,000
<b>Total:</b>	<b>2.6 million</b>

<b>Total number of AIDS deaths since the beginning of the epidemic</b>	
Adults	12.7 million
Women	6.2 million
Children	3.6 million
<b>Total:</b>	<b>16.3 million</b>

The major concentration of HIV infections is in the developing world, mostly in countries least able to afford care for infected people. In fact, 86% of people with HIV live in sub-Saharan Africa and the developing countries of Asia, which between them account for less than 10% of global Gross National Product (GNP). Infection rates are rising rapidly in much of Asia, Eastern Europe and southern Africa. The picture in Latin America is mixed with prevalence in some countries rising rapidly. In other parts of Latin America and many industrialized countries, infection is falling or close to stable. This is also the case in Uganda, Thailand, and in some West African countries. Nevertheless, although the situation is improving among many groups, large numbers of new infections occur every year in these countries.

- **The evolving picture of AIDS**

### **Sub-Saharan Africa: the epidemic shifts south**

Over two-thirds of all the people living with HIV in the world (nearly 21 million) live in sub-Saharan Africa, accounting for 83% of the world's AIDS deaths. An even higher proportion of the children living with HIV in the world are in Africa, an estimated 87%. There are a number of reasons for this. First, more women of childbearing age are HIV-infected in Africa than elsewhere. Second, African women have more children on average than those in other continents, so one infected woman may pass the virus on to a higher than average number of children. Third, nearly all children in Africa are breastfed. Breastfeeding is thought to account for between a third and a half of all HIV transmission from mother to child (see Fact Sheet 10). Finally, new drugs which reduce transmission from mother to child before and around childbirth are far less readily available in developing countries, including those in Africa, than in the industrialized world. In general, West Africa has seen its rates of infection stabilize at much lower levels than East and southern Africa, where the virus is still spreading rapidly, despite already high levels of infection. For example, in Botswana, the proportion of the adult population living with HIV has doubled over the last five years, with 43% of pregnant women in a major urban centre testing HIV-positive in 1997.

***In a large commercial farming centre in Africa, HIV prevalence in pregnant woman has increased from 32% in 1995 to 59% in 1996.***

### **Asia: low infection rates but rapid spread**

HIV came later to Asia, and mostly through drug injectors and sex workers. However, by 1997 HIV was well established across the continent. The countries of South East Asia, with the exception of Indonesia, the Philippines, and Laos are comparatively hard hit, as is India. While the prevalence remains low in China, they are beginning to record increasing numbers of cases. Only a few countries in the region have developed sophisticated systems for monitoring the spread of the virus, so HIV estimates in Asia often have been made on the basis of less information than in other regions. Overall, about 6.4 million people are currently believed to be living with HIV in Asia, just over 1 in 5 of the world's total. By the end of the year 2000, that proportion is expected to grow to 1 in 4. About 94,000 children now live with HIV.

### **Latin America and the Caribbean: most infections are in marginalized groups**

The picture is fragmented in Latin America with most infections being in marginalized groups. Men having unprotected sex with men, as well as drug injectors who share needles, are the focal points of HIV infection in many countries in the region. Rising rates in women show that heterosexual transmission is becoming more prominent with the proportion being around one fifth.

### **Eastern Europe: drug injection drives HIV**

Until 1994, mass screening of blood samples from people whose behaviour put them at risk for HIV showed extremely low levels of infection. But in the last few years, the former socialist economies of Eastern Europe and Central Asia have seen infections increase around six-fold. By the end of 1997, 190,000 adults were infected. The most common form of spread is through unsafe drug injecting, and to a lesser extent through sex workers. The rise in new cases of STDs may reflect dramatic increase in unprotected sex, which indicates that the risk of HIV infection is spreading rapidly throughout the general population of Eastern Europe.

### **The industrialized world: AIDS is falling**

In Western Europe, HIV infection rates appear to be dropping, with new infections concentrated among drug injectors in the southern countries, particularly Greece and Portugal. About 30,000 new cases were reported in 1997. Antiretroviral drugs have accounted for low mother to baby transmission. In North America 44,000 new HIV infections were reported with half that number being in injecting drug users. As in Western Europe, mother to baby transmission is rare. Although cases of HIV infections continue to rise in the industrialized world, the cases of AIDS are falling. This downturn is probably due to the new antiretroviral drug therapies which postpone the development of AIDS and prolong the lives of people living with HIV. In the United States, in some disadvantaged sections of society, AIDS continues to rise. This rise is partly due to the inaccessibility of expensive drugs, and to less successful prevention initiatives than in the predominantly well-educated, well-organized gay communities.

***In the United States, in some disadvantaged sections of society, AIDS continues to rise.***

### **North Africa and the Middle East: the great unknown**

Less is known about HIV infection in North Africa or the Middle East than in other parts of the world. Just over 200,000 people are estimated to be living with HIV in these countries, under 1% of the world total.

## **• The spread of HIV**

There are no simple explanations as to why some countries are more affected by HIV than others. Poverty,



illiteracy and engaging in identified risk behaviours account for much of the epidemic. People who are infected with HIV often have no symptoms of disease (see Fact Sheet 1) for many years and can infect others without realizing that they themselves are infected. Much still needs to be done to ensure better tracking of the epidemic and to find better prevention strategies and care for people living with HIV/AIDS.

## •Using epidemiology

It is important that nurses and midwives understand the epidemiological statistics for HIV and AIDS at the local, national and global level. Understanding these figures helps to persuade decision makers about the magnitude of the problem while also enabling them to make informed decisions about the allocation of resources for the care and prevention of HIV.

### **Incidence:**

refers to the number of times an event occurs in a given time, e.g. the number of new AIDS cases presenting each month or year, or the number of new HIV infections being detected during a specified period of time.

### **Prevalence:**

means the total number of specific conditions in existence in a defined population at a precise point in time, e.g. The number of AIDS cases or number of HIV infections which have so far been reported in your own country. The systematic collection of facts (data) about disease occurrence is part of surveillance.

Collecting information from the National AIDS Programme, or visiting health centres involved in testing and counselling people would be important sources of data. Also, visiting hospitals (to assess the number of in-patients who are HIV positive), visiting sexually transmitted disease (STD) services, blood transfusion services and other facilities where people go to access HIV-related care would provide important epidemiological information about the incidence and prevalence of HIV/AIDS. The more knowledgeable that nurses/midwives are regarding the magnitude of the problem in their area, the more they can do to influence decision makers, or make informed decisions about, HIV prevention and care.

### **Questions for reflection and discussion**

**How many people in your local community are now infected with HIV? (prevalence)**

**What is the rate of new infections in your country? (incidence)**

**What is the greatest mode of transmission of HIV in your country?**

**How many AIDS cases have so far been reported in your country? (prevalence)**

**How might you begin to collect this information if local and national statistics are not available?**

**How would you use this information?**

**How would you collaborate with others to utilize this information to develop and manage prevention and care initiatives?**

## References

AIDS Epidemic Update, December 1999 UNAIDS/99.53E -  
WHO/CDS/CSR/EDC/99.99 - WHO/FCH/HSI/99.6 [email: [unaids@unaids.org](mailto:unaids@unaids.org)]  
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## Fact Sheet 3 Continuum of care

- **Introduction: Comprehensive care across a continuum**
  - **Components related to comprehensive care**
  - **Sites in the continuum of care**
  - **Optimal professional service allocation for HIV/AIDS care**
  - **Basic principles in continuum of care**
  - **Integrating HIV prevention and care**
  - **Steps in linking services across the continuum**
    1. **Assess the level and type of need**
    2. **Developing links**
    3. **Staff and training**
    4. **Wider involvement**
    5. **Counselling**
    6. **Care at home**
    7. **Care costs**
    8. **Programme monitoring**
  - **Continuum of care checklist**
  - **Questions for reflection and discussion**
- 

### • **Introduction: Comprehensive care across a continuum**

Comprehensive care involves a network of resources and services which provide holistic, comprehensive, wide ranging support for people living with HIV/AIDS (PLHA) and their families. A continuum of care includes care between hospital and home over the course of the illness. There are many issues that need to be addressed before continuous can be provided. There need to be adequate resources (financial, supplies, services, staff, volunteers, government and community support), and connections between them. Care must incorporate clinical management, direct patient care, education, prevention, counselling, palliative care and social support.

## • Components related to comprehensive care include:

- Clinical Management and direct physical care to PLHA and his/her family (Fact Sheets 4 & 5)
- Education (for health workers, family, neighbours, volunteers, etc.) (Fact Sheet 9)
- Involvement of the PLHA
- Counselling (social, spiritual and emotional support) (Fact Sheet 7)
- Voluntary testing and follow-up (Fact Sheet 7)
- Adequate resources (medicines, medical supplies, linen, food, clothing, shelter, money)
- Advocacy and legal aid (Fact Sheet 6)
- Prevention strategies (Fact Sheet 12)
- Care for the caregivers (Fact Sheet 7)
- Protection and infection control (Fact Sheet 11)
- Strategies to promote acceptance of PLHA, and reduce stigma and isolation in institutions and communities (Fact Sheet 6).

Although many countries will not have adequate resources to address all these components, each country can be working toward comprehensive care.

## • Sites in the continuum of care

• **Home care** is care given to sick people in their homes. This might include people caring for themselves, or care given by family, friends, neighbours, health and social service workers and others. Such care can be physical, psychosocial, spiritual and palliative.

• **Community care** is care given by people within the community. This care might be given by nurses, midwives, trained volunteers, community health or TB workers, traditional healers, non-governmental organizations (NGO), local leaders, teachers, youth groups, lay or religious leaders etc. Health centre care is given to sick people in a community health centre by nurses, midwives, counsellors, social workers, traditional healers, volunteers and other staff.



*A nurse in the U.S. counsels the relative of a person living with HIV/AIDS. (Credit: UNAIDS/Kobre)*



• **District hospital care** is given to sick people by doctors, nurses, counsellors, social workers, education services, legal aid.

• **Optimal professional service allocation for HIV/AIDS care**

Human resources	Health facility-based care	Community care
Doctor	XXXX	X
Nurses	XXXX	XX
Counselors/Social workers	XX	XX
Traditional practitioners / community workers	X	XXX
Families	X	XXXX

• **Basic principles in a continuum of care**

1. Listen to the person with HIV/AIDS and his/her family, and enable them to plan for the future (Fact Sheet 7).
2. Care can, and should be integrated with prevention to provide for a comprehensive, holistic system of HIV management (Fact Sheet 12).
3. Care-givers/institutions must not be discriminatory or judgmental in order to provide accessible and acceptable programs of care and prevention based on respect for human dignity. (Fact Sheet 6).
4. Confidentiality must be respected and basic rights observed (Fact Sheets 1 & 7).
5. Providing and making referral to counselling and other support networks is important for to comprehensive, holistic care (Fact Sheet 7).
6. Preventing HIV-related infections is cost effective in preventing deterioration of the person's overall health status resulting in heavy costs to the health care system (Fact Sheets 4 & 5)
7. Expensive in-patient care can be kept to a minimum with available, accessible and acceptable links and referral mechanisms in a comprehensive, holistic care continuum.
8. The more involvement of the local community and its resources, the more cost effective, comprehensive and holistic is the care. Local people are well suited to

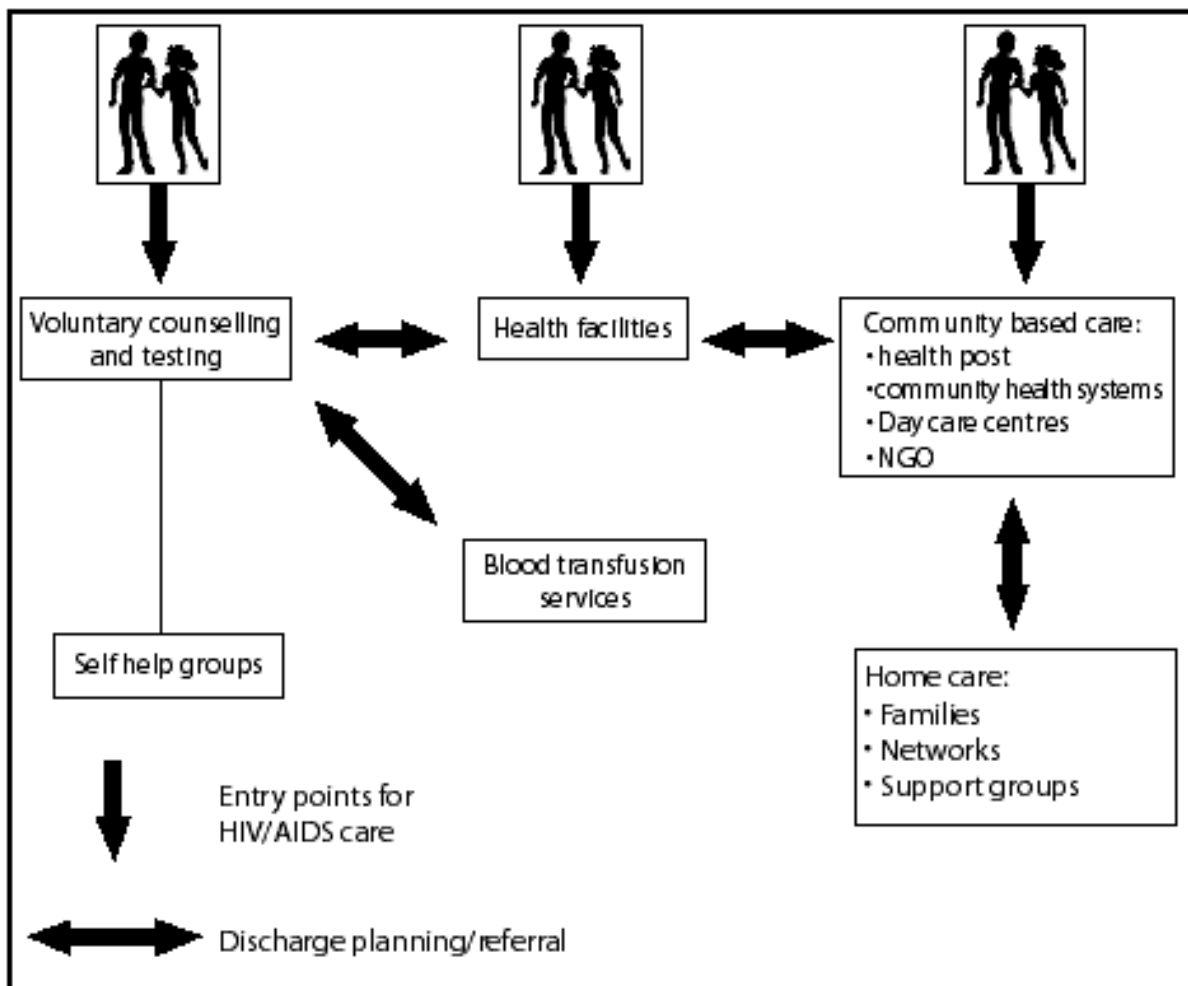
provide appropriate care.

9. Many people prefer to die at home, therefore, terminal care outside hospital should be a viable option. However, adequate support will be necessary (Fact Sheet 8).
10. Staff usually need, and benefit from education (Fact Sheet 9), supervision and support. Addressing the needs of the care givers helps reduce stress amongst the staff (Fact Sheet 7).
11. In many countries, people with HIV/AIDS and their families are good advocates and a useful resource in planning and providing comprehensive, holistic care.

## • Integrating HIV prevention and care

It is important to combine care with education and prevention strategies. Listening to and learning from the affected person/family is a vital component of care (Fact Sheet 7). Counselling services, sexually transmitted disease (STD) clinics, maternal child health clinics and other health and social services can play an important role. In this way, voluntary testing and counselling, education about risk behaviours, and the distribution of condoms is possible. Such activities should be combined with counselling, clinical management and physical care. It is important to build on the care that people already provide for themselves within their communities. Incorporating and strengthening existing programs such as cancer care or care for the chronically ill are important strategies.

The figure below provides a visual representation of a conceptual framework of comprehensive care across the continuum.



*Reproduced from: Osborne, C. M., van Praag, E. & Jackson, H. (1997). Models of care for patients with HIV/AIDS. AIDS (11B), 135-141.*

## • Steps in linking services across the continuum

### 1. Assess the level and type of need

What are the reported numbers PLHA with HIV related illnesses in your area? Refer to records in local hospitals, antenatal, STD or TB clinics where HIV testing has been carried out. If available, check the national HIV data base. If this information is not available, while maintaining the need to respect confidentiality, make an assessment yourself by observing and discussing these numbers with various community groups.

What are the local attitudes towards AIDS? How are PLHA viewed by their families and communities? What do PLHA and their families need? Often their needs are financial and material support such as lack of jobs, money, food, clothing, shelter, water, transportation, and medicines. Other major needs might include medical care, emotional and spiritual support, and education about HIV.

What care is already being provided? What is the impact on health services and staff? What are the trends for outpatient attendance, hospital admissions and bed occupancy rates? Are staff experiencing difficulty related specifically to HIV care?

What referral problems exist between hospitals and community health facilities?

Are appropriate medicines available at the relevant sites of care? What are the most commonly used medicines for treating HIV related infections? Who would pay for the medicines? Are there adequate supplies of condoms and other household and medical supplies?

How are HIV related illnesses treated in the community? Who treats the PLHA, in what manner?

How is contact maintained with people diagnosed with HIV and later discharged? To what extent are counselling and testing available and being used?

What community services already exist? Could they be expanded or further utilized to include care for the PLHA?

Could care for PLHA be incorporated into the care of people with other chronic illnesses?

Could links be improved with STD, family planning, TB, maternal/child health services or other social services?

What other services are there in the community? Are NGOs providing care, prevention, education or counselling?

This list of assessment measures might be too much for the isolated nurse/midwife. However, it is important to consider as many of these questions as possible within your region.

## **2. Developing strong referral systems**

Setting up a workable structure will require coordination with the hospital, clinics, voluntary and confidential counselling and testing and other support agencies (government and non-government). A good referral system is important between hospital, home, clinic and other people and agencies (e.g. traditional healers, community health workers).

## **3. Staff and training**

It is important to train community health workers and others in the care and prevention of HIV. This training can include management of common illnesses such as skin rashes, diarrhoea, and how to train family carers in basic nursing and home care (Fact Sheets 4 & 5). It might also be important to provide them with the basic essential medicines and supplies. These community health workers can be important to the team as they have first hand knowledge of the community.

## **4. Wider involvement**

Make strong community links by using established structures:

- organize meetings and workshops with local healers. These gatherings provide valuable opportunities for sharing knowledge and perceptions about HIV/AIDS, the roles for healers in prevention and care, infection control, and referrals to hospitals and clinics



- meet with local NGOs and community leaders including religious and traditional organizations to discuss their perceptions of the epidemic and possible ways to support families and provide community education

- develop and maintain close links with staff from other agencies, education and welfare departments, including social workers, counsellors, and others working with PLHA and their families.

## **5. Counselling**

Emphasize the importance of ongoing counselling, not just before and after HIV testing. It is important to combine care with emotional support and education on HIV prevention and infection control. Ideally, all staff need training in basic counselling skills (Fact Sheet 7). Also, referral systems should be maintained with the hospital based counsellor.

## **6. Care at home**

Visits by the home care team are valued by PLHAs and their families for medical care and advice. Transport to hospital (where available), emotional support, education and help with basic needs (food, shelter, supplies) are also important. One of the most important issues is money. Sources of income (e.g. welfare departments, NGOs, starter grants for income generation) should be investigated and a list provided. It is also important that, when the family is unable to cope, PLHA who are critically ill, are referred to hospital if at all possible. However, many patients choose to die at home, so counselling (Fact Sheet 7), palliative care (Fact Sheet 8), and practical support for the PLHA and his/her caregivers is very important. Help might also be required after the PLHA has died, and could include emotional support, instructions on how to safely prepare the body, and funeral arrangements. (Fact Sheet 8).

