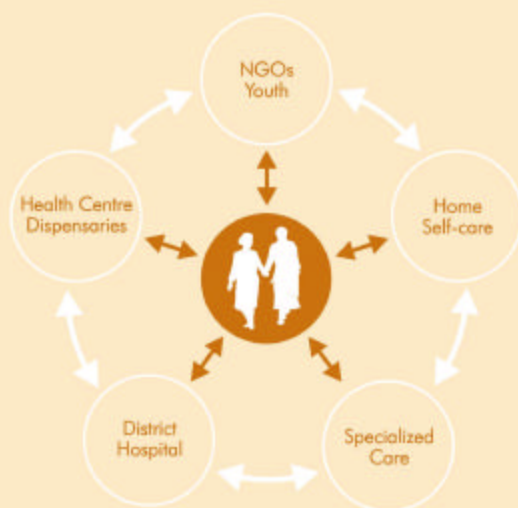


Planning and Implementing HIV/AIDS Care Programmes: *A step-by-step approach*



World Health
Organization
Regional Office for
South-East Asia
New Delhi

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*A step-by-step approach***

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PREFACE

The epidemic of HIV/AIDS continues to spread in the South-East Asia Region. This has brought the issue of HIV/AIDS care into the forefront of national priorities in many countries. Due to the rising incidence of HIV, the need as well as demand for provision of care to the people living with HIV/AIDS and to their families are expected to increase in the future. Therefore, the establishing, strengthening and evaluation of a care programme should be integral activities of all national AIDS programmes.

The guidelines outlined in this document have been prepared to assist national AIDS control programmes, nongovernmental organizations and community-based organizations in setting up an HIV/AIDS care programme. They embody a deliberate step-by-step approach based on country experiences on HIV/AIDS care, both within and outside the South-East Asia Region. We hope the document will be used widely in its present form or as adapted to the specific national and local situations. Suggestions for further improving these user-friendly guidelines are most welcome.

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1. INTRODUCTION

The HIV/AIDS epidemic continues to spread at alarming rates in many parts of South-East Asia. There are presently four million people infected with HIV in India; 900 000 in Thailand; 350 000 in Myanmar, and 25 000 in Indonesia. The HIV infection rate among commercial sex workers in Mumbai, India is presently 52%. In pregnant women, HIV infection rates of 8% in Chiang Mai, (Thailand); 4.2% in Mumbai (India), and 3-7% in parts of Myanmar, have recently been documented. As a result, an ever-increasing number of people are seeking care for their HIV-related illnesses and AIDS, resulting in a severe health and social burden on health systems, communities and families. This scenario is expected to continue well into the next century.

2. RATIONALE FOR HIV/AIDS CARE

The ability of science to develop curative solutions to diseases has been severely challenged by the HIV/AIDS epidemic. But in doing so, HIV/AIDS has also provided an opportunity to health care systems to examine alternative approaches to care delivery and as a result, the principles of primary health care are being revisited. Recently, specific interventions in care and counselling have shown effectiveness and are now being studied for their operational aspects for sustained implementation: voluntary counselling and testing to enable coping and care; Zidovudine to reduce mother-to-child transmission; Isoniazid (INH) for preventive therapy of tuberculosis, and co-trimoxazole for the prevention of pneumocystic carinii pneumonia and bacterial infections.

The approach to developing HIV/AIDS care described in this booklet will help programme managers, nongovernmental organizations (NGOs) and community-based organizations (CBOs) in planning for the development and strengthening of such programmes. The concept of comprehensive care across the continuum - from hospital to the community and home, and the key steps in setting up such programmes are outlined. The responsibilities of each partner, from the health institution to the home, in developing and sustaining this approach have been clearly defined.

