

Improving access to care



Jenny Matthews

Improving access to care needs collaboration between health workers, carers and people with HIV, such as this HIV support group in Uganda.

Good care can greatly improve the quality and length of life of people with HIV. Care includes practical, emotional and spiritual support for HIV-positive people, their carers, families and communities. It also includes treatment for people with HIV.

Many people affected by HIV do not have access to the care they need. People in resource-poor communities may have particular problems in getting access to good treatment.

Treatment includes preventive measures (such as the use of drugs to prevent infections, and good nutrition), curative measures (for example, diagnosis and treatment of tuberculosis) and palliative measures

(for example, pain and symptom control for the severely ill).

Treatment can be delivered through modern health care systems, complementary health care, such as physiotherapy and massage, and traditional health care systems, such as the traditional use of herbs and remedies or acupuncture.

This issue of *AIDS Action* suggests key principles that people involved in planning HIV and health programmes can follow to improve access to care. It looks at two strategies to improve access to care: making care services affordable, and advocating for an improved essential drugs list. Most people do not have access to antiretroviral therapy but want to

know more about it. Pages 6-7 give an introduction to antiretroviral therapy.

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A four-page insert on reducing mother-to-child HIV transmission.

Improving access to care

AIDS Action looks at some of the key principles health planners need to follow to improve access to care.

Good care will vary depending on local needs and resources. People who have HIV, or who are at risk of HIV infection, should have access to a basic care package which includes:

- voluntary counselling and testing services
- a good diet made up of foods that are locally available and affordable
- user-friendly and affordable local health services, including community or home-based care, and an effective referral system between these services and regional hospitals
- essential drugs for the treatment of HIV-associated infections and relief of pain
- information on the range of HIV care services.

This basic care package should be available to people at all stages of HIV, including those who are uninfected but at risk. Individuals, HIV support groups or organisations may need to advocate to make this care package available. Advocacy means persuading those with power, such as governments or commercial companies, to change their policies or practices to meet the needs of a particular group.

Key principles

The following can help health planners to make sure people in their area have access to a basic care package.

Prioritise care services. This means involving HIV-positive people and health workers in finding out about local needs and resources, deciding which needs are most important and the best way to meet these needs (see activity: 'Action for care'). This involves looking at the long-term costs and benefits of different approaches to care, including prevention activities and treatments for HIV-associated illnesses and HIV. It may also involve advocacy at local, national and regional levels.

Promote good quality health care. This includes making sure that health services have basic drugs and equipment, for example, simple effective antibiotics including TB drugs, antifungals, antiseptics, analgesics,

gloves and disposable syringes, as well as basic diagnostic equipment. It also includes having skilled staff. Cost is an important issue, so developing cost-recovery systems, such as subsidised pharmacies can help (see page 4). Good quality health care also needs efficient supply and distribution systems for drugs and equipment, monitoring and follow-up of care and referral systems. Developing national guidelines for managing HIV-associated illnesses can help promote good quality health care, for example, developing treatment protocols which can be implemented at all levels from hospital to community (see page 3: 'Developing national guidelines').

Promote collaboration between different groups that provide care. Collaboration between health centres and hospitals, traditional health systems, community-based organisations and HIV support groups helps to ensure a 'continuum of care'. This means providing care for people at all stages of HIV, from prevention to palliative care and at local, district and national levels.

Promote voluntary testing and counselling. This is very important. If people know that they are HIV positive early, and receive good counselling, it can encourage them to access available care, for example, by joining an HIV support group, eating healthy food, and getting early treatment for illnesses. People who test HIV negative and receive good counselling have a better chance of reducing their risk behaviour and staying negative.

Involve people with HIV in planning their own care. The more that people feel they can make informed choices about their own health care, the more likely they are to stay healthy. People need to be encouraged to voice fears and concerns about treatment and to share in decisions about their care. Involvement of people with HIV and their carers is essential when advocating for improved access to care.