## **7. Care costs**

Sufficient resources need to be allocated in order that the continuum of care programme to be sustainable in the long term. Although training community volunteers can reduce some long term costs, consideration must be given to costs associated with on-going training and supervision (Fact Sheet 9). Direct costs to the family, such as payment for medical and traditional treatments, extra food and other items, should also be taken into account. Other costs, some of which are less easy to measure include: loss of earnings, loss of agricultural productivity, and the additional workloads put on women and girls.

## **8. Programme monitoring**

Indicators for measuring the success of the continuum of care efforts need to be established at the start, and team members need to keep accurate records in order to assess the quality of care. A successful continuum of care involves using existing services appropriately so that the PLHA can use the site and service to best suited to their health and/or social service need. Team members may wish to monitor the following indicators of quality of care:

number of PLHA accessing resources in the continuum of care

number of referrals

number of PLHA who use the appropriate site to fit their health/social service needs

types of linkages between resources and services

number of drugs, medical supplies and condoms distributed

changes in hospital attendance

changes in community attitudes

the number of PLHA sharing news of their diagnosis with family/friends

satisfaction with treatment

support for the PLHA and his/her carers and health care workers

volunteer training given

- **Continuum of care checklist:**

**Does the district plan or the review consider:**

- Comprehensive care policies and guidelines for (a) clinical management, (b) nursing care, (c) counselling and voluntary counselling and testing, and (d) social support?
- Resource mobilization across the continuum of care to provide (a) discharge planning, (b) referral networks, (c) government/NGO links, and (d) community support to PLHAs and caregivers?
- Integration of HIV/AIDS care with existing services such as (a) in- and out-patient care, (b) health centres and dispensaries, (c) tuberculosis, sexually transmitted disease and maternal/child and family planning clinics?
- Prevention intervention as part of care by (a) counselling partners of PLHAs, (b) supplying condoms, (c) educating family members, and (d) stimulating support groups among PLHAs?

**Questions for reflection and discussion**

**How can a continuum of care be implemented in such a way that services are provided for the PLHA and his/her family where they are most needed?**

**How can prevention and care be integrated across the continuum?**

**How can the PLHA, the family or caregivers be directly involved in planning care?**

**How can stigma and fear of HIV be addressed? What can you do to help change people's attitudes?**

**What strategies do you consider to be necessary to sustain a continuum of care model?**

**How can you ensure that patients are linked with other services and referred to other care options when necessary?**

**If you are working in a situation where you have little support, how can you contribute to the continuum of care?**

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## Fact Sheet 4 Nursing care of adults with HIV-related illness

- **Introduction**
  - **Making a diagnosis of AIDS when HIV testing is unavailable**
  - **HIV and TB: the dual epidemic**
  - **Opportunistic infections and common treatments**
  - **Antiretroviral therapy (ARV)**
  - **Basic nursing care for PLHA with opportunistic Infections**
  - **Questions for reflection and discussion**
- 

- **Introduction:**

Nursing care of the person with HIV-related illness is the same as the nursing care for any person who is ill. Consequently, all trained nurses/midwives are competent to care for patients with HIV-related illness as the same principles of nursing practice apply. In addition, many of the health care problems people will have as a result of HIV infection will be familiar to nurses because of their knowledge and experience of caring for people with other chronic, progressive diseases. The use of universal precautions for infection control are critical in the care and prevention of HIV (Fact Sheet 11).

Almost all (if not all) HIV-infected people will ultimately develop HIV-related disease and AIDS. This progression depends on the type and strain of the virus and certain host characteristics. HIV infects both the central and the peripheral nervous system early in the course of infection, often causing a variety of neurological and psychiatric problems. As HIV infection progresses and immunity declines, people become more prone to opportunistic infection and other conditions. Opportunistic infections are those that can invade the body when the immune system is not working adequately.

**Opportunistic infections include:**

Tuberculosis (see Fact Sheet 13)

Other sexually transmitted diseases (STDs)

Septicaemia

Pneumonia (usually pneumocystis carinii)

Recurrent fungal infections of the skin, mouth and throat

Other skin diseases

Unexplained fever

Meningitis

#### **Other conditions may include:**

Cancers such as Kaposi sarcoma

Chronic diarrhoea with weight loss (often known as "slim disease")

Many adults will have been tested for HIV and their status is known when an HIV-related illness presents. However, in many cases, testing is not done. Reasons for not testing include: fear, stigma, other psychosocial factors, lack of resources to provide testing, or inadequate voluntary HIV testing and counselling services.

## **• Making a diagnosis of AIDS in adults when HIV testing is not available**

A case definition for AIDS is made in the presence of at least 2 major signs and at least 1 minor sign.

#### **Major signs:**

- weight loss greater than 10% of body weight over a short period of time
- chronic diarrhoea for more than 1 month prolonged fever for more than 1 month

#### **Minor signs:**

- persistent cough for more than 1 month (for people with TB, this cough would not be considered a minor sign of AIDS)
- generalized itching skin rash
- history of herpes zoster in last 2 years
- fungal infections of mouth and/or throat
- chronic progressive or generalized herpes simplex infection
- generalized enlarged lymph nodes

**Please note: The presence of either generalized Kaposi's sarcoma or cryptococcal meningitis is sufficient for a case definition of AIDS.**

## • HIV and TB: The Dual Epidemic

***Although both tuberculosis (TB) and HIV are considered potentially lethal diseases, the interaction between TB and HIV is life threatening if TB is undiagnosed or left untreated.***

Unlike HIV, the TB germ can spread through the air to HIV negative people and is the only major AIDS-related opportunistic infection to pose this kind of risk. Because HIV effects the immune system, it is estimated that TB carriers who are infected with HIV are 30-50 times more likely to develop active TB than those without HIV. Worldwide, over the next four years, the spread of HIV will result in more than 3 million new TB cases. Antituberculosis drugs are just as effective in HIV-infected individuals as in those not infected with HIV, and are considered cost effective, even in the poorest countries. DOTS is a programme of directly observed treatment by a short course of prescribed medicines and provides cost effective treatment for TB. (see Fact Sheet 13) This programme, available in most countries throughout the world, claims to cure 95% of TB cases. In addition to treating TB, health workers should consider offering preventive therapy with isoniazid (INH) to HIV-infected patients at high risk of developing TB such as those living in communities with a high incidence of TB. Protocols for TB prevention therapy are now available in many countries. Check the Ministry of Health or those of the District Health Management Team for guidelines in your country.

## • Opportunistic infections and common treatments

In most circumstances, a doctor will make the diagnosis of an opportunistic illness and prescribe treatment. However, it is useful for nurses and midwives to be familiar with the most common medical treatments for HIV-related infections. Drugs prescribed for HIV-related illnesses must be considered in relation to those used for other health problems, especially problems likely to occur because of HIV, such as TB, other respiratory ailments and chronic diarrhoea. For example, an HIV-positive patient who is receiving TB treatment should not be prescribed Thaicetazone (a TB drug common in some countries), because this can cause severe reaction in people with HIV. Antiretroviral therapy (if available) may have reactions with other drugs. It is important to check that any drugs prescribed for the patient will not react with other drugs the person is taking.



The list of common medical treatments presented here is very superficial and reference to other resources on pharmaceutical treatments including the handbook "**Standard treatments and essential drugs for HIV-related conditions**" (WHO DAP/97.9) would be helpful (see reference list). Other useful resources might include the National AIDS Control Programme and Ministry of Health for national guidelines for treatment of opportunistic infections developed in your country.



*A nurse treats the open wounds of a woman at Elim Hospital in Zimbabwe. (Credit: UNAIDS/Szulc-Kryzanowski)*

**Tuberculosis:** Isoniazid (for prevention), and rifampicin, pyrazinamide, streptomycin, ethambutol (for treatment, see DOTS programme, Fact Sheet 13)

**Other sexually transmitted diseases (STDs):** antibiotics, antifungal agents, gentian violet, antiviral treatments (topical, oral). Treatment will depend on the STD diagnosis

**Septicaemia:** antibiotics

**Pneumonia (usually pneumocystis carinii):** This requires complex treatment. The first line of treatment is usually sulfamethoxazole and trimethoprim (which can also be used as prophylaxis). Later treatments might include petamidine, prednisolone, dapsone, eflornithine and methylprednisolone. Simple pneumonia is treated with antibiotics.

**Recurrent fungal infections of the skin, mouth and throat:** gentian violet application, polyvidone iodine and chlorhexidine mouth wash, and antifungal tablets and lozenges.

**Other skin diseases:** calamine, topical steroids, antibiotics orally or topically

**Unexplained fever:** aspirin, paracetamol

**Chronic diarrhoea with weight loss (often known as "slim disease"):** lopamide, diphenoxylate

**Meningitis:** antibiotics

## • **Antiretroviral therapy (ARV)**

ARV is very expensive and unavailable to many PLHA worldwide. However, where ARV is accessible and affordable certain guidelines must be followed. A joint publication by WHO and UNAIDS "Guidance Modules on antiretroviral treatments" (WHO/ASD/98.1 & UNAIDS/98.7) provides comprehensive guidelines.

## The minimum requirements for introducing ARVs include:

1. Availability of reliable, inexpensive tests to diagnose HIV infection.
2. Access to voluntary and confidential counselling and testing.
3. Reliable, long-term and regular supply of quality drugs.
4. Sufficient resources to pay for drugs on a long-term basis (a life-long commitment).
5. Support from a social network to help PLHA stay with the treatment regimen.
6. Appropriate training for health care workers in the correct use of ARVs.
7. Laboratory facilities to monitor adverse reactions.
8. Capacity to diagnose and treat opportunistic infections with the availability of affordable drugs.
9. Access to functioning and affordable health care services.
10. Joint decision-making between health care worker and patient in all aspects of ARV treatment (including the decision to begin ARV).

## • Basic nursing care for PLHA with an opportunistic infection

### **Infection control:**

Maintain good hygiene. Always wash hands before and after caring for the PLHA. Make sure linen and other supplies are well washed with soap and water. Burn rubbish or dispose of it in leakproof containers. Avoid contact with blood and other body fluids and wash hands immediately after handling soiled articles (see Fact Sheet 11 on Universal Precautions ).

### **Skin problems:**

Wash open sores with soap and water, and keep the area dry. Use the medical treatment, and prescribed ointment or salve. Local remedies, oils and calamine lotion might also be helpful.

### **Sore mouth and throat:**

Rinse mouth with warm water mixed with a pinch of salt at least three times a day. Eat soft foods that are not too spicy.

### **Fevers and pain:**

Rinse body in cool water with a clean cloth or wipe skin with wet cloths. Encourage the person to drink more fluids than usual e.g. water, tea, broth or juice. Remove thick clothing or too many blankets. Use antipyretics and analgesics such as aspirin, paracetamol etc.

**Cough:**

Lift head and upper body on pillows to assist with breathing, or assist the person to sit up. Place the patient where he/she can get fresh air. Vaporisers, humidifiers, and oxygen might be helpful.

**Diarrhoea:**

Treat immediately to avoid dehydration, either using oral rehydration or intravenous therapy if necessary. Ensure that the person drinks more than usual, and continues to take easily digestible nourishment. Cleanse the anus and buttocks after each bowel movement with warm soap and water and keep the skin dry and clean. Antibiotics used to treat other infections can worsen the diarrhoea. Always wash hands and, where possible, wear gloves when handling faecal or soiled materials (Fact Sheet 11).

**Nutrition:**

Where available, encourage foods that are high in fat and protein as they will help reduce weight loss.

**Local Remedies:**

There are often local remedies that alleviate fevers, pains, coughs, cleanse sores and abscesses. These local remedies can be very helpful in alleviating many of the symptoms associated with opportunistic infections. In many countries, traditional healers and women's associations or home care programs are collecting information about remedies which alleviated symptoms and discomfort.

**Questions for reflection and discussion**

**What are some common symptoms which might lead you to consider the person could have HIV (where HIV testing is unavailable, or unacceptable to the person)?**

**What are some of the important reasons to treat active TB in an HIV-positive patient?**

**What minimal requirements should be in place before commencing ARV?**

**What are some of the basic nursing care treatments for common opportunistic infections?**

**Which sources would you consult for basic medical and drug treatments for opportunistic infections?**

**References**

Gilks, C. et al. (1998). Sexual health and health care: Care and support for people with HIV/AIDS in resource-poor settings. Department of International Development (DFID), London.

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Further reading: Primary AIDS Care: Third Edition, C. Evian, January 2000. Available from Jacana, South Africa. Tel (+2711) 648-1157; Fax (+2711) 648-5516. Email: marketing@jacana.co.za

## Fact Sheet 5 Care of HIV infected and affected children

- **Introduction**
- **Common symptoms of HIV infection in children**
- **The course of HIV infection in infants and children**
- **Making a diagnosis of HIV/AIDS when HIV testing is unavailable**
- **Care for infants and children with HIV-related illness**
- **Basic nursing care for child with an opportunistic infection**
- **Assessing the family's ability to cope for a child with HIV-related illness**
- **Children orphaned by AIDS**
- **Strategies for the care of orphaned children**
- **Questions for reflection and discussion**

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### • **Introduction:**

The number of children under 15 who have lived or are living with HIV since the start of the epidemic in the late 1970's has reached about 4.8 million - 3.6 million of them have already died. Nearly 600 000 children were infected with HIV in 1999, mostly through their mothers before or during birth or through breast feeding (vertical transmission).



*An HIV-positive child at a center run by the Missionaries de la Charité in Port-au-Prince, Haiti. (Credit: PAHO/Waak )*

### **HIV infection can be transmitted to:**

- the unborn child (in utero infection)
- neonates during labour and delivery (intrapartum infection)
- neonates, when exposed to infected maternal birth fluids
- infants, after birth, through breast milk (post partum infection) (30 percent risk of transmission)

### **Other sources of HIV transmission to infants and children include:**

- transfusion with HIV-contaminated blood or blood products
- use of non-sterile equipment in health care facilities
- use of non-sterile equipment by traditional healers (surgeries, male and female circumcisions, scarification)
- sexual abuse
- injecting drugs
- sexual initiation practices involving sex workers
- child prostitution

The lives of children who do not have HIV themselves are affected when family members have AIDS. Families face increased poverty and stress because adults have to leave their paid employment, or are too sick to farm their land. Women may be ill themselves, as well as caring for other sick family members and looking after young children (Fact Sheet 10).

Girls in particular often become the care providers for sick relatives and their brothers and sisters. Sometimes children have to leave school to look for work or care for other family members. In addition, denial or neglect of girls' human rights results in gender discrimination, giving young women little access to socioeconomic opportunities (Fact Sheet 10). These girls (and boys to a lesser extent) often become vulnerable to commercial sex and to the drug trades (Fact Sheet 10).

## **• Common symptoms of HIV infection in children**



HIV-infected children have an increased frequency of common childhood infections such as ear infections and pneumonia. In developing countries, diseases such as chronic gastroenteritis and tuberculosis are also frequent. In HIV-infected infants, the symptoms common to many treatable conditions, such as recurrent fever, diarrhoea and generalized dermatitis, tend to be more persistent and severe. Moreover, HIV-infected infants do not respond as well to treatment and are likely to suffer life-threatening complications. Enlarged lymph nodes and an enlarged liver are common in children infected with HIV. Opportunistic infections occur as the immune system becomes more affected, and most of these children have some type of neurological involvement, such as developmental delay or infection in the brain. Fact Sheet 4 provides an overview of the common medical, pharmaceutical, and nursing care treatments for opportunistic infections in adults that can be adapted to the care of infants and children. When administering medicines, it is important to consider the amount to be prescribed (depending on the infant/child's size and body weight), and its suitability for use in children.



*An 8-year-old in Tanzania. The boy received an injection at the hospital, but the needle was infected with HIV. (Credit: UNAIDS/Szulc-Kryzanowski)*

## • The course of HIV in infants/children

The majority of infected infants develop disease during the first year of life and have a high mortality rate. With recent research and new antiretroviral therapies (ARVs), there has been significant improvement to child mortality in countries where this treatment is available and accessible.

The diagnosis of paediatric AIDS is difficult. In addition, in developing countries, diagnostic procedures might not be available or routinely used. Different countries might show slightly different patterns of the opportunistic infections that are common in HIV-infected children.

### The signs and symptoms most commonly found in HIV-infected children include:

- Weight loss
- Chronic diarrhoea
- Failure to thrive
- Oral thrush (This often recurs after treatment and can be the first indication of HIV infection.)
- Fever

## • Making a diagnosis of AIDS in children when HIV testing is not available

In infected women, the maternal HIV antibody is passively transmitted across the placenta to the fetus during pregnancy (Fact Sheet 10). This antibody can persist in the infant for as long as 18 months. Consequently, during this period, the detection of HIV antibody in infants does not necessarily mean that an infant is infected. Therefore, a case definition for AIDS is made in the presence of at least 2 major, and 2

minor signs.

<b>Major signs:</b>
<ul style="list-style-type: none"><li>● <b>weight loss or abnormally slow growth</b></li><li>● <b>chronic diarrhoea for more than 1 month</b></li><li>● <b>prolonged fever for more than 1 month</b></li></ul>

<b>Minor Signs:</b>
<ul style="list-style-type: none"><li>● <b>generalized lymph node enlargement</b></li><li>● <b>fungal infections of mouth and/or throat</b></li><li>● <b>recurrent common infections (eg. ear, throat)</b></li><li>● <b>persistent cough</b></li><li>● <b>generalized rash</b></li></ul>

*Please note: Confirmed HIV infection in the mother counts as a minor criterion.*

## • **Care for infants and children with HIV-related illness**

Most HIV-related illness is caused by common infections which can be prevented or treated at home or in a health centre. However, the illnesses often last longer in HIV infected children, and are slower to respond to standard treatments. The standard treatments are nevertheless the most appropriate treatments. The following general recommendations should be used in the management of HIV infected infants/children and in teaching/counselling mothers and other care-givers.

### **Maintain good nutritional status in weight loss and failure to thrive**

In most countries of the developing world, HIV-infected mothers are still breast-feeding their infants. However, with the knowledge that HIV can be passed through breast milk ( approximately 30% risk), this practice might be changing. (Fact Sheet 10). In some countries, substitutes for breast milk may be recommended for infants of HIV-infected mothers. However there needs to be a safe and adequate supply of affordable breast milk substitutes, access to a clean water supply and adequate means to boil water and to sterilize equipment. In some communities, where supplies and equipment are limited or unavailable, the risk of babies dying if not breastfed will be greater than the risk of passing on HIV. In countries where ARV is available, breast milk substitutes will probably be recommended. (Fact Sheet 10) Nurses and midwives are encouraged to refer to local policies and practices on nutritional counselling and breast feeding. Regular growth monitoring (preferably every month) is an appropriate way to monitor nutritional status. If growth falters, additional investigations should be done to determine the cause.

### **Provide early and vigorous therapy for common paediatric infections as early as possible**

All infants with HIV antibodies should be treated vigorously for common paediatric infections such as

measles and otitis media. (see Table below) Because the immune systems of children with HIV infection are often impaired, these diseases may be more persistent and severe, and the children may respond poorly to therapy and develop severe complications. Consequently, the mothers of all HIV-positive infants should be encouraged to take their infants for examination and treatment as soon as possible whenever symptoms of common paediatric infections develop.

<b>Paediatric infection</b>	<b>Treatment</b>
<b>Oral thrush (Often recurs after treatment and can be the first indication of HIV infection)</b>	<b>Treat with gentian violet application, polyvidone iodine and chlorhexidine mouthwash, and antifungal tablets and lozenges (depending on child's age)</b>
<b>Other skin diseases</b>	<b>Calamine, topical steroids, antibiotics orally or topically</b>
<b>Unexplained fever</b>	<b>Paracetamol; aspirin (in children older than 6 years of age)</b>
<b>Sexually transmitted diseases in the newborn</b>	<b>Antibiotics such as benzylpenicillin, kanamycin, erythromycin and others have been found to be effective for newborn treatment of syphilis, gonorrhoea, and chlamydia</b>
<b>Otitis media</b>	<b>Broad Spectrum antibiotics</b>

### **Emphasize early diagnosis and treatment of suspected TB for all family**

TB is one of the most common and deadly opportunistic infections and the HIV positive child is very susceptible to contracting this disease. Every effort should be made to ensure that TB prevention and treatment is available to family members. (See Fact Sheets 4 and 13)

### **Immunize according to standard schedules**

All infants and children should be immunized according to standard schedules. The only exception is that infants with clinical symptoms of HIV infection should not be given tuberculosis vaccine (BCG). It is important that correct sterilization procedures for immunization equipment be strictly followed (See Fact Sheet 11 on Universal Precautions).