3. WHAT IS COMPREHENSIVE HIV/AIDS CARE?

Comprehensive HIV/AIDS care is a holistic approach to meeting the needs of HIV-positive individuals. These needs are identified and met by different disciplines ranging from medical care to social support. Several studies have been conducted in the Region to assess the needs of persons living with HIV and AIDS. One such study from India identified the following list of needs:

- (1) Clinical and nursing care for the ill to alleviate the symptoms of HIV and AIDS;
- (2) Psychosocial support and counselling of individuals tested HIV positive and their families;
- (3) Financial support or opportunities for employment for persons discriminated against and rejected from employment due to HIV status;
- (4) Assistance to find appropriate housing in a neighbourhood that is sympathetic to HIV-positive persons;
- (5) Legal assistance to overcome discrimination at work and in the community;
- (6) Care and support of orphans and widows after the death of the primary bread winner, and
- (7) Information and training in HIV/AIDS care and prevention for care givers at home.

The identification of the needs of individuals and families affected by HIV/AIDS is the beginning of the planning process. To assist in this effort, WHO has developed a manual "Group interview techniques to assess the needs for people with AIDS" (WHO/GPA/TCO/HCS/95.2). Practical steps are outlined to conduct a rapid needs assessment and methods of analysing data.

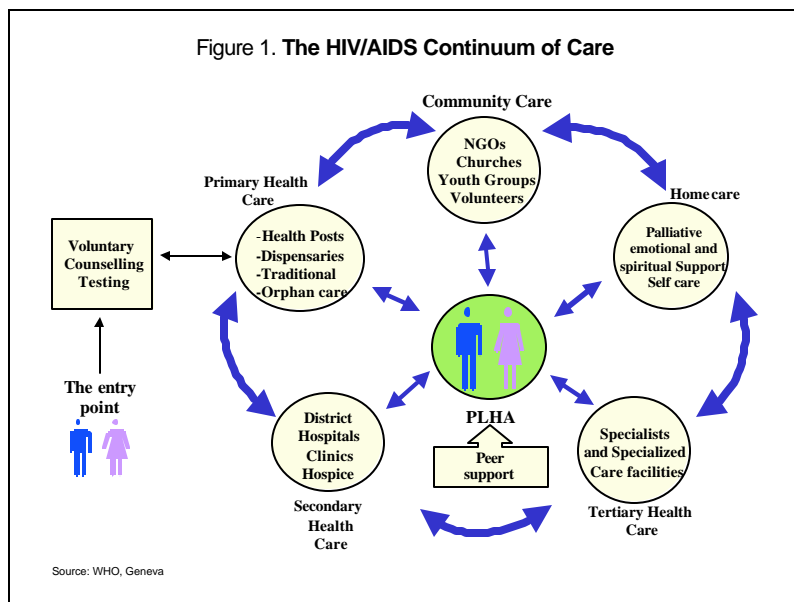
Developing responses for meeting all these needs requires a multidisciplinary approach as no one discipline can effectively meet the needs as outlined in the example above.

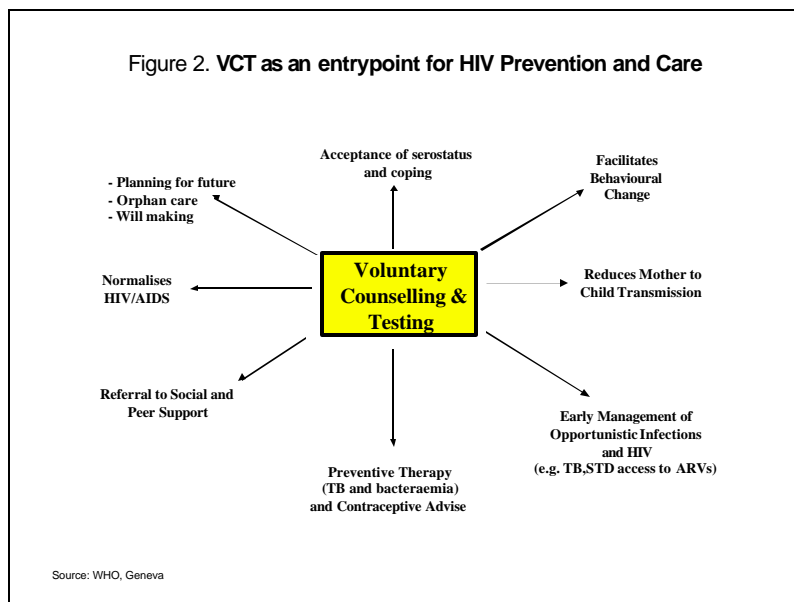
The concept of comprehensive HIV/AIDS care across the continuum (Figure 1) builds on HIV/AIDS care services in a team spirit and includes the following:

- (1) Voluntary counselling and testing (VCT) facilitates an entry point in the continuum of comprehensive care. Establishing a site where, in privacy, people can come to learn and accept their HIV sero-status allows access to effective care and prevention interventions (Figure 2).
- (2) Clinical management of symptomatic infection with early and appropriate diagnosis and rational treatment, nutritional support, discharge planning and referral to other service providers;
- (3) Nursing care to relieve the physical discomfort of illness, hygiene and infection control promotion, palliative and terminal care, training of family members in home care and preventive education and condom promotion;
- (4) Pre- and post-test counselling to help individuals make informed decisions on HIV testing. This should also include a supportive and accepting environment in which coping, behaviour change and positive living are promoted and should continue with follow-up counselling for the patient and other so identified;
- (5) Care at home and in the community, including the training of relatives and volunteers in the provision of care, treatment of common symptoms and palliative care.

Promotion of good nutrition, psychological and emotional support, spiritual support and counselling;

- (6) Formation of community support groups to provide emotional support to PWAs and their care providers. Opportunities for developing income-generating projects could be explored in these groups;
- (7) Eliminating the stigma of HIV/AIDS and developing of positive attitudes in the community towards persons and families living with HIV/AIDS. This includes health care workers in both private and public health institutions;
- (8) Social support or referral to appropriate social welfare services to meet the needs for housing, employment, legal support, and to monitor and prevent discrimination, and
- (9) Partnership-building between various providers (clinical, social, support groups) in order to be accessible through mutual referrals.





4. COUNTRY EXPERIENCES AND LESSONS LEARNT

The experiences of caring for patients living with HIV/AIDS (PWAs) from other parts of the world have been of help in developing appropriate care programmes in the South-East Asia Region. Programmes that have had to be set up in resource-constrained settings in Africa are of particular relevance to Asia as the conditions found in these two places are largely similar. However, adaptations from these experiences will need to take into account the political, cultural, economic and social conditions prevailing in different countries. There are several examples given of care approaches from the South-East Asia Region, in particular from northern Thailand and some small-scale areas in India. In these places, it has been possible to deliver comprehensive care across the continuum from hospital to home.

4.1 Specific Examples:

(1) Northern Thailand Community-based Care Project

Thailand's AIDS epidemic is the most advanced in Asia, with currently around 900 000 people infected with HIV. To date, 95 116 patients are reported to have developed full-blown AIDS, though the real figure will have been at least three times higher. The annual number of new cases of AIDS will continue to grow sharply over the next few years, even if the incidence of new cases of HIV could be dramatically reduced. The estimate of the cumulative number of AIDS cases in Thailand by the year 2000 should be 1.3 million.

Thailand's epidemic has been most severe in the north, covering the six provinces in the government's Communicable Disease Control Region 10 (CDC 10) - Chiang Mai, Chiang Rai, Phayao, Lampang, Lamphun and Mae Hong Son - and around half of the national reported cases of AIDS have been from this region.

The care of AIDS patients is mostly being handled by government and university hospitals and the country's health services are being overwhelmed. One way for Thailand to ease the impending crisis is to shift the burden of care from hospitals to the community and the home.

The first successful community-based prevention and care programme was started by CDC10 in 1992, in the village of Ban Dong Luang of Lamphun province. Having established links between the staff of local health centres and the village community, the project set up peer groups and trained 15 peer leaders as village care providers, five of whom were also trained as counsellors. The health staff strongly encouraged the acceptance of people with HIV/AIDS in the village, and cases of discrimination were recorded as having decreased. Ban Dong

Luang became the first community in the north to form an anti-AIDS association, raising money for people with HIV and AIDS.