Provide regular training for health workers. Training should cover how to diagnose HIV-associated illnesses early, how to treat them and when to refer people to specialist services.



It is important to help people with HIV-associated illnesses, such as herpes zoster, get early treatment.

'To be informed is empowering. It has enabled me to manage living with the virus. I know how to take care of myself. I know my body, I understand it. I know where to seek support if I need it. I know what kind of support I need. I feel courageous to ask questions. Even to protest. I know what are the choices for me. And I am capable of making careful considerations before making any decisions. All these wouldn't have happened, or might take an awfully long time to happen, if I wasn't informed.'

Suzana Murni, *Echidna*, no. 19, 1998

Ensure that health services are user-friendly and physically accessible. People are more likely to use health services if the staff are friendly and communicate well. Training in communication skills, for example using role play, can help. Health facilities must be near enough for people to visit them. This can mean providing facilities for people with special needs, for example, services to treat and prevent sexually transmitted infections near to where sex workers work.

Reduce stigma and discrimination against people with HIV. In many places, people who are thought to have HIV are feared and discriminated against. Stigma can be so strong that even people who work for HIV-related organisations do not tell their colleagues that they are HIV positive. Some people have even been killed for saying publicly that they have HIV. One way stigma can be reduced is through education. When people

understand what HIV is, and how it is transmitted, they are less likely to discriminate.

Provide information. Some people call information 'the cheapest form of therapy'. Health workers and people affected by HIV need up-to-date locally-relevant information on a range of issues, (see box above). For example, carers need information to help them understand the progression of HIV and to know what advice to give; people with HIV need information to encourage them to seek early treatment for common illnesses, such as TB. Health planners and community-based groups need to think about what information is needed, what is available and how information gaps can be filled.

Dr Elly T Katabira, Department of Medicine, Mulago Hospital, Makerere University Medical School, Kampala, Uganda.

Developing national guidelines on HIV care

Many health ministries, such as the Ministry of Health in Uganda, have developed national guidelines. These provide advice on how to manage HIV, how to make clinical care and referral systems efficient, and how to integrate HIV care activities into existing community health programmes.

National guidelines are for all health care workers, including traditional healers, particularly those working on HIV in health facilities, the community and in training institutions. They are also for HIV-positive people and support groups.

National guidelines should cover:

- clinical management of people with HIV, for example, guidelines on diagnosis and treatment of HIV-associated infections
 - access, cost and laboratory requirements, follow-up and monitoring of antiretroviral therapy
 - other therapies, such as physiotherapy, and their roles in the management of people with HIV.
- Guidelines should also include advice on:
- counselling people with HIV, their families and other carers
 - home care – involving the family and the community through volunteers and existing services
 - referral systems between health service and with other services.

ACTIVITY

Action for care

AIM To make action plans to improve access to care, based on local needs and resources

TIME Half a day or one day

PARTICIPANTS People with HIV, health care providers, carers and families, health educators, community leaders



1. Get people together in small informal groups and ask them to discuss:
 - what are the main care needs in our community?
 - what are the care needs of different groups, such as young children and orphans?
 - what helps people access care to meet these needs?
 - what are the main barriers to meeting these needs?
2. Ask each group to write or draw what their group thought were the most important care needs on large pieces of paper or a blackboard.
3. Ask the groups to come together and discuss the results and then to 'vote' for what they think are the most important care needs (probably 3-5).
4. Ask the large group to discuss:
 - what are the main barriers to meeting the priority needs?
 - how can these be overcome?
 - what resources are needed?
 - what resources are available locally?
 - what can be done to get other resources?
5. Finally, ask participants to agree:
 - what needs to be done
 - what can be done now
 - who will do it
 - by when
 - what to do next.



YRG CARE archives

Hospital stays may be made more accessible with subsidised charges.

Making care affordable

An Indian organisation explains how they reduce the cost of care for those who cannot afford the full price.