### **Ensure the child has good quality of life**

Most infants of HIV infected mothers are not infected with HIV (Fact Sheet 10). In addition, many of those who are infected will have months of asymptomatic life. Some will live for years without developing symptoms. Every effort should be made by members of the child's family and by the health care professional to help the HIV-infected child to lead as normal a life as possible.

## **Basic nursing care for the HIV-infected child with an opportunistic infection**

### **Infection control**

Maintain good hygiene. Always wash hands before and after care. Make sure linen nappies and other supplies are well washed with soap and water. Burn rubbish or dispose of in containers. Avoid contact with blood and other body fluids and wash hands immediately after handling soiled articles. (See Fact Sheet 11 on Universal Precautions )

### **Skin problems**

Wash open sores with soap and water, and keep the area dry. Salty water can be used for cleansing. Use medical treatment, such as prescribed ointment or salve, where available. Local remedies, oils, and calamine lotion might also be helpful.

### **Sore mouth and throat**

Rinse the child's mouth with warm water at least three times daily. Give soft foods that are not too spicy.

### **Fevers and pain**

Rinse body in cool water with a clean cloth or wipe skin with wet cloths. Encourage the child to drink more fluids (water, tea, broth, or juice) than usual. Remove thick clothing or too many blankets. Use antipyretics and analgesics such as aspirin, paracetamol, acetaminophen, etc.

### **Cough**

Lift the child's head and upper body on pillows to facilitate breathing, or assist the child to sit up. Place the child where she/he can get fresh air. Vapourisers, humidifiers can provide symptomatic relief.

### **Diarrhoea**

Treat diarrhoea immediately to avoid dehydration, using either oral rehydration salts (ORS), or intravenous therapy in severe cases of dehydration. Ensure that the child drinks more than usual, and continues to take easily digestible nourishment. Cleanse the anus and buttocks after each bowel movement with warm soap and water and keep the skin dry and clean. Antibiotics used for other infections can worsen the diarrhoea. Remember to wear gloves or other protective covering when handling faecally contaminated material (Fact Sheet 11).

### **Local Remedies**

There are often local remedies that alleviate fevers, pains, coughs, and cleanse sores and abscesses. These local remedies can be very helpful in relieving many of the symptoms associated with opportunistic infections. In many countries, traditional healers and women's associations or home care programs compile information on local remedies which alleviate symptoms and discomfort.

## **• Assessing the family's ability to care for a child with HIV and HIV-**

## related illness

The ability of a family to care for a child with HIV-infection or related illness is affected by their socio-economic status and their knowledge and attitudes about HIV infection. The following questions will help the health care worker to determine what care can be expected from family members and what care must be obtained from other sources.

- What does the family know about HIV infection? Do they know how HIV is transmitted (Fact Sheet 1) and how to prevent transmission? (Fact Sheet 12)
- Can the family acknowledge that the child is HIV-infected, in order to access appropriate services?
- What is the parents' state of health, including their emotional condition? Are they physically able to care for the child?
- Which individuals can offer support to this family? What is their state of health?
- Are they able and willing to help care for the child?
- What is the social service system like to support this family?
- What is the family's economic situation?
- What is the condition of their living space?
- What does the child eat? Is there a food shortage? Is clean drinking water freely available?

## • Children orphaned by AIDS

Approximately 8.2 million children around the world have been orphaned by the HIV/AIDS epidemic. AIDS orphans, defined as children who have lost their mother or both parents to AIDS before reaching the age of 15, are predicted to number 41 million worldwide by 2010. Nine out of ten (90%) maternal orphans are presently living in sub-Saharan Africa. The extended family system, which would traditionally provide support for orphans, is greatly strained in communities most affected by AIDS. This is especially true in populations which migrate.

**Nurses and midwives can play an important role in orphan care. This care could include direct physical care, being an advocate on behalf of the child, and helping to influence policy changes to respect the rights and dignity of children.**

When children are cared for by other family members, this places an added financial burden on these care givers. After their parent's death, children can lose their rights to the family land or house. Without education, work skills or family support, children may end up living on the streets. These children are especially vulnerable, often becoming sexually active at an early age and at risk from HIV themselves (Fact Sheet 10). Poverty is an overwhelming problem. These orphans not only lack money, but basics such as clean water, drugs, food, shelter and medical supplies. They do not have information about how to protect themselves, and have poor access to doctors, nurses, and other health care workers and facilities. Finally, these orphans often lack human rights and dignity. The magnitude of this problem will have to be addressed at international, national, local, and community levels. Government, non-governmental organizations (NGO) and other institutions and organizations will have to combine their efforts to provide effective programs and strategies to care for orphaned children. Nurses and midwives can play an important role in orphan care. This care could include direct physical care, being an advocate on behalf of the child, and helping to influence policy changes to respect the rights and dignity of children.

## • Strategies for the care of orphaned children

**Strategies for the care of orphaned children include the following, in order of preference:**

1. **The extended family:** Every reasonable attempt must be made to trace relatives.
2. **Substitute or foster care families:** Placement with non-relative family units after careful caregiver selection, or foster care on an informal basis, recognizing traditional norms and values.
3. **Family type group:** Paid foster mothers living together with small groups of orphans or similar arrangements.
4. **Child-headed households:** Adolescents caring for younger siblings with the support of the community.
5. **Orphanages:** As a last resort when all other options are inappropriate or unavailable. However, there is a limited role for orphanages, for example, in caring for abandoned babies or for very young children needing care until alternative solutions can be found for them.

**Questions for reflection and discussion**



**What are the most common symptoms in HIV-infected children? How can you treat these symptoms?**

**What might lead you to suspect a child may be infected with HIV (without HIV testing)?**

**What are some of the important nursing care practices to consider when caring for an HIV-infected infant/child?**

**What kind of strategies might you consider as you work with a family with an HIV-infected child?**

**What role might you be willing to play in addressing the problems of orphan care?**

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## Fact Sheet 6 HIV/AIDS: fear, stigma and isolation

- Introduction
- Emotional, cultural, sexual, religious, and legal issues
- Compromised care
- Nurses' and midwives' moral and ethical responsibilities
- Strategies to improve care
- Questions for reflection and discussion

### • Introduction:

HIV/AIDS is a condition that continues to generate fear, misunderstanding, misinformation, and discrimination, and there are few nurses and caregivers in the world who have not been affected in some way by the disease. In addition, nurses and caregivers are also living with HIV. As one nurse commented, "We continue to hear stories of people with AIDS being shunned and isolated, forced out of their jobs or homes, refused medical and nursing treatment, stripped of their human and civic rights. And all for a disease that doesn't even spread through casual contact. That people already suffering should be subjected to such indignity is intolerable and even more so when it occurs in health care institutions by health care professionals who should know better." (Report of the ICN Conference on HIV/AIDS, 1994 p.17).



*A nurse takes blood from a monk in the blood bank at Rangoon General Hospital. Blood samples are tested for HIV and discarded if contaminated. (Credit: WHO)*

- Emotional, cultural, sexual, religious, and legal issues facing nurses and caregivers

Emotional issues

**Fear of contacting HIV and becoming sick and dying from the disease.**

**Nurses and midwives witness not only their patients, but also their friends and loved ones dying from AIDS.**

**Nurses and midwives witness the fear, stigma, isolation, marginalization and discrimination that many people living with HIV (PLHA) experience. Witnessing such attitudes leads some nurses/midwives to treat PLHAs in similar ways.**

**Nurses/midwives are also infected with HIV. They often withhold this information from their colleagues for fear of discrimination, isolation and neglect.**

**Many nurses and caregivers find it difficult to talk about sexuality, death, drug use, prejudices, morals and religious beliefs.**

**Where rates of HIV/AIDS infection are high, there are significant numbers of nurses and caregivers who are themselves infected. As they care for PLHA, they witness firsthand how they too will become sick and die.**

## **• Cultural, sexual, religious, and legal issues**

Cultural, sexual, religious, and legal influences often make discussion about sexual practices, preferences, sexual desires, the number and type of sexual partners, and the use of birth control difficult. In addition, there is often a "cloak of silence" related to sexual practices and to illicit drug use. Such subjects are often taboo and associated with embarrassment, shame, guilt and rejection. Nurses and other caregivers may also experience these same feelings of embarrassment, shame, and guilt as they practice certain risk behaviours in their own personal lives. The additional fear of HIV/AIDS as a fatal illness compounds the problem of discussing these difficult subjects. In some societies, the use of condoms as a method of birth control (as well as control of HIV transmission) is not sanctioned by the religious leaders. Finally, the cultural norms of silence regarding sexual practices, preferences and desires can be problematic. These sexual practices might include men having sex with men, sexual abuse, child abuse, and heterosexual intercourse.

In conclusion, experiences of fear, stigma, isolation, discrimination and marginalization related to HIV/AIDS come from:

**misinformation about HIV transmission (Fact Sheet 1)**

**fear of contracting HIV**

**fear of caring for PLHA when the nurse/midwife fears that she/he too may have the illness**

**religious teachings and influences related to sexuality and birth control**

**the cultural norms of silence regarding sexual practices, preferences and desires**

**legal issues related to the misuse of legal and illegal substances, particularly intravenous drug use**

## **•Compromised care**

Negative attitudes, beliefs and values, or misinformation about HIV, significantly limit a caregiver's ability to provide effective, respectful and dignified care for PLHA and their families. Some documented negative behaviours of health care workers include:

**condemning the PLHA (referring to or considering the PLHA as a "bad person" or "careless person")**

**isolating or avoiding the PLHA because of embarrassment or not knowing how to handle the situation**

**refusing to treat or care for the PLHA or his/her family**

**reluctance to disclose one's own HIV-positive status to other health care workers for fear of discrimination, isolation, and condemnation**

**the inability to discuss sexual practices, preferences and desires because of embarrassment, shame or guilt etc.**

**ignoring or avoiding discussion and counselling about risky behaviours and HIV prevention and care.**

**inability or unwillingness to approach the PLHA and family in a nonjudgmental, caring and supportive manner.**

## **Nurses' and midwives' moral and ethical responsibilities**

In 1996, the International Council of Nurses (ICN) produced a document on Reducing the Impact of HIV/AIDS on Nursing and Midwifery Personnel. As part of this document, ICN stressed that nurses and midwives have a moral and ethical responsibility to care for all people, including those with HIV/AIDS. The ICN Code for Nurses affirms that "the nurse's primary responsibility is to those people who require nursing care."

The ethical issues in HIV/AIDS prevention and care include,

**the ethical duty of nursing/midwifery personnel to provide care, and**

**the responsibility of HIV-positive nursing/midwifery personnel to protect their patients.**

In situations where HIV/AIDS and human sexuality cannot be discussed openly, nurses and midwives often feel embarrassed and uncomfortable about discussing sexual issues or may totally ignore topics during health education sessions. This behaviour perpetuates the conspiracy of silence.

Because of the serious consequences of HIV/AIDS, nurses and caregivers should be prepared to break with tradition and to accept and provide counselling and education about these topics. Nurses and midwives must be perceived as competent professionals, capable of discussing issues openly and confidently, and of acting fairly and compassionately. If nurses could become the role models for such open and compassionate behaviour, others would soon follow their example.

**An important first step in attending to the care needs of PLHA would be to advocate for compassionate, dignified and competent care for our own HIV-infected colleagues.**

## • Strategies to improve care

### Looking inward

First, nurses and caregivers must examine their own beliefs, values, assumptions and attitudes toward HIV/AIDS. Recent documentation suggests that health care workers are some of the worst offenders in discriminating against, and refusing to care for, PLHA. Such behaviours are unacceptable. However, change will only come about through examining long-standing negative thoughts, feelings and behaviours. This can be done individually or with peer group support. The questions posed at the end of this Fact Sheet provide a starting point for this personal and group exploration.

### Education

The irrational and often exaggerated fears associated with HIV/AIDS (even by nurses and midwives) can be directly addressed through educational programmes based on sound medical, social and psychological knowledge. To be successful, such programmes must be sustained and supported over a period of time (see Fact Sheet 9). Knowledge about HIV/AIDS is constantly expanding, and nurses and caregivers must be continually updated through continuing education programmes and Fact Sheets such as these. They can then take on the important role of educating others. That is, they can advocate, not only for Universal Precautions (Fact Sheet 11), but also for universal tolerance and knowledge about AIDS.

### Prevention

Prevention strategies will continue to be compromised if fear, ignorance, intolerance and discrimination against HIV infected persons persist. Nurses and midwives have a responsibility to help normalise HIV so that the modes of transmission and prevention can be addressed without the emotional and attitudinal

overlay that limits open dialogue about AIDS.

## Care

Effective and dignified care can only be given where respect and compassion for others is the norm. Looking inward to examine and challenge long-held beliefs, values, assumptions and attitudes will go a long way to providing compassionate and respectful care. Such care can then be demonstrated to others. When health care is provided with both knowledge and compassion, it makes the difference between misery and isolation, and the provision of comfort, in a setting of dignity and respect.

### Questions for reflection and discussion

**What fears or misunderstandings do you have?**

**How might these fears or misunderstandings affect your practice?**

**Where do you think these fears/misunderstandings come from?**

**How might you overcome these fears/misunderstandings in order to provide care, support, counselling, education, and advice in the prevention and care of HIV?**

**How might you be influence others in their care of PLHAs and their families?**

**How do you see your role in providing and promoting safe, moral and ethical care to PLHAs and their care givers/families/communities?**

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## Fact Sheet 7 Counselling and HIV/AIDS

- **Introduction**
- **Pre test counselling**
- **Components of pre test counselling**
  - Assessment of risk
  - Assessment of understanding
  - Preparation for pretest counselling
  - Benefits of pretest counselling
- **Post test counselling**
- **HIV-positive test result counselling**
- **HIV-negative test result counselling**
- **Continued counselling and support**
- **Care for the caregiver**
- **Strategies to introduce and support counselling services**
- **Questions for reflection and discussion**

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### • **Introduction:**

Numerous studies suggest that good counselling assists people to make informed decisions, cope better with their health condition, lead more positive lives, and prevents further transmission of HIV. HIV/AIDS counselling is sometimes provided by trained counsellors, though nurses and caregivers are often in the ideal position to provide effective counselling, advice, and support.

However, when nurses and caregivers are busy, emotional caring and support are often overlooked, despite evidence that providing emotional support does not take any longer than not providing such care. Frequently, nurses and others indicate that they do not know how to



provide more subtle counselling and emotional support, and therefore avoid this aspect of care. The following pages provide useful information about effective communication in the context of providing care to HIV/AIDS patients.

*A nurse in Ghana counsels a mother on the possibilities of mother-to-baby transmission of HIV/AIDS. (Credit: Cathy Sagui, JHU/CCP)*

## **Effective communication and counselling require:**

**Fear of contacting HIV and becoming sick and dying from the disease.**

**self awareness of one's beliefs, values, and assumptions**

**a respectful, non-judgmental attitude**

**active listening, including accurate reflection of the issues or concerns**

**asking supportive questions that raise important issues, in caring, nonjudgmental ways**

**awareness of one's verbal and non-verbal behaviours**

**providing practical support, advice and information**

**discussing options for care, prevention, and support**

**encouraging patient and the family to make their own decisions**

**creating a quiet, private atmosphere**

Remember that good counselling skills are best learned through practice.

### **Active listening**

involves entering into the experience of the patient and trying to understand their circumstances. Accurate reflection means responding to the person, restating their concerns and highlighting the feelings expressed. Such practices lead to a deeper exploration by the person of his/her fears, misunderstandings and experiences. Active listening and reflection on the part of the nurse or caregiver can often be sufficient for the PLHA to feel cared for and supported, and can lead to improvements in their ability to cope, make informed decisions, and in their overall quality of life.

In conclusion, experiences of fear, stigma, isolation, discrimination and marginalization related to HIV/AIDS come from:

- **Pre test counselling**

The aim of pre test counselling is to provide information to the individual about the technical aspects of testing and the various implications of being diagnosed as either HIV positive or negative. Pre test counselling should focus on two main topics: (a) the person's personal history of risk behaviours, or having been exposed to HIV , and (b) assessment of the person's understanding of HIV/AIDS (including methods of transmission) and the person's previous experiences in crisis situations. Information should be up to date and given in a manner that is easy to understand. Pre-marital testing of couples and testing of blood donors is different from testing of those suspected of having HIV/AIDS. However, both groups require sensitivity. Testing should be discussed as a positive act that is linked to changes in risk behaviour, coping and increasing the quality of life.

## • Components of pre test counselling

### **Assessment of risk**

Assessing the likelihood that the person has been exposed to HIV requires considering the following:

**Frequency and type of sexual practices, in particular, high risk practices such as vaginal and anal intercourse without a condom, or unprotected sex with prostitutes;**

**Whether the person was/is part of a group with high risk prevalence for HIV infection (intravenous drug users, male and female prostitutes and their clients, prisoners, refugees, migrant workers, homosexual and bisexual men, and health care workers where the use of Universal Precautions (Fact Sheet 11) is erratic or incomplete.**

**Whether the individual has received a blood transfusion, organ transplant, or blood or body products. Note that in some developing countries, testing of blood for HIV might not occur.**

**Has the person been exposed to non-sterile invasive procedures, such as tattooing, scarification, female and male circumcision.**

### **Assessment of understanding**

The following questions should be asked in assessing the need for HIV testing:

**Why is the test being requested?**

**What are the behaviour patterns or symptoms of concern?**

**What does the person know about the test and its uses?**

**What are the person's beliefs and knowledge about HIV transmission and its relationship to at risk behaviours?**

**Who could provide emotional and social support (e.g. family, friends, etc.)?**

**Has the person sought VCT before, if so, when, from whom, for what reason and what was the result?**

**Has the person considered what to do or how he/she would react if the result is positive, or if it is negative?**

## **Preparation for pre test counselling**

Effective pre test counselling will prepare the person for the test by:

**Discussing confidentiality and informed consent for the HIV test including providing an understanding of the policies governing consent**

**Explaining the implications of knowing one is or is not infected.**

**Exploring the implications for marriage, pregnancy, finances, work, and stigma**

**Facilitating discussion about ways to cope with knowing one's HIV status (For example, has the person considered what to do or how she/he would react if the test is positive, or if the test is negative?).**

**Promoting discussion on sexuality and sexual practices.**

**Promoting discussion on relationships, with emphasis on the benefits of shared confidentiality between the person and his/her loved ones.**

**Promoting discussion on sexual and drug related risk behaviours, as appropriate.**

**Exploring emotional coping mechanisms and the availability of social support.**

**Explaining how to prevent HIV transmission.**

**correcting myths, misinformation and misunderstandings related to HIV/AIDS.**

## Benefits of pre test counselling

Pre test counselling helps people to make informed choices. However, it is important to note that people who do not want pre test counselling before taking the HIV test should not be required to have it. In addition, a decision to be tested should be an informed decision. Informed consent implies awareness of the possible implications of a test result (including the window period). In some countries, the law requires explicit informed consent; in others, implicit consent is assumed whenever people seek testing. The nurse/midwife must help the person understand the policy on consent, and should explain the limits and consequences of testing. Therefore, it is important to be knowledgeable about the policies and guidelines governing your region. Access to pretest counselling is not always available, and some people might refuse this option. However, if the test is positive, there are considerable benefits to providing this service which include:

**improved acceptance of HIV status and improved ability to cope**

**empowerment, including greater involvement of PLHA**

**facilitation of behavioural change**

**reducing the risk of mother-child transmission (Fact Sheet 10)**

**early management of opportunistic infections (Fact Sheets 4 and 5) and preventive therapy, (Fact Sheet 12)**

**contraceptive advice, and other information and education (Fact Sheet 8)**

**early social and peer support**

**normalizing HIV/AIDS**

**instilling hope and addressing the quality of life**

**planning for future care (Fact Sheet 3), making a will (Fact Sheet 8) and orphan care (Fact Sheet 5)**

## • Post test counselling

In post test counselling, it is important to put the person being counselled at ease. If possible, the room should be quiet, without the fear of being disturbed. Arrange the chairs so that bright light will not shine in anyone's eyes. The counsellor should then tell the person the test result. The result (either positive or negative) should then be discussed, including how the person feels about the result. Further information can be provided, though the person may be shocked, and may not fully understand all the information. In some circumstances, the post test setting might provide the only chance to counsel this person. Thus, asking them to repeat the information just presented, or to have some basic facts written down might be helpful. It is important for the person to have time to reflect on the result and understand the next course of action. Ideally, couple and/or family counselling should be started at this time and further counselling follow-up



arranged.