Several NGOs in the north have become active in community-based care over the past few years, including North Net and New Life Friends. There has also been support from religious groups, such as the Buddhist monks of Doi Saket and Prapong Thep.

The latest development in the north has been a project to develop a reproducible district model for comprehensive care. This started in March 1995, with the support of CDC 10 and WHO, in collaboration with CARE International. It has now moved beyond the first stage of gathering information and is holding field trials to measure the effectiveness of the model.

This model project is one of comprehensive care. That is to say, it aims to provide medical treatment and nursing care, as well as counselling and other social and psychological support for people with HIV and AIDS and their families and dependants. With the most affected age groups for AIDS being men and women in their 20s and 30s, large number of children and elderly people are being left out unsupported. At the same time, the model is concerned essentially with what is called a continuum of care - which means that it seeks to provide for any individual with HIV or AIDS appropriate services at various times in the home, in community centres and in national or district hospitals. What is important here is establishing an effective mechanism for the linkages between these three different places of care - a good referral network - so that someone being treated in his/her home, for instance, can quickly and efficiently be moved, if the need arises (together with relevant medical records) into a hospital, or from a hospital to a community centre. Generally speaking, in such a model, hospitals will provide diagnoses, clinical management and treatment of acute conditions, while care for chronic conditions will be given in the home and in community settings.

Drawing on the strong family links that exist traditionally in the northern provinces, care initiatives in the region are trying to extend these links into the community, and to health facilities at all levels. By involving communities, and making them a part of the daily struggles and anguish related to the epidemic, it is hoped that the quality of life of people living with AIDS - and for their families and dependants - can be substantially enhanced.

(2) Manipur North-East India

The "Manipur Continuum of Care" project was set up to train interdisciplinary teams of health care workers and NGO volunteers in the provision of comprehensive HIV/AIDS care in three districts. The project was developed in collaboration with the Government of Manipur and international donor organizations. Training modules were developed and an adaptation of the WHO AIDS Home Care Handbook undertaken to take into account the social and cultural context of Manipur. The target group is drug users. Various local NGOs working with injectible drug users, and support groups at drug users, are the key partners in providing care.

Referral systems have been developed to supplement a resource directory in linking the various actors together. The results after an year of starting the project show high acceptability and some success in continuous quality care provision. The support among families and the motivation among NGOs have both been strong. Coordination between the government and NGOs has also been strengthened. This has been achieved despite the lack of supplies in health institutions and a strong stigma and fear of AIDS prevailing within health institutions and communities.

4.2 Lessons Learnt

These examples show that appropriate care can be provided at both institutional and community levels. Care at both these levels recognizes the critical catalytic role of the community in developing this type of care. Partnerships among the public sector, NGOs and communities have also been an important driving force behind the success of comprehensive AIDS much as they were in the case of primary health care.

These programmes have also been shown to be mutually-supportive of the different partners. Indeed, well-accepted care activities and, in turn, prevention activities raise opportunities for early care-seeking. The intrinsic linkage of care and prevention is a more effective and realistic approach to prevention than conventional means.

By using the traditional strengths within communities like the family and local support groups, the religious/spiritual groups also can, with appropriate guidance and motivation, contribute to comprehensive care of individuals.

Lastly, the integration of comprehensive care into primary health care system will not only prevent the "flight" of resources from other disease programmes to AIDS, but will also provide an opportunity for cooperation in the use of scarce resources. Over time, this can be the only approach which can lead to a programme that is both cost-effective as well as sustainable.

The concept of comprehensive care across the continuum is now part and parcel of the WHO/SEARO HIV/AIDS policy advice to its Member Countries (ref. AIDS: The Challenge, SEARO document, 1997).

5. SETTING UP AN HIV/AIDS CARE PROGRAMME: *A step-by-step approach*

Care programmes to meet the needs of PWAs in hospitals, health centres, the community and the home can be developed by any of the following: health administrators, NGOs, CBOs and private health practitioners. Other groups such as metropolitan or council authorities may also want to set up such programmes. The extent to which these are implemented will depend on the capacity of the agency and the willingness to interrelate and collaborate in partnership.

Often it is more logical and economical to focus on the benefits that collaboration with other partners can bring. This can help develop a pool of skills in a particular group of service providers who can then be available from time to time to provide training or support. Some groups may only focus on one aspect of comprehensive care, following which an effective referral network should be developed to make their services available to others.

The delivery of comprehensive care across the continuum assumes the following support systems are developed and made operational for care provision to be effective and efficient in an integrated fashion:

- appropriate IEC materials to promote care seeking and de-stigmatize the disease;
- community mobilization programmes to develop community care programmes;
- partnerships between government agencies and NGOs interacting with health, social and community-based health care activities;
- referral procedures between hospitals and peripheral health care centres;

- referral procedures between patients and their families and social support institutions or NGOs;
- procedures for supervision of staff in health facilities and at peripheral levels including volunteers.

The following are some of the steps that can be taken to develop and implement specific HIV/AIDS care services:

5.1 Planning

Step 1 - Obtain an estimate of the extent of HIV illness and AIDS

The purpose of this is to obtain information on the number of individuals affected by HIV/AIDS and the possible number who will need care in the future. This should also identify the area the care programme will cover. The sources for this information can be several, for example the national AIDS control programmes may have this information for specific sites in the country. If this is not available, then interviews with hospital staff to estimate the burden or a community interview will be useful as well to identify if the burden is being perceived within the community.

Step 2 - Conduct a needs assessment

This involves assessing the needs of persons affected by HIV/AIDS. The WHO "Manual of group interview techniques to assess the needs of people with AIDS" is a useful tool for this purpose. Knowing what people expect in communities where HIV/AIDS is a problem; if there is a demand for voluntary counselling and testing; if confidentiality can be guaranteed, and how PWAs are coping, is important before the care programme is formulated.

Step 3 – Identify existing services and resources

The methods described in the manual will guide in setting up discussions of focus groups of health care professionals providing AIDS care and will thus help determine which of the existing services require strengthening so as to ensure a comprehensive approach across the continuum.

The health and social care services in existence in the area or those that have the capacity to provide elements of comprehensive care should be identified. This will help in planning the referral possibilities and form the basis for future partnership and collaboration. The existing training materials have to be assessed as to their relevance. And, the supply systems of drugs, test kits and laboratory supplies need to be reviewed as to their adequacy and regularity. Also, staff willing to be involved in AIDS care need to be identified. Other programmes for chronic illnesses and/or community-based care also need to be explored for collaboration mechanisms in order to ensure an integrated approach (see box for an example of HIV/AIDS care programme). For example, many TB patients will be HIV-positive and many people with HIV who are seeking care will either be having or will be developing TB. Therefore, close coordination with TB programme staff will be necessary for joint training, easy referral mechanisms and common drug supply lines. Similarly, the existing community-based care programmes may consider including AIDS home care activities instead of setting up separate vertical programmes.

Step 4 – Mobilize resources

Depending on the overall objectives and the number of activities the care programme intends to offer, the required resources will need to be mobilized. These include financial, personnel, supplies and materials. The possible sources of these include the government, national AIDS control programmes, donors, charitable NGOs, and the community. The interested collaborators

can also be approached to share the burden of caring and to develop referral systems that are workable. Appropriate materials for training different categories of care providers across the continuum from health staff to volunteers, will need to be developed, if none are available.

Step 5 - Define objectives, set priorities and prepare a workplan

Setting up of realistic objectives and targets for HIV/AIDS care activities will depend on the results of the four steps mentioned above.