## • HIV-positive test result counselling

When the test result is positive, the nurse/midwife should tell the person as gently as possible, providing emotional support and discussing how best to cope with the results. This is not a time for speculation, but rather a time to give clear, factual explanations of what the news means. Assess the emotional impact of the news, and validate the person's reactions as normal. Fear of dying, job loss, family acceptance, concern about the quality of life, the effects of treatment and response by society can be explored. If there is a concern that the person might not return for follow up counselling, then information about relevant health services should be mentioned. This would include available medical treatments such as antiretroviral therapy or treatment for opportunistic infections, and social services for financial and ongoing emotional support.

However, if follow up counselling is an option, then it would be advisable to leave this information to a later date when the person is better able to absorb the details and explore the available options. Assess the person's understanding and ability to use preventive methods. Free condoms can be given out during this session, together with advice on how to use them and where to get more.

### **How the news of HIV infection is accepted often depends on the following:**

**The person's physical health. People who are already ill often have a delayed response, and can only absorb information when they grow stronger.**

**How well the person has been prepared for the news.**

**How well supported the person is, both in the community and by family and friends.**

**The pre test psychological condition of the person. Where psychological distress existed before the result, learning the result could make the distress greater.**

**The cultural and spiritual values attached to AIDS, illness, and death. In some communities people might take a fatalistic attitude, whereas in other communities, AIDS is sometimes seen as evidence of antisocial or blasphemous behaviour.**

Counselling and support activities need to address feelings of shock, fear, loss, grief, guilt, depression, anxiety, denial, anger, suicidal activity or thinking, reduced self esteem, and spiritual concerns. In addition, social issues such as loss of income, discrimination, social stigma, relationship changes, and changing requirements for sexual expression need to be explored.

## • HIV-negative test result counselling

If the HIV test is negative, then counselling about at risk behaviours and methods of prevention are vitally important (see Fact Sheet 12). Also, the counsellor must explain about the "window period" (between 3-6 months) when a negative result may be a false negative. If there is concern about the HIV status of the person, counsel them to return for a repeat test in 3-6 months, and ensure that they take appropriate precautions in the meanwhile, explaining that they could become infected at any time. The counselling session is an ideal time to discuss sexual practices and preferences, potential drug abuse (particularly intravenous drug use) and other at risk behaviours. Upon learning their HIV-negative status, the person may be more open to learning about safe sex practices and modifying risk behaviours. Free condoms can be given out during this session together with advice on how to use them and where to get more when needed.

## • Continued counselling and support

The HIV-infected person and his/her family require further counselling and support following the initial meeting. Such support helps to improve their quality of life as well as to enhance their ability to cope and make informed decisions about ongoing care. Such counselling and support might include encouraging the PLHA to join a peer support group to learn where and how to access services, to find educational resources, and to obtain treatment. Spiritual and religious support might also be required, as well as support related to financial concerns and care for the family after the person's death. Where services exist, further individual counselling might also be beneficial. Such counselling might include discussions on safer sex practices, birth control counselling (Fact Sheet 12), and counselling and support during the ante natal, intra partum and post natal period (Fact Sheet 10 ) etc..

## • Care for the caregiver

In many communities, there is little value placed on counselling. Consequently, counselling receives little if any financial support. As a result, counselling services are often fragmented, with no designated time or place for counselling sessions. In addition, health care professionals are expected to fit counselling activities into their already overburdened worklife, with little financial compensation. If counselling is not valued by policy makers and governments, it will be difficult for nurses, midwives and other health care professionals to value their roles as counselors. There is considerable evidence to suggest that nurses, midwives and other counsellors themselves need ongoing support and care, since caring for the sick and dying is very stressful. Unless there is adequate education, supervision, counselling and other support services available for caregivers, the result can be "caregiver burnout." What follows are some strategies to address these concerns.

## Strategies to introduce and support counselling services

**Convince the decision makers of the need and value of counselling services by quoting evidence of effective services in other communities, as evidenced by reports from a small evaluation project in your area.**

**Select counsellors and counselling trainees appropriately. These people should have warm and caring personalities, be good listeners, be respected by others, and be motivated and resilient.**

**Provide training workshops followed by supervised practice and ongoing training for the counsellors.**

**Provide instrumental and psychological support to the counsellors.**

**Be sensitive to the location and time of services. The time of services should address accessibility for women, men, youths, and couples. In addition, the sites where services are provided could be expanded to include maternal and child health clinics, hospital out patient clinics, community based programs, and STD and TB clinics. These locations could help reduce the stigma attached to an exclusive HIV or STD clinic.**

**Have adequate supply of condoms (with information on use)**

**Approach sex workers, street workers, intravenous drug users in the places where they live and work.**

**Introduce educational campaigns that increase awareness of counselling services.**

**Provide counsellors with adequate referral services. This includes referrals to other counsellors, support services, treatment management, laboratory testing, ante natal care/breast feeding /family planning services, and orphan care.**

**Set up clear counselling standards and protocols.**

## **Questions for reflection and discussion**

**What are the essential elements in effective communication? Would you say that you are an effective communicator? If not, how might you strengthen this important role?**

**What are the important elements to consider in pre test counselling?**

**What are the benefits of pre test counselling?**

**What are the important elements of post test counselling? Why is this so important?**

**What role might you play in setting up relevant, accessible, and**

## acceptable VCT?

How would you consider maintaining this service? What barriers might you encounter, and how would you consider overcoming these barriers?

How do you care for yourself to prevent burnout? What else might you do to help you reduce some of the stress you might be feeling? Do you think that your workplace might do more to help you? If so, what would that be? How could you go about making this a reality?

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## Fact Sheet 8 HIV palliative and terminal care

- **Introduction**
  - **Palliative care philosophy**
  - **Challenges in terminal and palliative care of PLHA**
  - **Terminal/palliative care for PLHA**
  - **Caring for the caregivers**
  - **Bereavement counselling**
  - **Questions for reflection and discussion**
- 

- **Introduction:**

This Fact Sheet includes information about terminal and palliative care, and addresses the principles and practices of caring for people living with an illness for which there is no cure. Palliative care is the combination of active and compassionate therapies to comfort and support individuals and families living with a life-threatening illness. During periods of illness and bereavement, palliative care strives to meet physical, psychological, social and spiritual needs, while remaining sensitive to personal, cultural, and religious values, beliefs and practices. Palliative care should start at the time of diagnosis and can be combined with therapies for treating opportunistic illness; or it may be the total focus of care.

Palliative care requires a team approach including the PLHA, the family, caregivers and other health and social service providers and considers the needs of the whole person. It includes medical and nursing care, social and emotional support, counselling and spiritual care. It emphasizes living, encourages hope, and helps people to make the most of each day. The palliative caregiver must treat the PLHA with respect and acceptance, acknowledge their right to privacy and confidentiality, and respond caringly to their individual needs.

Terminal care aims to improve the quality of life at the end of life, by relieving symptoms and enabling a person to die in comfort, with dignity, and in keeping with their wishes.

- **Palliative care philosophy**

**affirms the right of the individual and family to participate in informed discussions and make treatment choices**

**affirms life and regards dying as a normal process**

**neither hastens nor postpones death**

**provides relief from pain and other distressing symptoms**

**integrates psychological and spiritual aspects of care**

**provides a support system to help PLHA live as actively as possible until death**

**provides a support system to help the family and loved ones cope during the person's illness and/or bereavement.**

With HIV/AIDS, there is a growing realization that comprehensive care must include care associated with death and dying. Caring for the PLHA in the terminal stages of AIDS puts a great strain on everyone involved. For individuals who choose to die at home, where resources are scarce, care for the dying has traditionally been provided by communities and families, and might involve spiritual support. Families, friends, communities, hospice, health care and social service agency workers, volunteers, and others will be affected in this process.

One of the most difficult aspects of caring for PLHA is deciding when to stop active treatment and to begin to prepare the person and his/her family for dying. In practice, the boundary between the two activities is often indistinct, with both terminal and interventional care continuing in tandem. The decision to stop treatment requires considerable skill, and sensitivity. Whenever possible, the decision should be taken by health care professionals, the PLHA, family members and loved ones.

It is often difficult to decide when aggressive medical treatment should end and when palliative care might begin. Palliative care would begin when:

**medical treatment is no longer effective, or the side-effects outweigh the benefits**

**the PLHA says she/he does not want to continue aggressive therapy**

**the body's vital organs begin to fail**

**enhance patient/family control and the quality of life**

**provide practical support/advice for the PLHA and their loved ones**

**provide adequate pain relief and symptom control**

**maintain the comfort and dignity of the individual**

**provide spiritual and emotional/grieving support for the PLHA and their loved ones**

**prepare the PLHA, their families and caregivers for death. This includes advice concerning avoiding any traditional death rites which could spread infection.**

**ensuring that appropriate provision is made for the children involved and that their rights are respected**

**provide bereavement support to the family and loved ones following death.**

## • **Challenges in terminal and palliative care of PLHA**

HIV poses a unique set of challenges to the caregivers, the PLHA, the families, the communities and health and social service workers. These challenges include the following factors: AIDS may affect whole families when parents and children become infected.

People who die from AIDS usually die at a young age.

The stigma and fear associated with HIV/AIDS often means that the illness and death are not openly discussed and adequate preparations for death might not be made.

Estrangement of family and friends often occurs. Sometimes the PLHA loses contact with family and friends due to conflicting values related to sexuality or lifestyle choices.

Community and family support might be lacking because of the stigma, fear and isolation associated with HIV.

The care of the terminally ill person is often left to the family (and to women in particular), who are often both unprepared and untrained.

The course of terminal care for the PLHA is unpredictable. Opportunistic infections and illnesses are often unpleasant and difficult to manage. These can include: foul odour, chronic diarrhoea, vomiting, skin lesions, seeing the person in pain, dementia, confusion, aggression, and depression.

The caregiver can develop feelings of powerlessness and helplessness.

Caring for someone who is dying at home is expensive. The caregiver must consider the loss of income, the cost of medical and pharmaceutical supplies, and the expense of a funeral.

Problems or complications with inheritance can further increase the poverty of women and children.

The physical burden of caring for PLHA.



The emotional burden for the carers of seeing a loved one dying.

**Remember: An essential part of effective palliative care is the provision of support for caregivers and service providers. Such support will enable them to work through their own emotions and grief related to the care they are providing.**

## • Terminal/Palliative care for PLHA

Care for the PLHA at the end stage of the illness might occur in a hospice or a special terminal care facility. In most cases, however, the PLHA will die at home. In some resource poor countries, dying at home is the only option. The primary concern in terminal and palliative care is to make the PLHA as comfortable as possible by providing medical, spiritual, emotional, practical, and psychosocial support both to the individual and to his/her loved ones. Even where resources are severely limited, good palliative care can be given. The decision to stop medical treatment must be made by the PLHA (if this is possible) and the family or loved ones, and in conjunction with the health workers. Care then shifts to make the dying person as comfortable as possible, and to prepare emotionally and spiritually for death. Such care includes both practical and nursing care issues, as discussed below.

### **Practical issues:**

The PLHA (if able) should make the choice about a suitable place to die. This choice might include a hospice or terminal care facility, or their own home. In most instances, the person will remain at home to die. Hospice and terminal care centres usually have specially trained staff to care for both the person who is dying and their loved ones. If the PLHA remains at home, then the family, and other caregivers will require special training to provide appropriate terminal care for the PLHA.

The following considerations for providing good palliative/terminal home care will be dependent upon adequate resources. However, whenever possible, care should include:

- **Providing health service support. The local health centre should be briefed about the person's condition, so that staff can provide the people caring for the PLHA with advice and appropriate medical supplies.**
- **Ensuring adequate community and family support. This will help reduce the pressure on the caregivers, who are usually the women in the family. It will mobilise relatives and friends to help in household or other work, and will provide companionship for the sick person. The health worker should discuss how to mobilise the support of local community leaders, non-governmental agencies, neighbours, and members of community or religious associations . This might be an important time to facilitate reconciliation with estranged family and/or friends.**
- **Placing the PLHA in a light, well ventilated room that is quiet, comfortable, and yet close enough to the rest of the family to remain involved in family life.**

## **Nursing care issues**

## **Providing effective pain relief**

The nurse can help the PLHA and caregiver by providing the appropriate medications to control pain. Where adequate resources are available, even in the terminal stages of AIDS, the PLHA should be able to remain pain free. Being pain free involves giving routine doses of a suitable analgesic. Pain relief is a three stage approach:

1. aspirin or paracetamol may be given.
2. If pain relief is not maintained, give codeine or dihydrocodeine (with or without non-steroidal anti-inflammatory drugs such as ibuprofen or diclofenac).
3. If the pain persists, morphine can be given, with or without a co-analgesic) or synthetic pethidine and fentanyl should be given. Some form of sedation such as valium might also be considered.

It is essential to maintain pain control. This means that the person might require more than the usually prescribed 3-4 hour regimen. Nurses and midwives should consult their local treatment protocols for pain relief for the terminally ill PLHA. Many AIDS patients have more than one pain related to different opportunistic illnesses. Each needs to be diagnosed and treated. Psychological and spiritual concerns related to HIV may make physical pain worse. These psychological and spiritual concerns should be addressed at the same time as treating the physical pain. At this stage of the illness, there is no fear of patient addiction to medications; the overall concern is for patient comfort. Other nursing care measures might include placing a cool, clean, moist cloth over the painful site, or applying heat if necessary. Massage and deep breathing exercises might also help the patient to relax.

## **Keeping the patient nourished and hydrated**

Diarrhoea can be a major problem, sometimes persisting for several months, with stools that may be mucoid and foul smelling with pus. Nourishment should be light and given at frequent intervals. Dehydration can be prevented by administering fluids such as water, unsweetened fruit juices, soup, rice water, and weak tea. If the person is vomiting, sips of water should be given frequently. Oral rehydration therapies such as homemade sugar and salt solutions may be given. In some circumstances, intravenous rehydration may be necessary. Medicines (see Fact Sheets 4 & 5) might also be prescribed. Always use Universal Precautions (Fact Sheet 11) when handling faecally contaminated articles.

## **Maintain basic physical care**

This includes keeping the PLHA clean, dry, and comfortable should be maintained. It is important to change the person's position frequently, and to keep the room well ventilated. Air freshener sprays, although expensive, are useful, as is the burning of incense or other herbal mixes. See Fact Sheets 4 & 5 for other suggestions for providing physical care for the PLHA.

## **Mental confusion or dementia**

These affect many people with HIV-related illness. The individual may move clumsily and become unaware of what is happening around them. They may be forgetful and unable to think clearly. Their awareness of being confused may come and go, which can be very upsetting for the caregivers.

Those who are confused need constant attention and reassurance, and might also need to be restrained from hurting themselves. Dangerous objects (and medications) should be removed from their reach. Severe dementia may require sedation (consult local drug protocols).

Looking after a confused person is exhausting and distressing. Caregivers need to be encouraged to take

turns in caring for the PLHA. Nurses and midwives should help the family understand that the individual's behaviour is not intentional. They must also ensure that adequate care for the PLHA is available. Medication lists should be reviewed regularly in order to assess whether some medication might be compounding the problem.

### **Severe skin abscesses or ulcers can become infected**

Nursing care should include dressing the skin lesions, lancing boils, and keeping the area clean (See Fact Sheet 11 on Universal Precautions). In addition medications given locally, orally or by injection might be necessary (see Fact Sheet 4 & 5 for further treatment regimens). Nurses are advised to consult their local drug protocols.

### **Emotional distress is a common experience**

It can be experienced by the PLHA, the family members or other caregivers. It is particularly likely at the first disclosure of the individual's HIV status. Counselling can help in these situations.

## **Issues that might need to be addressed during counselling include:**

### **Fear of death**

Fear is a normal reaction and can make people angry, depressed, or aggressive. Caregivers should not give false reassurances, but should encourage the person to talk about their fears. Spiritual support might also be helpful.

### **Loneliness and depression**

Sometimes when someone is dying, people stop coming to visit because they fear death, or do not know how to react. Such isolation can lead to a sense of loneliness and depression. People should be encouraged to visit (if the PLHA wishes). In some cultures, people will also need an opportunity to discuss their feelings about being with someone who is dying.

### **Feelings of guilt and regret**

The PLHA may feel responsible for exposing his/her partner to infection, or may feel guilty for having brought shame to their family or friends. Failure to settle debts, fulfill ambitions, or attend to their responsibilities to children can all cause feelings of guilt, sorrow, and regret. A person may seek forgiveness or wish to discuss ways of resolving problems for which he/she feels responsible.

### **Spiritual support**

This support can come either through an organized religion, or through the exploration of the PLHA's own spirituality, beliefs and values is very important. The PLHA might have been cut off (whether by him/herself or by their community) from his/her religion. Caregivers should acknowledge a person's spiritual needs, respect their religious beliefs (or lack of them), identify an appropriate person who can provide spiritual support, and discuss whether the person wants any religious observances to be performed, including funeral arrangements, in the event of their death.

### **Making a will**

A will helps to make clear what a person wishes to happen after his/her death. The surviving women and children are often left impoverished and unprovided for unless a will is made.

**A will must be made in accordance with local law and may:**

ensure that property, land and valuables are passed on to people that the PLHA stipulates

make clear who has custody of children; and, if there is no partner, appoint guardians

specify trustees of executors who will ensure the will is acted upon

provide instructions about funeral arrangements

### **To be valid, a will must usually be:**

written in permanent ink or typed

signed by the person and clearly dated. Signing and dating must be witnessed. (Those who benefit from the will should not be witnesses.)

written when the person is of sound mind, and not being forced to do so by someone else.

### **When death comes it is important not to leave the dying person alone.**

Many people are very afraid of dying alone. Respect should be given to rituals, observances, and customs related to laying out the body. Mourners can be given time alone with the body if they wish. However, all persons should be warned about the risk of contamination.

## **• Caring for the caregivers**

Family members, loved ones, caregivers and health care workers all need to be supported and cared for as they provide terminal care to the PLHA. Support groups, counselling (both individual and group), and instrumental care are all helpful strategies to support the caregivers. Instrumental support includes the provision of adequate resources (medical supplies, medicines, and personnel) to make effective terminal care possible. Emotional and spiritual support should also be available. The kind of support that caregivers need will vary. Acknowledging the need for such support and providing ways to access such support are essential. If such support is not available, the burden of care can become too great and caregiver exhaustion may follow.

## **• Bereavement counselling**

Families and friends often have little social support, or may have become isolated while caring for the PLHA. Bereavement support should be made available before the person dies, and for as long afterwards as people need it. People react to death in different ways, and need different types of support. For some, it can take months or years to come to terms with loss. Additionally, people's responses may be affected by the way the person died: for example, whether the PLHA died alone and in pain, or died peacefully, surrounded by loved ones. Those left behind often blame themselves if they think they could have done

more.

### **Bereavement counselling should:**

give people an opportunity to talk about events leading up to the death, about the death itself, and the observances and rituals immediately after the death

reassure people that feelings of disbelief, denial, sadness, pain and anger are normal

allow people to express their feeling and concerns, especially if it is difficult for them to do this with friends and family

enable people to accept their loss and start to look to the future.

### **Questions for reflection and discussion**

**What are some of the major issues that might get in the way of effective palliative care?**

**How can these issues be overcome?**

**What is the basic philosophy of palliative care?**

**Why can good palliative care be provided without the benefits of adequate financial and other practical resources?**

**Why is making a will important?**

**How can you help provide emotional support to PLHA, the caregivers and others (including yourself). Why is such support important?**

**What are the essential characteristics of bereavement counselling? Do you think you could help conduct bereavement counselling?**

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## Fact Sheet 9 Teaching/learning about HIV/AIDS

- **Introduction**
- **Continuing education for nurses and midwives**
- **The nurse and the midwife as educator**
- **Basic principles of adult education**
- **Preparing educational sessions**
- **Methods of teaching/learning**
- **Questions for reflection and discussion**

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### • **Introduction:**

Education is the key to change in knowledge, attitudes, and behaviour. Education about HIV/AIDS must be improved in order to reduce gaps between policies and their grassroots implementation, and to ensure the adoption of effective prevention strategies. This Fact Sheet examines the different methods of teaching/learning, not the actual information to be taught. This Fact Sheet is divided into four major components:

- the importance of continued education for nurses and midwives,
- nurses/midwives as health educators,
- some of the basic principles of adult education, and
- some teaching/learning strategies.



*In Nigeria, a woman speaks to an audience about HIV/AIDS.  
(Credit: JHU/CCP)*

### • **Continuing education for nurses and midwives**

Research, practice and treatment for the prevention and care of HIV are changing so rapidly that nurses/midwives need to have continued education to remain up-to-date in their knowledge, skills and practices. Educational opportunities are not always easy to access, and nurses and midwives may have to look for the latest information. There is no doubt that good practices are dependent upon adequate,



accurate and up-to-date information. Much of the misinformation, myths and folklore surrounding HIV/AIDS can be corrected with ongoing education. Such education will reduce the fear, stigma, isolation, and denial of care for people living with HIV/AIDS (Fact Sheet 6).

Although continued education is not always a priority in health care settings, nurses/midwives should advocate for refresher courses and other ongoing education. In addition, nursing/midwifery students should request and advocate for comprehensive HIV education in their basic training. HIV/AIDS is one of the greatest public health challenges of this era. Consequently, adequate educational preparation of nurses/midwives (as well as other health care workers) should be viewed as a priority, and advocated by schools of nursing and midwifery, nursing/midwifery associations, and other organizations.

## • **The nurse and the midwife as educator**

Nurses/midwives are increasingly required to act as HIV/AIDS health educators. The general public including youth, pregnant women, school children, parent groups, sex workers, and drug users, all need information about HIV/AIDS. In addition, traditional healers, trained birth attendants, other health care workers, volunteers, family members, caregivers, friends, counsellors, religious and civic leaders, community health workers and other health and social service personnel will require continued education from nurses/midwives on issues related to prevention and care of HIV.

## • **Basic principles of adult education**

Before starting any educational session, it is important to assess the learning needs of the group and to be familiar with the cultural environment from which the participants come. It is then possible to plan the most relevant educational sessions and materials and to deliver information that is meaningful and useful to the participants. Evaluation of the educational strategies used and the learning outcomes of the participants is also critically important. Most adults learn best by being actively involved in the learning process. It is also important to realize that different people learn through different educational strategies. Consequently, no single learning tool should be used in all situations.

For example, it might be important to provide an opportunity for learners to practice one particular technique, while at other times, a lecture, text book, or other written document would be more appropriate. Also, learners need time to reflect on their learning and to revisit what they have learned, perhaps through practice, discussion, critical questioning, research, or active participation in teaching others. Educational sessions should be conducted such that learners feel safe to admit when they do not understand something, and feel empowered to seek additional teaching/learning and support. If students fear ridicule, they are less likely to admit their ignorance -- a circumstance which could later lead to unsafe and unethical practice.

Timing is also important in the teaching/learning process. Learners learn best when they feel they have a need to know. It is the responsibility of the teacher to foster this "need to know." In addition, retention of learning should be assessed periodically and supported over time. Rarely is knowledge that is learned only once, through one medium, retained. Therefore, it is helpful to use a variety of teaching/learning techniques and to repeat important information over a period of time, in order to reinforce learning.

Prevention and care of HIV involves consideration of sensitive issues such as sexuality, different sexual practices, drug use, and other risk behaviours. Traditionally, nurses/midwives have not been educated to feel comfortable with openly discussing sensitive, embarrassing, or offensive practices. Practice in discussing these subjects should begin in a safe learning environment. Finally, it is important to teach risk analysis and risk avoidance strategies.

## • **Preparing educational sessions**

Ask these questions as you begin to prepare an educational session:

- **How can nurses and midwives work together to support learning?**
- **Who is the audience? Are they male, female, young or older, educated or less well educated? It is important to know the participants before choosing or producing educational materials. What is the level of their knowledge on the subject?**
- **What do you hope to achieve? What is your expected outcome of the educational session? What is your main message? Do your expected outcomes for learning to match the learning needs of the group?**
- **How will you access the information you need to conduct the educational session?**
- **How much will the educational session cost? Are there enough funds available?**
- **How long will the educational session take? Will the participants be able and willing to stay for the entire session?**
- **What equipment will you need? Is the equipment available, or can you adapt your session by using available equipment?**
- **Is there existing material available? If material is available, use this (and adapt if necessary) rather than starting from scratch.**
- **Is the language appropriate? Are you presenting the information at the educational level of the learner? Is your language too complex, or too simple for the participants? What is the literacy level of the group?**
- **Are the illustrations appropriate? Are the illustrations culturally sensitive and appropriate? Are they clear so that the participants can understand them? Do the illustrations reflect issues and images with which the participants are familiar?**
- **Do the educational materials look good and attract people's attention? Is the design and colour attractive? Are they culturally sensitive? Can the participants identify with the materials?**
- **Does the educational material avoid discrimination? Does the material show people of similar racial origin, age, and sexual orientation? Do the illustrations foster stigma or fear? For example, showing a person dying of AIDS might lead some people to believe that all people living with HIV are about to die.**
- **Does the educational material generate feelings of fear? Messages such as "AIDS Kills" might scare people away, and such scare tactics rarely help promote effective behavioural change. Positive messages often promote changes in attitude and behaviour. However, some illustrations that catch people's attention, even negative illustrations, can be effective in raising people's awareness. The key is to know the target group well and choose your messages accordingly.**
- **Does the educational material avoid moralizing and preaching? People resist listening to someone telling them what they should and should not do. Such practices often lead the learners to become silent and less likely to engage in open and**

productive discussions. For example, if young people are told that they should not engage in sexual intercourse before marriage, they are less likely to then enter into discussions about safe sexual practices. The best materials provide information in a clear, respectful way and enable people to make their own decision.

- Do the educational strategies build upon already acquired skills, and promote confidence? It is important to build on the expertise of the group. What do they already feel confident in doing? How can that confidence be translated to other circumstances?
- Does it help to build a supportive environment? People learn best when they feel cared for and supported. If people work together toward the same ends, much can be achieved. Does the learning session provide an opportunity for ongoing support for one another? Can this group be supported in promoting effective change in other people, in changing health care practices, and even changing legislation?
- What educational materials work best for the participants? Consider using attractive posters, local radio, TV or newspaper announcements, leaflets, fact sheets, and training aids such as flip charts, or flash cards. Open discussions, interviews with PLHAs and their families, listening to stories from other care providers, or patients, and advertisements are also deliver powerful educational messages. It will be important for participants to visit PLHAs in hospital and in the community.
- How will you distribute educational material? Sadly, there are often excellent educational materials that are not used simply because the methods of distribution are inadequate.
- Do the learners leave with any materials to help reinforce learning? Learning takes place over a period of time and with reinforcement. What methods of reinforcement of learning have you considered? Do you have Fact Sheets available, or are there posters to reinforce learning? Do you provide additional educational sessions? Do you test the learners at a later date? Do you require supervised practice after a teaching/learning session? Is there a library available and a list of recommended reading? What other strategies have you considered to reinforce learning?
- Have you considered pretesting the educational material before it is printed or published? Pretesting educational material can be a very important step towards ensuring that the message is understood, well received and has the potential to motivate behavioural change, or to promote the best practices.
- What methods of evaluation of the educational sessions have you considered? Evaluation of student learning can be done through conducting pre and post testing. Observation of practice, and observation or anecdotal reports of behaviour change are other forms of evidence. Have the participants been asked to evaluate the teacher, and the educational sessions? Has behavioural change been observed over time (i.e. retention of learning)? What other forms of evaluation have you considered? What will you do with the evaluation information? Will you make changes to your educational material and teaching/learning processes if necessary?

## • **Methods of teaching/learning**

There are many teaching methods or strategies to promote learning, including:

### **Group discussion**

This method is useful if group members feel comfortable with one another and individuals are not hesitant to speak. Feelings of group safety can take time, and is not always achieved, but can be facilitated by the instructor's skills and encouragement. Group discussion exposes other members to the beliefs, values, and practices of others. Such discussion can lead to peer support. One of the best ways to encourage group discussion is through problem posing and problem solving. These problems can be developed by the educator, or from the experiences of the participants.

### **Role play and simulation**

Students often find it beneficial to practice new learning by acting in, or observing, a role play or simulated exercise. They are then more able and confident to transfer this learning to the "real world."

### **Building on success**

Find out what the learners have been successful in achieving and use the experience of this success toward teaching other subjects. This strategy provides students with a sense of confidence and empowerment.

### **Visual aids**

Posters, photographs, pictures, overhead projections, slide presentations, videos, and works of art all can be powerful educational tools. Discussion can follow the use of such visual aids. For example, the group can be asked what the visual aid meant to them, what they liked or disliked about it, what was unclear, disturbing, or helpful.

### **Group activities**

There is considerable evidence to suggest that people learn best when they are actively engaged in their learning. Often the group develop their own teaching/learning sessions. Evidence shows that young people learn best from their peers, and when they are actively engaged in the development of peer group learning.

### **Group participation**

Evidence also shows that people learn best when they participate in the learning rather than behave as passive observers. In the past, students were often placed in rows, while the educator lectured to the group. Although this method is sometimes useful to communicate important messages in a short period of time, reinforced learning leading to behavioural change is best accomplished through the active participation of the learners.

### **Learning aids**

Flip charts, fact sheets, flash cards, wall charts, drawings done by the group or others, diagrams, tables, and graphs provide clear and easy access to information. These visual aids can also be used to promote group discussion. For example, questions such as "What does this graph tell you?", "What is missing from this information?", "How could you go about getting this information?" , "What does this drawing tell you?", "How would you have drawn this picture differently?" , "Why is that so?" all promote discussion. Models of anatomy can be used to help the learners understand how HIV and other sexually transmitted diseases are passed from one person to another. Models are also suitable for practicing correct condom usage and many basic nursing care procedures.

### **Social marketing and use of the media**

These can be powerful methods of sharing information. Posters can be displayed where people live, work and play. Leaflets and written information can be left for people at health centres, shopping centres, parks, or recreational facilities. The media can be involved in providing educational messages to the larger community. Nurses and midwives can be interviewed by the media, or students can be encouraged to participate in media presentations. Cartoons and comic strips can reach wide audiences and be useful methods of peer support and education.

### **Story telling and sharing one's experiences**

These can be an effective method of learning. People like to hear about the experiences of others, and often find they can relate to these experiences better than trying to grasp facts that seem to have little relevance for themselves. Fictional stories are also helpful in sharing important messages. Although the story might be about a fictional character, the message is one that the listener can easily relate to and understand.

## **Participating in drama**

Dramatic events can also be a powerful way of expressing important information. Not only do the participants of the drama learn from this method, but the audience can also be brought into the drama. Young people are particularly open to this form of learning.

## **Learning through games and play**

Board games making models out of clay or play dough and Puppets can be used to present important messages. Puppets often help to make the subject matter more playful and less intimidating. Puppets can be made by the students who can also participate in creating the story to go with the puppet show.

## **Community fairs or meetings**

These events can be used to present important information. Such community gatherings can increase public awareness of the issues and challenges of HIV/AIDS and encourage the wider community to become actively involved in the care and prevention of HIV.

### **Questions for reflection and discussion**

**When you think about preparing to teach a session about safe sex practices, what principles of teaching/learning might you consider?**

**What methods of teaching/learning have you used? Did you find them helpful?**

**What other methods might you now consider?**

**What methods of evaluation (both student and teacher) might you consider? Why would it be important to obtain this information?**

**What role do you see yourself playing in providing information to a wider audience?**

**What methods might you use to encourage learner participation? Why might it be important to actively engage the learner in his/her own learning?**

**What preparation do you see yourself needing in order to be an effective educator? How would you go about gaining this knowledge?**

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## Fact Sheet 10 Women and HIV and mother to child transmission

- **Introduction**

- **The vulnerability of women**

  - Biological

  - Social and economic vulnerability

- **Fostering empowerment**

- **Mother to child transmission of HIV**

- **Antenatal care**

  - Termination of pregnancy

  - Antiretroviral therapy

  - Benefits of voluntary testing and counselling

- **Infant feeding**

  - For the non breastfed infant

  - For the breastfed infant

- **Post natal care of HIV infected mother her infant**

  - Post natal counselling

- **Questions for reflection and discussion**

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- **Introduction:**

Over 12.2 million women world wide have been infected with HIV since the start of the epidemic and women account for 42% of the 30.6 million adults now living with HIV. Because of the particular vulnerability of women, the risk of women contracting HIV is rising worldwide. Although these figures are increasing in industrialized and developing countries, in sub Saharan Africa there are already 6 women with HIV for every 5 men, with close to four-fifths of all infected women being African.





In African countries, where young people (age 15-24) account for 60% of all new infections, HIV infection in young women outnumbers infection in young men by 2 to 1. More than four-fifths of all infected women get the virus from their male sex partner, often by their one partner (their husband). The remainder become infected from blood transfusions or from injecting drugs with a contaminated needle. Women with sexually transmitted diseases (STD) such as gonorrhoea are often unaware of the disease because the infection is silent. Conclusive proof now exists that STDs facilitate the spread of HIV. An untreated STD in either partner increases the risk of HIV transmission during unprotected intercourse (without a condom) ten-fold. AIDS prevention campaigns often fail women by assuming that they are at low risk, or by urging prevention methods that women have little or no power to enforce, such as condom use, abstinence and mutual faithfulness within a relationship (Fact Sheet 12).

*In a Tanzanian hospital, a woman cares for her husband who has AIDS. The pandemic imposes a double burden on women. Already more vulnerable to HIV infection because of their subordinate status, they are also affected by the AIDS epidemic in their role as providers of care in the family and the community. (Credit: WHO, Gubb)*

Women continue to make strides towards equality with men. However, for millions of women, this is far from reality. These women are the most vulnerable to HIV infection. In many parts of the world, nurses and midwives suffer the same vulnerabilities as women in the general population.

## • The vulnerability of women

### Biological vulnerability

Research shows that the risk of becoming infected with HIV during unprotected vaginal intercourse is as much as 2-4 times higher for women than men. Women are also more vulnerable to other STDs (multiplying the risk of contracting HIV tenfold). One major reason for this is that women have a larger surface area of mucosa (the thin lining of the vagina and cervix) exposed to their partner's secretions during sexual intercourse. Additionally, semen infected with HIV typically contains a higher concentration of virus than a woman's sexual secretions. Younger women are even more at risk because their immature cervix and scant vaginal secretions put up less of a barrier to HIV., and they are prone to vaginal mucosa lacerations. There is also evidence that women again become more vulnerable to HIV infection after menopause. In addition, tearing and bleeding during intercourse, whether from rough sex, rape, or prior genital mutilation (female circumcision), multiply the risk of HIV infection, as does anal intercourse, which is sometimes preferred to vaginal intercourse because it is thought to preserve virginity and avoid the risk of pregnancy. Anal intercourse often tears the delicate anal tissues and provides easy access to the virus.

### Social and economic vulnerability

Prevention messages urging abstinence, fidelity (faithfulness to one partner), condom use, needle exchange programs (for intravenous drug users) and encouraging and enabling people to get prompt STD treatments have all helped avoid HIV (Fact Sheet 12). However, for millions of women, their ability to make these decisions and to act upon them is crippled by their socio-economic circumstances. The majority of women in the world lack economic resources, and are fearful of abandonment or of violence from their male partner. Thus they have little or no control over how and when they have sex, and hence have little or no control over their risk of becoming infected with HIV.

This vulnerability is compounded by:

### Lack of education

Millions of young girls are brought up with little knowledge of their reproductive system or how HIV and STDs are transmitted and prevented.

### Sexual customs and norms

Typically, women are expected to leave the initiative and

**REMEMBER!** The Fact Sheets can be adapted for primary and secondary schools.

decision-making in sex to males whose needs and demands are expected to dominate. There is often a tolerance of predatory, violent sex, as well as a double standard where women are blamed or thrown out for infidelity (real or suspected), while men are expected or allowed to have multiple partners.

### **Lack of economic opportunities**

There is a failure to respect women's right to equal access to education and employment opportunities, thus reinforcing their dependence upon men. Their reliance may be on a "sugar daddy," that is, a partner who may give gifts to pay for sex, a husband or stable partner, a few steady male partners who have fathered their children, or, for prostitutes, a succession of clients. In fact, in many cultures, sex is seen as a "currency."

### **Lack of control in relationships**

Even when a woman suspects her partner has HIV, she often cannot risk losing his support by refusing sex, or insisting on condom use. She would be breaking the "conspiracy of silence" that surrounds extramarital sex by either partner. Although some men agree to use condoms, many react with anger, violence and abandonment.

### **Condom use and pregnancy**

Couples wanting children need to know their HIV status. However, couples are often unwilling to openly discuss issues of sexuality, and voluntary HIV testing and counselling services are not always available (Fact Sheet 7).

### **STDs and HIV**

Because STDs carry an especially heavy social stigma for women, they tend to avoid STD clinics and treatment. In addition, health care workers are often unsympathetic, judgemental, and unprepared to diagnose and treat STDs (Fact Sheet 6). Women are often socialized to accept ill health and women's troubles as their lot in life.

### **HIV and prostitution**

Prostitutes have little power to protect themselves from HIV. In some countries, girls are forced into sex work, even before puberty. Such young girls are generally unaware of the AIDS risk and they are unable to take protective action, or run away. Women also turn to prostitution as an alternative to poverty, or because their lives have been disrupted by war, divorce or widowhood where, because of inequitable laws and customs, they have lost their property and their husband's earnings. Many sex workers risk violence or loss of income if they request the use of condoms. However, in some brothels, sex workers have banded together to insist on condom use.

## **• Fostering empowerment**

Women's vulnerability comes from lack of power and control over their risk of HIV. One important remedy is to create opportunities to foster empowerment:

**REMEMBER!** The Fact Sheets can be adapted for teaching women's groups.

### **Combat ignorance**

Improve education for women, including education about their bodies, STDs and AIDS, and the skills to say no to unwanted or unsafe sex. See fact sheet on prevention (Fact Sheet 12) and education (Fact Sheet 9).

### **Provide women-friendly services**

Ensure that girls and women have access to appropriate health and HIV/STD prevention and care services at places and times that are convenient and acceptable to them. Expand voluntary testing and counselling (Fact Sheet 7) and teach about condom use and make condoms easily available without embarrassment.

### **Develop female-controlled prevention methods**

Barrier methods that prevent HIV infection without the knowledge and cooperation of the male partner are urgently needed. Such methods might include the female condom and vaginal microbicides (a virus-killing cream or foam) that women can insert vaginally before intercourse. UNAIDS is facilitating the development

of and access to these and other methods.

### **Build safer norms**

Support women's groups and community organizations in questioning behavioural traditions such as child abuse, rape, sexual domination, and mutilation. Educate boys and men (Fact Sheet 9) to respect girls and women, and to engage in responsible sexual behaviour (Fact Sheet 12).

### **Reinforce women's economic independence**

Encourage and strengthen existing training opportunities for women, credit programmes, saving schemes, and women's cooperatives, and link these to AIDS prevention activities.

### **Reduce women's vulnerability through policy change**

At community and national levels (as well as through international initiatives), the rights and freedoms of women must be respected and protected. This will only be achieved when women have a greater political voice.