One set of activities at the planning stage will be to formulate operational procedures with regard to discharge, referrals and networking mechanisms. As different staff members (e.g. doctors, nurses/ counsellors, pharmacists, social workers) and different organizations, such as community-based NGOs, organizations for people living with HIV/AIDS, religious groups and others are involved in care, procedures relating to when and where to refer need to be clarified and that information needs to be accessible to all involved. Some programmes may wish to make a directory on "who does what in AIDS care" for a specific geographic area. Also, job descriptions need to be updated to reflect AIDS care activities such as counselling, and be approved by institutional authorities.

A decision as to whether the programmes will focus their resources on voluntary counselling and testing or on symptomatic care of related illness, or on AIDS home care or a combination of these activities, needs to be made as this will have a bearing on both cost and staff requirements. On initiating the programme, not all the needs may be met due to resource constraints. A decision therefore needs to be made as to what are the priorities and which objectives will be carried out first. Deciding upon activities or areas that require immediate attention or what needs to be carried out first is important. The order in which these are

carried out will depend on the availability of personnel and resources. These can be started independently or integrated into the existing health care programmes or social services.

For selecting priority activities, consider the following criteria:

- the number of people with HIV infection and their families who will benefit from the activity;
- the feasibility of carrying out the activity;
- the relative ease with which an activity can be integrated into the existing health programme or disease control activities;
- the availability of financial, human and material resources, and
- the extent of commitment from community leaders, decision-makers and health staff to carry out activities.

It should be kept in mind that prioritization of activities across the continuum will ultimately help improve the extent and quality of health and social care for individuals living with HIV/AIDS.

5.2 Implementation

Step 1 - Train staff

Current staff may not have the knowledge and skills to implement AIDS care activities in addition to their ongoing duties. Understandably, their attitudes may be affected by fear. Training through small workshops where all staff are together as a team and regular updates of information on “what is new in HIV care” are essential. National AIDS programmes, academic institutions and NGOs active in this field need to be contacted to assist in these workshops.

One particular area of attention is refresher training on universal precautions and restoring confidence in caring for patients independent of their serostatus.

Step 2 – Establish and ensure supply lines

Care for HIV/AIDS puts an additional burden on necessary supplies. Drugs for the prevention and treatment of opportunistic infections, test kits, condoms and protective materials need to be made available through strengthening of the existing supply lines. Close collaboration with staff responsible for supplies and involving them in a team approach need to be ensured.

Step 3 – Follow the Workplan

These are activities to be carried out as part of an HIV/AIDS care programme. They should contain the following elements - the activity to be carried out; the period over which the activity will be carried out; the individuals responsible for carrying out the activity, and the targets to be reached within the time period. Wherever possible, these elements should be agreed upon by all the parties involved in the provision of these services so that there are no delays or lapse in implementation.

5.3 Monitoring and Evaluating a Care programme

(1) Monitoring and evaluation indicators

For verifying the attainment of objectives by a care programme, a conducive and effective working environment is essential. The following elements need to be addressed: leadership and team work; work motivation and commitment, and measuring and analysing progress through simple indicators. Regular staff meetings should address all these elements.

Indicators should specify:

- Defined target groups to be reached, e.g. people attending health clinics at a hospital; drug-using communities;
- Quantity (how much), e.g. how many patients, after being discharged, are cared for properly at home; demand for VCT;
- Quality (how well), e.g. are people satisfied with the treatment provided for the relief of symptomatic illnesses at home;
- Time (by when), e.g. when is it appropriate to refer a patient to community-based volunteers;
- Location (where), e.g. how accessible are health services to patients in a particular area;
- Staff satisfaction, and
- Laboratory procedures.

Properly formulated indicators will provide a good basis for monitoring and evaluation. The following points should be considered about the selection of indicators:

- whether easily available means of verifying data are available, e.g. data can be checked by interviewing patients.
- whether up-to-date and reliable means of verifying the data are available, e.g. whether alternative methods of HIV testing are available to check the reliability of an HIV test results.
- generating the required information at reasonable cost, e.g. the cost of collecting information should be within acceptable budget limits and not too prohibitive.
- indicators should be relevant as measures of the achievement of the objective, e.g. if the smile on a patient's face is used to measure patient satisfaction of home care, it should be the most correct and accurate

measure of patient satisfaction as compared to any other factor.