## **• Mother to child transmission of HIV**

### **Mother to child transmission (MTCT) of HIV is the major means of HIV infection in children.**

An estimated 600,000 children are infected in this way each year, accounting for 90% of HIV infection in children (Fact Sheets 2 & 5). Without preventive treatment, up to 40% of children born to HIV-positive women will be infected. Of those who are infected through MTCT, it is believed that about 2/3 are infected during pregnancy and around the time of delivery, and about 1/3 are infected through breast feeding. Most of the transmission in pregnancy occurs at the time of labour and delivery (more than 60%). Using the most widely available tests (see Fact Sheet 1), it is not possible to tell whether a newborn infant has already been infected with HIV. The child of an infected mother may have maternal antibodies in his/her blood until 18 months of age (Fact Sheet 5). Therefore, testing cannot be used to help make decisions about whether or not to breast feed.

## **• Antenatal care**

Voluntary HIV testing and counselling (VCT) (Fact Sheet 7) should be available in antenatal clinics. Many HIV-positive women will be diagnosed for the first time during pregnancy, therefore, this service is critical to the ongoing treatment, care and support for the mother, her family and new born child. The benefits of VCT in antenatal care include:

**Knowledge of a negative result can reinforce safer sex practices.**

**Women diagnosed with HIV can encourage their partners to be counselled and tested.**

**Knowing their HIV status enables women and their partners to make more informed choices related to breast feeding and future pregnancies**

**A woman (and her family) who knows she is HIV infected can be encouraged to enter into the continuum of care in order to seek early medical treatment and care of opportunistic infections for herself and her child (Fact Sheet 4 & 5), as well as be linked to other health and social services and resources (see Fact Sheet 3).**

**Widespread access to VCT can help normalize the perception of HIV in the community.**

**Knowledge of their HIV-positive status can enable women to access peer support.**

Access to VCT is important in antenatal clinics because there are ways to prevent transmission, such as:

- **termination of pregnancy,**
- **antiretroviral therapy (ARV),**
- **modifying midwifery and obstetrical practices, and**
- **modifying infant feeding.**

However, prevention of MTCT is dependent upon the identification of the HIV-positive woman.

### **Termination of pregnancy**

Where termination of pregnancy is both legal and acceptable, the HIV-positive woman can be offered this option. However, many women learn of their HIV status during pregnancy, and will not be diagnosed in time to be offered termination. If termination is an option, the woman, or preferably the couple, should be provided with the information to make an informed decision without undue influence from health care workers and counsellors.

### **Antiretroviral therapy (ARV)**

A recent study showed that the administration of zidovudine (AZT) during pregnancy, labour, delivery and to the new born reduced the risk of MTCT by 67%. This regimen has become standard practice for HIV-positive women in most industrialized countries and many women are receiving a combination of ARV treatments. This long-course regimen is often not available for women in developing countries because of cost and lack of adequate infrastructure. However, there is a concerted effort to provide short term AZT to all HIV-positive pregnant women. Short course AZT is taken orally from 36 weeks of pregnancy through labour and delivery. This treatment does not prolong the life of the mother, but has been found to be effective in reducing transmission of HIV to the infant.

**Nevirapine** is a much cheaper antiviral drug than AZT, costing about \$4 per mother and baby treated. Recent studies have shown it to be effective in reducing MTCT if a single dose is given to mothers just prior to delivery and to newborns immediately afterwards. In terms of both cost and infrastructure requirements

Nevirapine offers a more optimistic and realistic alternative for ARV for developing countries. Many countries are in the process of developing guidelines and an effective infrastructure to support ARV. Because ARV treatments vary considerably throughout the world and are still in the experimental stages, nurses/midwives are encouraged to learn more about the ARV treatments and protocols available within their community and country.

## • Labour and delivery

About 60% of HIV transmission from mother to child is thought to occur around the time of labour and delivery. Several factors have been associated with an increased risk of MTCT at the time of labour and delivery. These include:

### **The mode of delivery**

Vaginal deliveries are more likely to increase the risk of MTCT while elective Caesarian sections have been shown to reduce MTCT. However, the potential benefits have to be balanced against the risk to the mother. Higher rates of post operative death in HIV positive women have been reported, especially from infective complications. In addition, elective Caesarian sections are not available to the vast majority of women worldwide.

### **Prolonged rupture of membranes**

Rupture of membranes for longer than 4 hours has been associated with an increased risk of transmission. Artificial rupture of membranes is practiced routinely in many countries. Membranes should not be ruptured artificially unless there is fetal distress, or abnormal progress in labour.

### **Episiotomy**

Routine episiotomy is not recommended. This procedure should only be used where there are specific obstetric indications. Forceps deliveries and vacuum extractions do not necessarily require an episiotomy.

### **Intrapartum Haemorrhage**

This has been associated with increased MTCT transmission in some studies. Should a blood transfusion be required, there is the added risk of receiving HIV contaminated blood (Fact Sheet 1).

### **Invasive fetal monitoring**

Penetrating scalp electrodes may be associated with increased risk of transmission.

### **Multiple births**

The first baby delivered of a multiple pregnancy has a higher rate of HIV infection than the subsequent births.

Other areas for consideration during labour and delivery include:

### **Universal Precautions**

Fact Sheet 11 provides a detailed overview of Universal Precautions that should be followed by nurses/midwives in all aspects of care regardless of the HIV status of the woman or the nurse/midwife at the time of labour delivery. Frequent hand washing and glove use (whenever possible) are critical practices in precaution.

### **Vaginal cleansing**

The use of chlorhexidine 0.25% to cleanse the birth canal after each vaginal examination and during labour and delivery has been shown to be effective in reducing MTCT transmission.

### **Education of traditional birth attendants**

Traditional birth attendants (TBAs) play an important role in the labour and delivery of many women worldwide. Educating the TBA about HIV prevention (Fact Sheet 12) and care and the use of universal

precautions (Fact Sheet 11) is often the responsibility of nurses/midwives. This education should include the use of ARV and STD treatments. They should also be encouraged to avoid traditional practices that may increase the risk of HIV transmission such as the use of vaginal herbal potions and scarification.

## • Infant feeding

Approximately one third of infants who are infected through MTCT are infected through breast milk. Where alternatives such as replacement feeding exist, HIV positive mothers should avoid or limit breastfeeding their infants. For HIV-negative mothers, breastfeeding still remains the best option.

Where resources are limited, the option of using replacement feeding may be unavailable. Many communities do not have a safe water supply, have limited resources to provide sterile feeding equipment, and have no methods of refrigeration. Replacement feeding is also expensive and many families cannot afford this added expense. In addition, where breast feeding is the cultural norm, seeing a mother artificially feed her infant can lead people to suspect she has AIDS. One must also consider additional problems associated with gastro-intestinal infections, malnutrition, stigma and discrimination (Fact Sheet 6). Decisions about whether to breast feed or to provide replacement feeding must be made in light of the above considerations. If replacement feeding is an option, breast milk substitutes include: commercial infant formula, or home-prepared formulas which are made from animal milk, dried milk or evaporated milk with additional ingredients. Once the decision has been made about whether or not to breast feed, then other considerations must be taken into account:

### **For the non breastfed infant:**

- Ensure access to an adequate supply of replacement milk substitutes, with adequate funds to pay for them, adequate utensils for feeding, and fuel for sterilizing equipment and heating the milk substitute.
- Educate the mother about safe preparation of replacement feeds, correct cleaning of utensils, and methods of sterilization.
- Monitor the growth and development of the child to ensure adequate infant feeding and nutrition.
- Monitor the safe preparation of replacement feeds.
- Appropriate care of the mother's breasts to prevent engorgement.

### **For the breastfed infant:**



- Teach the mother to inspect her child's mouth for thrush and breakages in the mucous membrane (an added risk for HIV transmission (see Fact Sheet 5)).
- Teach the mother about the increased risk of HIV transmission should she suffer from mastitis, breast abscesses, and bleeding or cracked nipples.
- Discuss replacement feeding after three months (to reduce some risk of transmission).
- Stop breastfeeding after 6 months when the baby can be safely weaned.
- Use expressed milk that is boiled and then cooled. (Boiling kills the virus.)
- Use the breastmilk of other women who are HIV-negative (wet-nursing).

## • Post-natal care of the HIV-infected mother and her infant

In many instances, the basic post natal care of the HIV-infected woman and her infant will be no different from routine postnatal care. However, the mother (and possibly partner/family) might need additional counselling and support (see Fact Sheet 7). Such counselling might include decisions on infant feeding (although this decision should have been made in the antenatal period), and advice on birth control. It is important that the woman and her family are involved in a continuum of care (Fact Sheet 3), so that comprehensive linking of resources and services can be provided where and when they are most necessary and effective. HIV-infected women are more prone to medical complications such as urinary tract infections, chest infections, episiotomy sepsis, and uterine and Caesarian section wound sepsis. Nurses/midwives should be alert for signs of infection such as fever, rapid pulse, episiotomy or lower abdominal pain, and foul smelling lochia (vaginal discharge). HIV infected women should be taught about perineal care and safe handling of blood and lochia.

### Postnatal counselling:

Specific counselling for the HIV-infected mother might include:

- **Contraceptive advice. The only contraceptive methods that will prevent the spread of HIV are barrier methods such as the male and female condom (Fact Sheet 12).**
- **Support for her infant feeding choice and further education as appropriate.**
- **Information about the possibility of infection in the child and details of how and where the child can be checked and treated (Fact Sheet 5).**
- **Discussion about disclosure of her HIV status to her partner, family, and trusted friends.**
- **Exploration of feelings, particularly guilt, grief, fear, and denial. It is also important to address the possibility of her having infected her infant (Fact Sheet 7).**
- **Encouragement to access peer support.**
- **Discussion on how to cope with possible stigmatization, particularly if not breast**

**Don't forget that the women's family - close and extended -- and her community must be educated so that they support the women in their choices.**



## Questions for reflection and discussion

Why do you think women are particularly vulnerable to HIV?

How can nurses/midwives help reduce vulnerability in women?

Have you experienced feeling vulnerable in your work or personal life? If so, what effect did this experience have on your ability to control the outcome of events?

What are the important considerations in caring for HIV-positive women in the antenatal period; during labour and delivery and during the post partum period?

What elements would you consider as you counsel an HIV-positive woman about whether to breast feed or not?

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## Fact Sheet 11 HIV and the workplace and Universal Precautions

- **Introduction**
- **Risk of HIV transmission in the health care setting**
  - To patients
  - To health care workers
- **Creating a safe work environment**
- **Universal Precautions**
  - Safe handling and disposal of sharps
  - Sharps accidents
  - Post exposure care and follow-up
  - Evaluating sharps practices
- **Safe decontamination of equipment**
  - Sterilization and disinfection
  - Cleaning
  - Safe disposal of waste contaminated with body fluid
- **Planning and management**
  - Planning and management
  - Gaining and maintaining adequate supplies and resources
  - Developing creative strategies
  - Setting and maintaining standards, and political action
  - Care for the caregiver
  - Initiating a package of services

## • Questions for reflection and discussion

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### • Introduction:

HIV and other blood borne illnesses such as Hepatitis B may be transmitted in the health care setting from patient to health care worker, patient to patient, or from health care worker to the patient. HIV has been isolated from: blood, semen, vaginal and cervical secretions, urine and faeces, wound secretions, saliva, tears, breastmilk and cerebrospinal, amniotic, synovial, and pericardial fluids. HIV is likely to be present in other body fluids, particularly where visible blood is present. However, blood is the only fluid known at this time to be associated with HIV transmission in the health care setting (see Fact Cheetah). The risk of transmitting HIV and other blood borne diseases is dependent upon health care personnel practices, the prevalence of the illness, and the amount and frequency of exposure. The occupational risk of becoming HIV infected from patients in health care settings is low (approximately 0.3%) and in most cases is associated with needle-stick injuries from a patient with HIV. Patient-to patient transmission results primarily from contaminated equipment that has been incorrectly (or inadequately) disinfected, or from blood transfusions.



*Many forms of contact with HIV/AIDS patients do not require the use of Universal Precautions. (Credit: WHO/Waak)*

**Most patient care does not involve any risk of HIV transmission. Therefore, routine HIV testing of all health care workers or patients is NOT recommended.** Most HIV-infected health care workers are infected through sexual contact, and, to a lesser degree, through intravenous drug use, blood transfusions and invasive surgical procedures, including organ transplantation. Occupational exposure is rare. To minimize the risk of occupational transmission of HIV (as well as other infectious diseases), all health care workers should adopt appropriate infection, risk assessment and accident prevention procedures.

### These include:

Understand and use Universal Precautions with all patients, at all times, in all settings, regardless of the diagnosis;

Reduce unnecessary blood transfusions, injections, suturing, invasive procedures such as episiotomies and other questionable surgical procedures;

Make adequate supplies available to comply with simple standards of infection control, even in resource poor settings;

Adopt locally appropriate policies and guidelines for the proper use of supplies, and for the education and supervision of staff;

Assess and reduce risks during regular supervision in health care settings.

### • Risk of HIV transmission in the health care setting

HIV can be transmitted in the following ways:

## **To patients**

through contaminated instruments that are re-used without adequate disinfection and sterilization; transfusion of HIV-infected blood, skin grafts, organ transplants; HIV-infected donated semen; and contact with blood or other body fluids from an HIV-infected health care worker.

## **To health care workers**

skin piercing with a needle or any other sharp instrument which has been contaminated with blood or other body fluids from an HIV infected person; exposure of broken skin, open cuts or wounds to blood or other body fluids from an HIV infected person; and splashes from infected blood or body fluids onto the mucous membranes (mouth or eyes).

## **• Creating a safe work environment**

The context and environment in which health care is provided influence not only the quality of care delivered, but also the safety and well being of care providers. Measures that promote a safe and supportive work environment include:

education of employees about occupational risks (Fact Sheet 9), methods of prevention of HIV and other infectious diseases (Fact Sheet 12), and procedures for reporting exposure;

provision of protective equipment such as gloves, goggles, plastic aprons, gowns, and other protective devices;

provision of appropriate disinfectants to clean up spills of blood and other body fluids;

increasing the accessibility of puncture resistant "sharps" containers;

maintaining appropriate staffing levels;

ensuring that Universal Precautions are implemented, monitored and evaluated;

providing post-exposure counselling (Fact Sheet 7), treatment, follow-up and care;

implementing measures that reduce and prevent stress, isolation and burnout;

controlling shift lengths and providing supervision of inexperienced staff;

addressing the healthcare, compensation and financial needs of HIV positive health care workers;

providing flexible work allocation for HIV positive personnel and continuing their employment for as long as possible. Their participation will be dependent upon their condition, job demands, and the need to protect them from other infections such as tuberculosis ;

providing dispute settlement mechanisms for HIV infected personnel.

In many resource poor situations, it might not be possible to meet all of the above requirements. However, working toward these goals should be the responsibility of nurses and midwives, other health care workers and their employers. Preventive measures are difficult to practice when supplies and protective equipment are not always available. Priorities must be set and low-cost alternatives sought. Yet, even when supplies are available, the use of Universal Precautions may be influenced by management policy, personal practices, attitude and complacency of staff.

Prevention of occupational exposure to HIV also includes risk assessment and risk reduction activities such as:

using Universal Precautions;

wearing heavy-duty gloves when disposing of "sharps";

assessing protective and other equipment for risk and safety;

adopting safe techniques and procedures, such as disposing of needles without recapping, or recapping using the single-handed method, using sterile nasal catheters and other resuscitation equipment, using a separate delivery pack for each delivery, and not using episiotomy scissors to cut the umbilical cord.

making appropriate disinfectants and cleaning materials available;

sterilizing equipment properly;

eliminating unnecessary injections, episiotomies, and laboratory tests; avoiding, or covering, breaks in the skin, especially the hands.

## • Universal Precautions

Universal Precautions are simple standards of infection control practices to be used in the care of all patients, at all times, to reduce the risk of transmission of blood borne infections. They include:

careful handling and disposal of "sharps";

hand washing with soap and water before and after all procedures; use of protective barriers such as gloves, gowns, aprons, masks, goggles for direct contact with blood and other body fluids;

safe disposal of waste contaminated with blood or body fluids;

proper disinfection of instruments and other contaminated equipment;

proper handling of soiled linen.

## Safe handling and disposal of "sharps"

The greatest hazard of HIV transmission in health care settings is through skin puncture with contaminated needles or "sharps". Most "sharps" injuries involving HIV transmission are through deep injuries with hollow-bore needles. Such injuries frequently occur when needles are recapped, cleaned, disposed of, or inappropriately discarded.

Although recapping needles is to be avoided whenever possible, sometimes recapping is necessary. When this is the case, a single-handed scooping method should be used. To do this, place the needle cap on a hard, flat surface and remove your hand. With one hand, hold the syringe and use the needle to scoop up the cap. When the cap completely covers the needle, use the other hand to place the cap firmly on the hub of the needle.

Puncture-resistant disposal containers must be available and readily accessible for the disposal of "sharps".

Many easily available objects, such as a tin with a lid, a thick plastic bottle, or a heavy plastic or cardboard box, can work as suitable "sharps" containers. These can be burned in a closed incinerator, or can be used to transport the "sharps" to an incinerator. It is important to empty containers when they are 3/4 full, to wear heavy-duty gloves when transporting "sharps" containers, to incinerate used equipment at a hot enough temperature to melt the needles. Where the sharp container is not burned, bury it in a deep pit. Added precautions to prevent "sharp" injuries include wearing gloves, having an adequate light source when treating patients, locating sharps containers directly at the point of use, never discarding "sharps" in general waste, and keeping "sharps" out of the reach of children. Whenever possible, needle holders should be used when suturing.

## "Sharps" accidents

Each health care facility should develop standards, policies and procedures to be followed in case of "sharps" injury or other exposure. Many health care workers neglect to report such injuries. This can lead to inaccurate data on health care worker exposure and more importantly, to a lack of follow-up counselling, testing, treatment and care (Fact Sheet 7). Following a "sharps" injury, immediate first aid should be given, such as flushing the site with running water, hand washing with soap and water, and, where there is bleeding, allowing the site to bleed briefly. Any exposed mucous membranes should be flushed with large amounts of water. Antiseptic solutions can have a caustic effect and have not been proven to be effective. However, in the absence of water, antiseptic solutions should be used. Following exposure, the type of exposure and the actions taken should be recorded and the appropriate authorities notified. Accident forms should be completed including information about the type of injury, any witnesses and the name of the patient if known. The accident victim should then report to the accident or emergency department for further care and advice. Voluntary confidential counselling should be available immediately, and HIV testing and follow up counselling made available (Fact Sheet 7). Post exposure prophylaxis (PEP) with antiretroviral treatments (ARV) can reduce the risk of becoming infected. PEP should be guided by local policies and is dependent upon the availability of drugs. If available, a combination of ARV should be taken as soon as possible after the accident (within 24 hours) and for four weeks following exposure. Many health care workers find reporting and undergoing voluntary testing and counselling stressful, and some chose to remain silent. This silence is often due to the fear, stigma and discrimination associated with HIV (Fact Sheet 6).

## Evaluating "sharps" practices

If the same accident occurs more than twice, "sharps" practices must be evaluated. Methods for avoiding "sharps" use should be considered, for example, drugs might be given by methods other than injection; stapling rather than suturing; using adhesive tape or skin closure strips; and avoiding unnecessary incisions such as episiotomies.

## • Safe decontamination of equipment

Efficient cleaning with soap and hot water removes a high proportion of any microorganisms. All equipment should be dismantled before cleaning. Heavy gloves should be worn for cleaning equipment and if splashing with body fluid is likely, then additional protective clothing such as aprons, gowns, and goggles should be worn. The following table helps in selecting the method for decontamination:

Level of Risk	Items	Decontamination Method
High risk	Instruments which penetrate the skin/body	Sterilization, or single use of disposables
Moderate risk	Instruments which come in contact with non-intact skin or mucous membrane	Sterilization, boiling, or chemical disinfection



Low risk	Equipment which comes in contact with intact skin	Thorough washing with soap and hot water
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## Sterilization and disinfection

### All forms of sterilization will destroy HIV.

Recommended methods of sterilization include steam under pressure (e.g., autoclave or pressure cooker), or dry heat such as an oven. Disinfection will usually inactivate HIV. Two commonly used disinfection methods are boiling and chemical disinfection. If boiling, equipment should be cleaned and boiled for 20 minutes at sea level, and longer at higher altitudes. Chemical disinfection is not as reliable as sterilizing or boiling. However, chemical disinfection can be used on heat sensitive equipment, or when other methods of decontamination are not available. Equipment should be dismantled, thoroughly cleaned and rinsed after disinfection. Chemicals that have been found to inactivate HIV include chlorine-based agents (for example, bleach), 2% glutaraldehyde, and 70% ethyl and isopropyl alcohol.