- the collection, preparation and storage of information are activities within the care strategy, e.g. the data required to measure the success of the care strategy should be routinely collected while filling out the patient's medical needs.
- complement qualitative data by holding discussions among staff or in focus groups at regular intervals.

Appropriate indicators of improvement in care and social support services might include the following examples at various levels across the continuum;

Health institution:

- proportion of health staff trained to provide clinical/nursing management and counselling for HIV/AIDS.
- the number of condoms distributed to clients in the outpatient departments.
- proportion of patients being referred to other social welfare services.

Home and community:

- number of community volunteers who are trained to provide basic care and counselling in the home.
- number of care givers in the home who are trained in caring for the sick at home.
- proportion of patients who are receiving appropriate care and support services at home.

(2) Programme review and evaluation

The purpose of internal review is to assess the progress and identify the constraints being faced by various partners. This will help in making recommendations regarding the need for changes in the strategy and management of care plans. The review is generally conducted by representatives of various agencies participating in care activities. Included in these reviews is also an analysis of the impact on usefulness at the project for the target group.

The evaluation to assess the impact and relevance of the project should be undertaken jointly by external experts and internal staff. The aim is to provide a mechanism that would be implemented every three-four years and which would provide guidance and direction for the HIV/AIDS care programme based on an assessment of what has been achieved and what constraints need to be overcome.

For both these activities, the indicators developed earlier will be of help.

Annex

RESOURCE MATERIALS ON HIV/AIDS CARE

The following documents and publications give more detail on the different aspects of comprehensive care across the continuum. They are available on request from the WHO South-East Asia Regional Office, World Health House, Indraprastha Estate, New Delhi 110 002, India.

WHO SEARO Publications

1. Understanding and Living with AIDS, 1992
2. AIDS in South East Asia: No Time for Complacency, 1992 (revised in 1997!)
3. HIV/AIDS Care at Institutional, Community and Home Level, 1993
4. An Orientation to HIV/AIDS Counselling - A Guide for Trainers, 1994
5. Information, Education and Communication - A Guide for AIDS Programme Managers, 1995
6. Handbook on AIDS Home Care, 1996
7. AIDS Prevention and Care in the Workplace: Enhancing the Role of the Private Sector, 1996.
8. TB/HIV - A Clinical Manual, 1997
9. Guidelines for Clinical Management of HIV and AIDS at District Level, 1998
10. AIDS: The Challenge, 1997

WHO/HQ

1. Source book for HIV/AIDS Counselling and Training, WHO/GPA/TCO/HCS/94.9, 1994
2. TASO Uganda the Inside Story, WHO/GPA/TCO/HCS/95.1, 1995
3. Guidelines for the Clinical Management of HIV infection in children, WHO/GPA/IDS/HCS/93.3, 1993
4. National AIDS Programme Managers Training Module on HIV/AIDS Care and Social Support, WHO, 1993
5. HIV Prevention and Care Teaching Modules for Nurses and Midwives, WHO/GPA/CNP/TDM/93.4, 1993
6. Guidelines for Blood Donor Counselling on HIV, WHO/GPA/TCO/HCS/94.2, 1994
7. Manual of group interview techniques to assess the needs of people with AIDS, WHO/GPA/TCO/HCS/95.2
8. Implications of antiretroviral treatments, WHO/ASD/97.2
9. Guidance modules on antiretroviral treatments, WHO/ASD/98.1
10. HIV and Infant Feeding, Guidelines for decision makers, WHO/FRH/NUT/ CHD/98.1
11. HIV and Infant Feeding. A Guide for health care managers and supervisors, WHO/FRH/NUT/CHD/98.2
12. Weekly Epidemiological Record: Recommendations on the safe and effective use of short-course ZDV for prevention of mother-to-child transmission of HIV. N° 41, p. 313-320 - 9 October 1998.
13. Weekly Epidemiological Record: The importance of simple/rapid assays in HIV testing. No. 42. p. 321-328 - 16 October 1998.