### Cleaning

Detergents and hot water are adequate for the routine cleaning of floors, beds, toilets, walls, and rubber draw sheets. Following a spillage of body fluids, heavy-duty rubber gloves should be worn and as much body fluid removed with an absorbent material. This can then be discarded in a leak proof container and later incinerated or buried in a deep pit. The area of spillage should be cleaned with a chlorine-based disinfectant and the area thoroughly washed with hot soap and water.

All soiled linen should be handled as little as possible, bagged at the point of collection and not sorted or rinsed in patient care areas. If possible, linen with large amounts of body fluid should be transported in leakproof bags. If leakproof bags are not available, the linen should be folded with the soiled parts inside and handled carefully, with gloves.

### Safe disposal of waste contaminated with body fluids

Solid waste that is contaminated with blood, body fluids, laboratory specimens or body tissue all should be placed in leak proof containers and incinerated, or buried in a 7 foot deep pit, at least 30 feet away from a water source. Liquid waste such as blood or body fluid should be poured down a drain connected to an adequately treated sewer or pit latrine.

## • Planning and management

Proper planning and management of supplies and other resources are essential in reducing the occupational risk of HIV infection. Such measures should include risk assessment, setting of standards and protocols that address safety, risk reduction, post-exposure follow-up and first-aid. In addition, occupational risks can be reduced by introducing measures to prevent or reduce stress, maintain an optimum workload, orientate new staff and provide education and supervision. Staff burnout, characterized by feelings of depletion, loss of vitality, energy, and motivation is a major occupational hazard and can lead to increased risk for occupational exposure to HIV. In addition, fear of occupational exposure to HIV in health care settings may discourage potential recruits from pursuing nursing and midwifery as a career, thus reducing the future supply of trained professionals. Strategies that address these concerns include:

### Gaining and maintaining adequate supplies and resources

Nurses/midwives need to explore different approaches to meet their resource needs, such as:



Finding out what can be obtained from government and non governmental sources, through regular distribution systems;

Finding out what is locally available and can be bought. To what extent can patients and their relatives contribute?

Reviewing the quality of available supplies;

Developing or improving systems for ordering, transporting, and storing, and ensuring there is not an oversupply that will be wasted;

Developing a schedule for obtaining and maintaining supplies which includes taking into consideration travel, delivery time, and weather;

Establishing sustainable acquisition and payment procedures.

## **Developing creative strategies**

In resource poor settings, some supplies may not be available. In such cases, nurses/midwives must creatively about how to manage care. Can plastic bags or condoms be used instead of gloves; can cooking utensils be used for boiling equipment; are there herbal and traditional alternatives to detergents and soaps? Can leaves, thimbles, or plastic wrap be used instead of bandaids to protect cuts? Are the resources that are available being used appropriately? For example, if gloves are in short supply, prioritize -- they are less necessary for giving routine injections and making beds than for deliveries and suturing.

One way to assign priorities is to classify the commonly performed procedures into low, medium and high risk, and allocate resources accordingly. Consideration should be given to cost effectiveness as opposed to cost containment noting that the cheapest equipment is not always the safest or most cost effective in the long run. In home care settings, nurses/midwives will need to be even more creative in finding solutions to infection control. Wherever possible, a home care kit should be available to all health care personnel working in the community and in homes. This kit should include disinfectants, soap, utensils for boiling, gloves, protective garments, and containers for safe disposal of equipment and waste.

## **Setting and maintaining standards, and political action**

Nurses and midwives should be active in developing and maintaining quality assurance programs, and in developing and participating in infection control committees. Nurses and midwives must also develop, maintain, and evaluate standards, procedures and protocols for safe, adequate and effective control of infections. In addition, nurse managers should exert political pressure upon employers and upon national and international agencies to provide funds for essential supplies and equipment for providing safe quality care.

## **Care for the care giver**

Understandably, many nurses and midwives fear becoming infected with HIV. Stigma, prejudice and discrimination surrounding HIV and its life threatening effect may compromise their ability to provide quality care, and even their commitment to remain in the profession (Fact Sheet 6). There should be adequate insurance and compensation for HIV-infected health workers. However, such compensation will depend upon the country's ability to pay, the place of employment and the employer. Particular attention should be given to:

## **Continued employment**

Being HIV-infected is not a cause for termination of employment, regardless of whether HIV was acquired on the job or not. As with any other illness, HIV-infected nurses/midwives should be allowed to work as long as they are fit, provided they practice universal precautions. HIV infected health care workers can make considerable contributions to care by helping to educate others, reducing the stigma and discrimination associated with HIV, and providing sensitivity training, support and counselling. Employers should provide work assignments that both support the HIV infected worker's ability to perform tasks and enable them to

avoid infections (particularly TB).

## **Workplace issues**

Health care workers, like the general population, may feel fear, stigma and discrimination towards HIV-infected individual (see Fact Sheet 6). In fact, HIV- infected health care workers are often subjected to severe sanctions from their colleagues. As a result, many careworkers are reluctant to be tested and to enter into counselling, treatment and care. This is problematic, because if nurses/midwives do not know their HIV status, they can put themselves and others in the health care setting at risk. Therefore, employers should develop policies that:

- protect the privacy of the HIV-infected employee;
- prevent social isolation of the HIV-infected employee by co-workers;
- keep HIV-positive personnel in a supportive occupational setting as long as possible;
- educate all employees, management and union leaders about the rights and care of HIV-infected health care workers.

## **Initiating a package of services**

Depending on the stage of the disease and the resources that are available, HIV positive nursing/midwifery personnel require a package of services that might include:

- convincing employers, managers and insurance agencies not to discriminate against HIV positive personnel;
- providing support, legal assistance and referral;
- fostering networking with other HIV positive employees;
- counselling on career change and job retraining opportunities;
- advising about continued practice and the disclosure of their HIV status;
- developing and disseminating position statements on issues such as mandatory testing (not supported), ethical obligations for HIV positive personnel, and ethical treatment by health care workers for people living with HIV;
- providing up-to-date and accurate information about compensation benefits, occupational risks, and follow-up care;
- clarifying professional ethical norms and obligations in regard to health care and HIV.

## Questions for reflection and discussion

What resources would you consider essential to provide safe care to patients and staff?

How might you go about making sure these resources are available?

Reportings of needle stick injuries and other accidents that might lead to HIV infection are very low. What might you consider to help improve this situation? Why is this important?

What creative ideas do you have to improve Universal Precautions in resource poor areas?

What actions might you consider to make your work environment a safer place?

What do you think the essential elements are in providing adequate care for the caregiver?

What role might you play in ensuring adequate care for the caregiver?

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## Fact Sheet 12 Strategies for prevention of HIV

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  - Man to Man
  - Woman to Woman
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- **Other mood altering drugs**

- **Populations at risk**
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  - **Questions for reflection and discussion**
- 

- **Introduction:**

There are four major sources of HIV infection:

**sexual transmission,**

**transfusions of blood or blood products, or transplanted tissue or organs obtained from HIV-infected donors,**

**using skin piercing instruments or injecting equipment that is contaminated with HIV (Fact Sheet 1), and**

**transmission from mother to child during pregnancy, labour, or following birth through breast feeding (Fact Sheet 10).**

This Fact Sheet will attend to prevention through sexual transmission, blood transfusions and injecting drug use.

There is ample evidence globally that well-designed prevention programmes can reduce the incidence of HIV. In societies where services and programmes were in place before the epidemic, the creation of new initiatives and the re-orientation of existing initiatives led to a gradual decline in the incidence of HIV by the mid-1990's. A similar trend is observed even in resource-poor settings, in part a result of rigorous prevention efforts.

However, prevention is a very complex challenge. Some prevention strategies need to be addressed at the greater society (or macro) level, such as strengthening or changing government policies, modifying laws, and enforcing new laws or human rights policies. Other prevention strategies must address the behavioural, social and cultural context (the micro level) of the individual. At both the macro and micro level, policies, programmes and practices should address both harm reduction and prevention of HIV.

At the macro level, governments and governing bodies have to be aware of the magnitude of the HIV epidemic in their country, and be mobilized to face this challenge. Nurses and midwives can play an important role in promoting such awareness. However, it is at the micro level, where behavioural, social and cultural influences have the most affect on communities, families, and individuals, that nurses and midwives can make the greatest contribution to HIV prevention. Although HIV prevention and harm reduction have been separated into challenges at the macro and micro level, in practice, they are interdependent and closely related.

- **Sexual transmission**

The most common form of HIV transmission (as well as other STD transmission) is through sexual

intercourse or through sexual contact with infected blood, semen, or cervical and vaginal fluids transmitted from any infected person to his/her sexual partner, whether it be man to woman, man to man, or woman to woman, although the latter is less likely. HIV transmission through sexual contact can occur vaginally, orally, anally or rectally.

Man to woman transmission, usually from a single partner, is now the most common form of HIV sexual transmission. Women (and to a lesser extent men) who remain faithful in their partnership, contract HIV when their partner has sexual contact with an HIV-infected person outside (or before) their relationship. Although this is the most common form of transmission, women still suffer more stigma, discrimination, and isolation (Fact Sheet 6) than their male partners. As a result there is often denial or a "conspiracy of silence." Acts of violence may also be directed toward the woman (Fact Sheet 10). In addition, other sexually transmitted diseases, which often go undiagnosed in women, contribute to a higher rate of HIV transmission.

### **Man to man transmission (Men who have sex with men: MSM)**

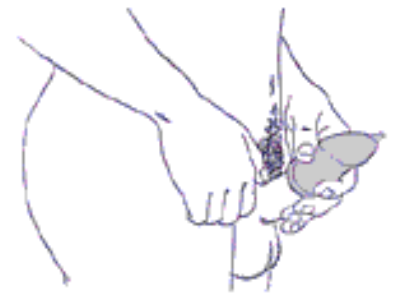
Unprotected penetrative anal sex carries a high risk of HIV transmission, especially in the receptive partner. This risk is several times higher than vaginal intercourse because the lining of the rectum is thin and can easily tear, and even small lesions can allow the virus easy access. Worldwide, a large percentage of MSM are married, or have sex with women as well. These men often do not identify themselves as homosexual or "gay." In addition, MSM is often stigmatized or criminalized, and therefore there is difficulty in reaching these men. The results are inadequate or inappropriate health care, and health promotion/preventive programmes.

### **Woman to woman transmission**

Transmission of HIV from woman to woman is less common than MSM or heterosexual contact. However, the risk still remains. HIV transmission can occur through rough sex play where the mucous membrane of the external genitalia, vagina or cervix is torn. Also, if the woman has an STD, the likelihood of HIV transmission is increased.

## **• Prevention of sexually transmitted HIV**

The safest form of prevention of sexually transmitted HIV is abstinence. However, in most instances, such practices are neither realistic nor desirable. Barrier methods that prevent semen and other bodily fluids from passing from one partner to another are the next most effective preventive methods. These barrier methods also reduce the risk of STDs, however, they also act as a contraceptive. Such barrier methods include the male and female condom.



*Male condom (Credit: JHU/CCP)*

### **Male condom**

The male condom is placed over the erect penis before penetration occurs. The condom then remains on the penis until after ejaculation when it should be immediately removed, knotted and discarded in a safe place such as a toilet, latrine, or in a safe disposal unit. It is vitally important that people are given accurate information and an opportunity to practice using condoms. Information should include:

how to place the condom on the erect penis, leaving space at the top to receive the ejaculate,

how to unroll the condom down to the base of the penis,

how to ensure that the condom remains in place throughout intercourse, and

how to remove the condom before the penis loses its erection.



It is important to emphasize that individuals may practice using condoms on a model or other object, such as a banana or cucumber. A new condom must be used for each sexual act. Condoms should be easily accessible for both men and women, and are best distributed in places where a sense of privacy is increased and embarrassment is reduced. Wherever possible, free condoms should be available.

## **Female condom**

The female condom is a soft yet strong polyurethane sheath, about the same length as the male condom, only wider. A plastic ring at the closed end helps keep the condom fixed within the vagina during sex. A larger ring at the opening stays outside the vagina, spreading over the woman's external genitalia.

The female condom provides extra protection to men and women because it covers both the entrance to the vagina and the base of the penis, both of which are areas where STD sores make it easy for HIV to enter. Female condoms should only be used once and do not require a prescription. However, they are more expensive than male condoms and not as easily acceptable or accessible. Because the external ring is visible outside the vagina, using a female condom might require the agreement of both partners. However, because it can be inserted hours before intercourse, it can provide protection in situations where consumption of alcohol or drugs may reduce the chances that a male condom will be used. Less is known by the public about the female condom than about the male condom, and use of the female condom is less widespread. Therefore, there needs to be education for both health care workers and women in general.

The condom is inserted with the finger, making sure no damage is done to the polyurethane by finger nails or other sharp objects. The condom should then fit snugly against the cervix. During intercourse, it is necessary to guide the penis in or check that the penis has entered the condom and not entered the vagina outside the condom wall. The condom should be removed as soon possible after male ejaculation, and disposed of in the same ways as the male condom.

## **Other barrier methods**

Other barrier methods exist to help reduce the sexual transmission of HIV, but these are less reliable, and often not as readily available. The female diaphragm prevents semen from entering the cervix. However, it does not protect the vagina or the external genitalia from exposure to HIV. Special mouth condoms are available for oral sex. However, these are not readily available and are rarely used. Scientists are working on a vaginal cream that would kill the HIV virus, but it is not yet available.

## **• Blood transfusions**

There is a 90-95% chance that someone receiving blood from an HIV infected donor will become infected with HIV themselves. Millions of lives are saved each year through blood transfusions, even in countries where a safe blood supply is not guaranteed. However, recipients of blood have an increased risk of HIV-infection. This risk can be virtually prevented by a safe blood supply, and by using blood transfusions appropriately. Difficulties hindering a safe blood supply include:

lack of national blood policy and plan

lack of an organized blood transfusion service

lack of safe donors or the presence of unsafe donors

lack of blood screening, and

unnecessary or inappropriate use of blood.

## • Minimizing the risk of HIV infected blood transfusions

In many countries, regulations on blood donations, screening and transfusions exist, but are not adhered to. It is vitally important that regulations be established and rigorously enforced.

### Three essential elements must be in place to ensure a safe blood supply:

1. There must be a national blood transfusion service run on non-profit lines which is answerable to the Ministry of Health.
2. Wherever possible, there should be a policy of excluding all paid or professional donors, but at the same time, encouraging voluntary (non-paid) donors to come back regularly. People are suitable donors only if they are considered to have a low risk of infection.
3. All donated blood must be screened for HIV, as well as for hepatitis B and syphilis (and hepatitis C where possible). In addition, both donors and patients must be aware that blood should be used only for necessary transfusions.

## Screening

The majority of tests done for detection of HIV detect the presence of antibodies to HIV, not the virus (Fact Sheet 1). However, there is a window period (with the most sensitive tests about 3 weeks, and longer with less sensitive tests) when the test may provide a false negative result and the blood be infected with HIV. Tests also exist (called HIV antigen tests), that detect the virus in the blood, but these are more expensive and of limited value. In many countries, correct screening of blood is still applied to some but not all blood donations. For example, in many developing countries, blood is screened in the capital city, and perhaps in one or two other larger towns, but not screened in rural districts. Lack of screening is most often due to lack of funding, and it is expensive to set up a national system to test all donated blood. Good organization, planning, and management are necessary, as well as trained staff at all levels and the availability of test kits.

## Selecting blood donors

Paid donors very often come from the poorest sectors of society. They may be in poor health, undernourished and at risk of having infections that can be passed on through transfusions. In some places, paid donors sell blood in order to buy drugs to inject themselves, often using shared, unsterile equipment. In addition, paid donors are more likely to give blood too frequently, making their blood substandard, and increasing the possibility of damage to their own health. The practice of paying donors usually goes hand-in-hand with the practice of selling blood to people who need it. Under such a system, poor families may not be able to afford vitally needed blood.

Replacement donors have also been found to be problematic. In the replacement donor system, families of people needing a transfusion are asked to donate the same quantity as that given to their relation. This blood may be used directly for the relative, or placed in the general pool. This practice is strongly discouraged because the "relation" is often a paid donor, and even if the person is a relative, there are doubts about the safety of the blood, as normal criteria for selecting donors cannot be applied.

Therefore, the safest type of blood donor is the voluntary, unpaid donor. Such donors give their blood for humanitarian reasons and are more likely to meet national criteria for low-risk donors. Every effort should be made to educate, motivate, recruit and retain low-risk, unpaid donors.

## Avoiding unnecessary or inappropriate transfusions

Unnecessary transfusions increase the risk of transmitting HIV, especially in places where there is no adequate screening programme. Additionally, unnecessary or inappropriate transfusions can create a

shortage of the blood supply, which in turn encourages professional donors to become more active, thus reducing the safety of the supply.

Doctors and other health care workers should be educated to avoid prescribing inappropriate transfusions. Blood substitutes should be given where appropriate. In addition the underlying cause for the blood transfusion should be considered. For example, blood transfusions are often given for anaemia. Instead, the underlying cause of the anaemia should be investigated. Anaemia may be due to malnutrition, slow blood loss, and to infections such as malaria. Blood is often needed during complications accompanying childbirth. However, providing proper care for women before, during and after delivery, can decrease the need for blood transfusions.

### **Creating a national blood transfusion service**

A national blood transfusion service means making all transfusion centres and blood banks part of a national network accountable to a government appointed nonprofit organization. This service must be developed within the framework of the country's health service, and must have an adequate budget and trained staff. There must be a national system of regulations, and regular, independent monitoring of the blood transfusion service. There is no guarantee that blood can be 100% free of HIV, however, with political commitment, good organization, sufficient funding and donation of blood from low-risk, voluntary, non-paid donors, the risks can be reduced to a minimum.

### **Body organs and tissue transplantation**

HIV transmission can also occur through transplantation of body tissue or organs from an HIV-infected donor. This body tissue should follow the same screening programme as blood.

## **• Injecting drug users and other skin piercing practices**

This Fact Sheet focuses on HIV prevention in injecting drug users (IDUs). Prevention of HIV infection through other skin piercing such as accidents at work, surgical interventions, tattooing, female and male circumcision, and scarification have been described earlier (see Fact Sheet 11 Universal Precautions).

### **Injecting drug users**

HIV can spread very rapidly among IDUs, and from them to their sex partners and children. However, this spread can be prevented or slowed significantly if interventions are designed which take into account specific local characteristics of the IDUs. IDUs are usually a hidden and stigmatized group, because their drug-usage behaviour is illegal. Often caught in a cycle of poverty and faced with the cost of the drugs, IDUs often engage in criminal activities such as theft, and in high risk behaviours for HIV infection such as commercial sex work and paid blood donation. To date, the only effective responses to HIV transmission among IDUs to date are those based on the philosophy of harm reduction. Harm reduction is compatible with proven public health principles, and need not conflict with demand and supply reduction (law enforcement) programs. Harm reduction programs approach drug abuse primarily as a public health rather than a law and order issue. Such programs take into account:

### **Promoting use of sterile equipment**

The most common pathway for HIV transmission among IDUs is the sharing of non-sterile injecting equipment. Scarcity, or lack of access to safe injecting equipment, and legal sanctions against possessing injecting equipment, are the two main reasons for reusing or sharing needles and syringes. Other reasons include ignorance of the risks of HIV infection and prevention methods.

The two strategies that have proven effective are:

the sale of needles and syringes at minimum prices through pharmacies or other outlets,

needle and syringe exchange programs.

These exchange programs ensure that dirty syringes and needles are exchanged for sterile ones. In addition, if community acceptance of these programs is to occur, then needles and syringes must be safely and discretely disposed of after use, and must not pose a threat to the non-IDU community. Ball (1998) recommends a **hierarchy of decision making** related to the prevention of HIV through intravenous drug use:

reducing the frequency of sharing, and the number of sharing partners,  
cleaning injecting equipment with bleach,  
not sharing injecting equipment,  
using sterile needles and syringes, and not sharing other equipment,  
changing from the injection of illicit drugs to use of non-injecting drugs,  
reducing the frequency of non-injecting drug use, and  
abstaining from all drug use.

This hierarchy of decision-making can be a useful framework to consider HIV prevention programmes. However, it should be noted that people do not fall neatly into any one of these categories. For example, a person may regularly engage in a needle and syringe exchange program, but, because of unforeseen circumstances, finds him/herself sharing used injecting equipment. This hierarchy also assumes that there is collaboration between the principles of public health (i.e.. Safe injection practices) and law enforcement. This is often not the case. In order for DU HIV prevention programs to be effective, national and local policies must achieve a balance between their attempts to reduce the supply and use of illicit drugs and their efforts to decrease unsafe injection practices.

The principles of harm reduction that have been proven effective in reducing HIV transmission in IDUs include:

education, especially peer education (Fact Sheet 9) and counseling (Fact Sheet 7);  
promotion of the use of sterile injecting equipment for every injection; increasing the availability of equipment; removing barriers that prevent access to the use of sterile equipment (especially policing and legal barriers);  
increasing drug treatment availability, accessibility and options;  
increasing access to primary health care, particularly through services designed to be "friendly" to, and appropriate for, the DU community;  
research and education performed in collaboration with the affected community.

## • Other mood altering drugs

It is important to note that although DU carries the greatest risk of HIV transmission, taking other mood

altering drugs can also promote at risk behaviours. Alcohol, and other legal and illegal drugs taken orally or as an inhalant can affect a person's decision making abilities. In such circumstances, the use of condoms is less likely, and other behaviours and sexual practices that increase the risk of transmission of HIV/AIDS might occur.

## • Populations at risk

The vast majority of people who become infected with HIV are from vulnerable segments of the population. Children and youth (including street youth), women (Fact Sheet 10), prisoners, refugees, migrant workers, ethnic minorities, the military and people who live in poverty are some of the most vulnerable populations.

### Youth

Over 50% of new infections with HIV are now occurring in young people ages 10-24. That is, 7,000 young people are infected with HIV every day with young women being infected and affected more frequently than young men (Fact Sheet 10).

The reasons for these alarming figures are very complex. The life situations of many young people may contribute to infection. They may be gay or bisexual youth, use alcohol or drugs, have been sexually abused, or live on the margins of society. Many live on the streets, where violence, abuse, and drug use (particularly intravenous drug use) are common. In addition, young people often feel invincible, and do not consider themselves to be at risk for HIV or any other life threatening situations.

### Women

Women are particularly vulnerable to HIV because of their status in many societies. Poverty, lack of education, poor access to health care and jobs, and social and cultural practices all contribute to women's lack of power and control over decision making (see Fact Sheet 10).

### Infants

Mother to child transmission accounts for most HIV infections in infants (Fact Sheet 10).

### Prisoners

Prisoners are often injecting drug users before they enter prison. They continue (or begin) this practice while in prison, often with shared, unsterilized needles and syringes. In addition, they may have unprotected penetrative sex with other men, and may be tattooed with shared, unsterilized equipment.

### Refugees and migrant workers

Poverty, drought, flood, earthquakes, and war or civil strife cause many people to leave their homes and communities. These people end up in special camps where there is increased danger of HIV transmission. Blood transfusions are often required in large numbers, especially during times of war. Social systems and ties disintegrate and unprotected sexual contact and prostitution is common. Refugees, particularly women and children, are highly vulnerable to sexual violence, rape and drug trafficking. Where drug injecting occurred before the emergency, it is likely to continue in the camps where the sharing of injecting equipment increases the risk of HIV infection.

### Military personnel

People in the military (mostly men) are separated from their homes, communities and social support networks and are often placed in positions where they can exert considerable control over others. This situation often leads to violence and abuse (physical and sexual) of the people they are charged with protecting. In such circumstances, HIV transmission is common.

### Ethnic minorities

Like women, youth and children, people who are part of a visible minority are particularly at risk of HIV infection. These people often have limited social support, live on the margins of society, are poor, less educated, with little or no political representation. Such people have limited power or control, and are



vulnerable to abuse, violence, and sexual exploitation. In addition, injecting drug use is common, often involving the use of unsterile, shared equipment.

## **Poverty**

Poverty is the single common factor related to the transmission of HIV. People who are economically deprived usually have little access to education, social and health care services, and other forms of social and financial support. As a result, these people are often forced into becoming sex workers or in exchanging sex for food and supplies. Drug trafficking and injecting drugs with shared, unsterile equipment is also common. Also, poverty often leads people to sell their blood for transfusion, blood which can be infected with HIV.

## **• Principles and strategies for prevention**

Prevention programs have to take into account strategies that must be addressed at the macro (national/regional) level, and those requiring change at the micro (community) level. At the macro level, public health policies and law enforcement must focus on harm reduction. National and local policies must be developed and enforced that promote the reduction in HIV transmission. Where there is potential for law enforcement and public health policy to conflict (for example, prevention programs for IDUs), then partnerships must be forged to overcome these difficulties. At the micro level, the behavioural, social and cultural context within which people live must be taken into account. Strategies to promote the prevention of HIV transmission include:

### **Peer support and education**

It has been widely documented that behavioural change is most likely to occur if peers educate and support each other (see Fact Sheet 9). Youth programs that are run by youth, women's collectives, groups involving street children, refugees, and IDUs, are all effective in promoting practices and behaviours that lead to reduction in HIV transmission. Frank discussions about sexual practices, drug taking, and other at risk behaviours are more likely to be explored and understood within these safe environments. It is important to note that these groups should be run by and for their particular populations. There are many powerful examples throughout the world of peer involvement in prevention strategies. Nurses and midwives can play an important role in facilitating the formation of these groups and providing expert knowledge where necessary. See fact sheet 9 for effective educational strategies.

### **Involving PLHA**

People living with HIV/AIDS (PLHA) are often the best advocates and activists for social and behavioural change. The personal story of someone living with HIV presents a powerful message. These messages can mobilize people and resources, and thus initiate successful prevention programmes. In addition, involving PLHAs in various prevention programs helps to ensure that they are relevant and meaningful to the different population groups.

### **Combining resources**

The combination of counselling, education, support, care services, and resources is necessary to provide a holistic continuum of prevention and care (Fact Sheet 3). For example, STD, antenatal, family planning, home care, hospital care, and community care, as well as other resources and services, can be combined to provide a comprehensive programme. In this way, programmes and services can be combined that address the various modes of HIV transmission without the stigma and discrimination often associated with HIV specific programs.

### **Forging partnerships**

Governments, policy makers, law enforcement agencies, health and social service agency personnel, non-governmental organizations (NGOs), religious leaders and religious groups should join together in preventing HIV transmission. Nurses and midwives can play a central role in advocating for, and creating and participating in, such partnerships.

## **Cultural/religious/social sensitivity**

There is no one programme that will be relevant, meaningful, and effective for all people. Prevention programmes must be sensitive to the local customs, cultural practices, religious beliefs and values, as well as to other traditional norms and practices. However, where such beliefs, values and practices conflict with the prevention of HIV (eg. circumcision, scarification, sexual abuse of children), then these must be challenged. Nurses/midwives can play an important role in supporting local practices and traditions while also challenging those practices that cause HIV transmission.

## **Facilitating empowerment**

Involving individuals, groups, and communities in addressing their own health concerns and finding solutions to their problems promotes empowerment. People who are empowered are more likely to implement effective HIV prevention programs.

## **Challenging denial**

HIV is surrounded by a conspiracy of silence and denial. People are afraid to be tested for HIV or admit their HIV status because they fear discrimination, violence, stigma and isolation (Fact Sheet 6). Nurses and midwives can help support and counsel people to be HIV tested (Fact Sheet 7) and to be open about their HIV status. Only when HIV becomes a public concern can prevention strategies that address the complex and diverse issues related to HIV transmission be addressed.

## **Combating stigma, isolation and marginalization**

Nurses and midwives have a responsibility to care for all people, regardless of their health or social status (Fact Sheet 6). They can act as role models to others in helping combat stigma, discrimination and isolation of PLHA. Prevention strategies will be more successful if HIV is treated like any other chronic illness.

## **Ensuring the use of Universal Precautions**

Nurses and midwives should play a central role in monitoring and ensuring that universal precautions are practiced in their workplace (Fact Sheet 11). Maintaining quality assurance programs and ensuring the availability of adequate supplies and human resources help promote a safe work environment. In addition, adequate care for the care provider is an important consideration.

## **Building on success**

Many groups, communities and individuals have been successful in improving their quality of life. The strategies they developed for this improvement can also be applied to prevention programs. For example, if communities have been successful in lobbying for improved housing, these same lobbying tactics can be applied to HIV prevention programs. In addition, people can learn from one another. Stories of successful HIV prevention programs throughout the world should be shared with others so that they too may initiate similar programs.

## **Respect for human rights**

Nurses/midwives should advocate for vulnerable populations to ensure that their human rights are respected and not violated (Fact Sheet 6). Prevention programs will only succeed where human rights are respected and maintained.



## Questions for reflection and discussion

**What are the most common ways that HIV is transmitted?**

**Which populations are most at risk for HIV transmission? Why is this the case?**

**What role could you play in HIV prevention within your local community?**

**What role might you play in promoting larger societal change?**

**What strategies and policies do you consider to be essential before effective HIV prevention programs could be implemented?**

**What role might you play in ensuring these strategies and policies are considered?**

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## Fact Sheet 13 Tuberculosis (TB)

- **Introduction**
- **The threat of tuberculosis to public health**
- **Signs, symptoms and treatment of tuberculosis**
- **The DOTS strategy**
- **The role of primary health workers in preventing, detecting and treating tuberculosis**
- **Questions for reflection and discussion**

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### • **Introduction:**

This Fact Sheet on Tuberculosis (TB) and DOTS treatment is included here because HIV increases a person's susceptibility to infection with *Mycobacterium tuberculosis*. Compared to an individual who is not infected with HIV, an individual infected with HIV has a 10 times increased risk of developing TB. The presence of TB may allow HIV to multiply more quickly. This may result in more rapid progression of HIV and AIDS. Pulmonary TB is the most common in HIV patients, although other forms of TB, such as lymphadenopathy and meningitis, are frequently found.

The information which follows addresses the diagnosis, treatment and prevention of TB. For further information contact StopTB (details at the end of this Fact Sheet).



*Boy in a TB ward. (Credit: Bob Madey, StopTB Initiative) HIV is the most powerful factor known to increase the risk of TB.*

### • **A Major Killer**

Tuberculosis (TB) is a serious public health, social and economic problem, estimated to cause 8 million cases world wide each year. Although the DOTS (Directly Observed Treatment -Short Course) strategy has been proven to cure more than 85%, only a small fraction of cases (16%) have access to these curative regimens. There are more than 1.9 million deaths due to TB each year. TB kills more youth and adults than any other infectious disease. The disease burden is heaviest in developing countries , where 95% of the cases occur. Even in developed countries, TB is re-emerging as a public health concern. The main reasons for the increasing global burden of disease are:

- increasing poverty, social upheaval and crowded living conditions in developing countries

and inner city populations in developed countries;

- inadequate health coverage and poor access to health services;
- inefficient TB control programmes, with low cure rates, because of inadequate and interrupted treatment;
- reluctance to report TB suspects to poorly administered programmes;
- impact of the HIV epidemics, mainly in Africa and Asia;
- lack of political leadership and commitment to implement, sustain and expand DOTS.

TB causes more maternal deaths than any other single cause of maternal mortality, estimated to be in the order of more than one million women per year. It is the commonest cause of death in AIDS patients, because it is reactivated by the failing immune system. It impacts children because they are left without care by their parents' illness and an unknown number of children themselves fall ill and die of TB annually. The tools for controlling TB are in hand, but wider application of the DOTS strategy is desperately needed. This will require a coalition of health workers, policy makers and the public who have a right to freedom from TB.



*India: Community Health promotion to educate about TB (Credit: Bob Madey, StopTB Initiative)*

## • What is TB?

The symptoms of TB are a cough, which is persistent and not responsive to antibiotics, fever and weight loss. TB may occur outside of the lungs in lymph nodes, bones, kidneys, the central nervous system. These sites may cause serious illness, but patients are not likely to transmit the disease unless they also have TB of the lung.



*TB is a major health hazard in prisons (Credit: Bob Madey, StopTB Initiative)*

## • How TB is spread

TB infection is spread by coughing the germ, *Mycobacterium tuberculosis*, into the air where it may be inhaled by persons sharing the same breathing space. Only one in ten infected by the germ actually develops active symptomatic TB. The remainder have a healthy immune system which contains the infection in a dormant state. However, many years or decades later, dormant infections may reactivate and cause disease when the immune system fails.

It is estimated that as much as one third of the world's 6 billion population (1.9 billion) has been infected. Most of the new cases of active tuberculosis develop from this pool of infected persons. The chance that anyone person will become ill with TB after infection is low (one in ten), but in the HIV infected person the chance of developing TB is accelerated by the failing immune system, and may be as high as 50% lifetime risk or 10% per year.

As the HIV infection progresses previously dormant TB reactivates and new infection progresses rapidly. TB accelerates HIV disease and is responsible for 32% of all HIV related deaths. TB treatment is almost as

effective in the HIV infected patient and DOTS is doubly important to assure curative treatment in those with dual infection.

## • How to find and cure TB

The primary health worker is usually the first contact for the sick patient. And it is this worker who must know when to suspect TB and refer for sputum examination. In many countries, nurses represent the main providers of primary health care services, as well as the trainers and supervisors of other health care workers who must be knowledgeable about TB control. Once a laboratory has confirmed the diagnosis, treatment must be provided with the support of the health care worker. Treatment must continue for 6-8 months until the patient is cured, and verified as negative by sputum testing.

Primary health care providers are the ones who find TB suspects, refer them for diagnosis and ensure they complete treatment. These tasks are the backbone of the DOTS strategy. To make sure that DOTS is implemented in every district, national nurses associations and individual nurses must lobby their governments for a long term commitment to TB control.



*Free TB clinic promoting DOTS treatment (Credit: Bob Madey, StopTB Initiative)*

## • What is the DOTS strategy?

DOTS is composed of five elements, all of which are essential to a successful TB control programme outcome. These are:

1. Government commitment to make TB a priority programme and to provide resources for nation-wide coverage.
2. Case detection from among persons with persistent cough mainly through sputum smear microscopy in a country-wide laboratory network.
3. An uninterrupted drug supply provided to health centres for the treatment of all TB patients.
4. Use of standardised short-course chemotherapy and a commitment of the patient and health worker to complete treatment ensuring that each dose of drug is taken.
5. A recording and reporting system for monitoring treatment outcome; cohort analysis to reach targets of 85% cure, and training and supervision to assure that this is accomplished.

## • Treatment of TB

TB treatment not only cures and saves lives, but also prevents the spread of infection and development of

drug-resistant TB, which is far more difficult and costly to treat. Poor treatment can cause drug resistance. In fact, no treatment at all is better than poor treatment. The recommended treatment for TB requires a 6-8 months of combination drug taken daily to achieve cure. The cost of the drugs has been reduced in some countries to as little as US\$13 to cure a patient. Treatment of TB has been declared by the World Bank as one of the most cost-effective health intervention strategies in terms of years of life saved.

Remembering to take the drugs for 6 to 8 months can be a problem. It is recommended that a health care worker or volunteer help the patient complete treatment by whatever possible means including direct observation of treatment.

## • Role of Nurses and other the Health Care worker in DOTS

The World Health Organization (WHO) has worked with country representatives and donors to implement the DOTS strategy within national TB programmes in more than 100 countries. Every element of the strategy depends on a trained and committed health care workers and volunteers without whom the strategy cannot work. Behind the workers is a community that wants to be free from tuberculosis. TB control needs community support and involvement! A successful DOTS strategy requires partnership between the primary health care team, other sectors and the community.

The nurse or other primary health worker may be the first to suspect TB in patients who have been coughing for more than three weeks, or who have not responded to antibiotics, have lost weight or are feeling tired. The village volunteer, who extends the primary health care team into the community, helps TB patients complete their treatment by keeping a regular supply of drugs and assuring they are taken correctly.

Patients suspected of TB must be referred to the district medical officer and laboratory for sputum smear microscopy will identify the bacillus. The doctor will then prescribe the treatment regimen but the health worker will be responsible for teaching the patient about the disease and its treatment. Treatment is the best method of preventing the spread of TB but it is also important to teach the patients to cover their mouths when coughing. The importance of taking drugs every day for 6-8 months under supervision of the treatment supporter must be made clear. Finally sputum checks are done at about two month intervals to monitor the progress towards cure.

Nurses are the best patients' allies in recognising TB symptoms, referring them for diagnosis and assuring treatment. They must:

- ensure that correct treatment is started and the treatment card filled out,
- ensure a regular supply of drugs is sent to the treatment supporter for the duration of the treatment;
- report and refer drug side effects;
- report completion of treatment and outcome.

Nurses also need to work closely with their community, with laboratory staff, doctors and National TB programme managers to:

- provide information and education on the DOTS strategy;
- build community support (through community leaders, schools and the media) for a strong National TB programme;
- register all TB cases;
- train and supervise the primary health workers to find, educate and treat the patients.

Nursing organisations should be vocal advocates for the DOTS strategy for TB control and can help maintain strong National TB control programmes in every country

## • What you can do

- Increase community awareness of the right of all to free access to effective TB care.
- Make friends, neighbours and colleagues aware of DOTS and how your country's National Tuberculosis programme can save lives and prevent the spread of TB.
- Contact your National TB Programme, your Nursing Association and your Minister of Health today to find out how you can participate in the STOP TB initiative.

Stop TB is working to stimulate political movement toward TB control everywhere.

For further information, please contact STOP TB

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**Questions for reflection and discussion**



**How could you enhance your role in preventing, detecting and treating TB in your community?**

**Why would you suspect the presence of TB in the community and in individuals?**

**What are the elements of the DOTS strategy?**

**Would DOTS be a successful strategy in your community? Discuss the reasons for your responses.**

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## EVALUATION FORM: FACT SHEETS ON HIV/AIDS FOR NURSES AND MIDWIVES

Please use and adapt this Evaluation Form if you would like to. We would be interested in knowing how these Fact Sheets are used, and how people hear about them. We would therefore like you, the recipient, to return the evaluation form to Barbara Stilwell.

Contact details are provided at the end of the form. The Evaluation Form cannot be submitted electronically. Instead, please print this page and send it by either fax or mail. Information is given below.

Q1: What country are you working in?

Q2: What is your professional position?

Q3: How did you get a copy of the Fact Sheets (please check one)?

sent to me by WHO Geneva

sent to me by a regional or country office

requested by me

passed to me by someone else

don't know

Please give details when you can. (e.g., the Fact Sheets were requested by my boss from the WHO representative. She saw them on the web. She passed them to me.)

Q4: a) Do you have the CD-ROM too?

Yes

No

b) Do you have access to the Internet?

Yes

No

Q5: How will you be using the Fact Sheets?

reading only for personal information

using in training courses

copying or printing for others to read

Q6: If you have answered b) or c) to Q3, will you be adapting the materials to suit your regional or country situation?

Yes, I will be adapting them.

No. I will use them as they are.

Q7: If you will be adapting them, how will you decide what changes to make (check all that apply)?

I will work alone.

I will convene a small advisory group.

I will work with a local institution.

Contact details are provided at the end of the form. The Evaluation Form cannot be submitted electronically. Instead, please print this page and send it by either fax or mail. Information is given below.

Please give details about the process you will use. (E.g., I will ask the Chairman of the National AIDS Programme, the head of the School of Nursing and two local NGOs to act as an advisory group.)

Thank you for filling in this Evaluation Form. Please send it by fax, post or pouch to:

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