'Sangeta had just given birth to a son. She was delighted. But when her husband came to see her, the doctor told him Sangeta had tested positive for HIV. She had received no counselling. She did not know about HIV or that she had been tested for it. After her diagnosis, her husband would not let her touch their son, and the medical staff left her alone.'

This is a common story. Often, the situation is made worse by lack of access to appropriate and affordable care. YRG CARE (Centre for AIDS Research and Education) in Chennai, India, is addressing this problem. It runs an integrated care programme, which includes voluntary counselling and testing and hospital and home-based care services. YRG CARE has developed several strategies to ensure that everyone who needs care can afford it. These include:

Two different fees for the HIV test. People on high incomes pay Rs100 (US\$2.30) for an HIV test. Those who can afford it are also

asked for donations. These payments help the centre subsidise the cost of the test for people on a low income, who pay Rs50 (US\$1.15). People who test negative are encouraged to continue to be involved with YRG CARE and to donate time or money for care work.

Free counselling service. YRG CARE provides free pre- and post-test counselling.

Different charges for other care services. These are based on income. Very poor people are not charged. Other people are charged a quarter, half or the full cost of the services. YRG CARE receives donations in

money or kind from organisations, groups and individuals, which help it subsidise the cost of services for those who cannot pay.

Subsidised pharmacy. YRG CARE reduces the cost of the drugs in its pharmacy by:

- buying drugs direct from manufacturers and wholesalers
- getting free samples from manufacturers, and drugs through the drug component of its clinical research projects and from overseas hospitals
- getting unused drugs from YRG CARE's hospital and community-based patients.

People on higher incomes pay the full price for the drugs. This income, as well as money raised from businesses, is used to subsidise reduced prices for other users. The pharmacy does not sell antiretroviral drugs because they are too expensive.

Subsidised meals. YRG CARE runs a diet centre, which provides nutritious food. Staff and most relatives pay the full cost for their meals and this income is used to subsidise the cost of meals for other people. YRG CARE also receives food donations from hotels and offices in return for HIV-awareness training.

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Ron Cilling/Still Pictures

Subsidised pharmacies are one way to improve access to drugs for people with HIV.

Making drugs accessible

In West Africa, a community-based organisation has been advocating to include drugs for common HIV-associated illnesses on the national essential drugs list.

La Bergerie - Foi, Univers Compassion (La Bergerie - FUC) is a christian organisation, based in Ouagadougou, Burkina Faso. It has a health section run by volunteers (nurses, pastors, a midwife, pharmacy assistant and doctor). The volunteers were distressed by the experiences of HIV-positive people in hospital: 'Many people were selling everything they had in order to pay for treatment. They were even selling their homes. Others were abandoned by their families.'

Most of these patients were already dying. They were often in pain but, because they could not afford drugs, the doctors could do little for them and sent them home. So La Bergerie - FUC established a day care centre for HIV-positive people and started home visits. Volunteers provided emotional and spiritual support for

people with HIV and their families and treated HIV-associated infections. They used drugs supplied to La Bergerie - FUC by a French church, and oral rehydration salts from the Ministry of Health. They used money from a donor to buy more drugs from a national provider at a reduced cost. But La Bergerie - FUC did not have enough drugs to meet the needs of all its patients.

La Bergerie - FUC decided on two strategies to improve its drug supply. The first strategy was to raise money to buy drugs. They asked IPC (Initiative Privée et Communautaire de lutte contre le SIDA), a local NGO support organisation, if it would give some money for drugs. At first IPC refused, because it felt that the money would be better used supporting prevention activities. However, La Bergerie - FUC

DEFINITIONS

Essential drugs are safe, affordable and effective drugs that satisfy the health care needs of the majority of the population. Most countries have national essential drugs lists that include drugs for the common illnesses in their particular country.

Essential drugs lists usually list the generic name of the drug. A drug's generic name is its official name. Most drugs also have a commercial name (brand name), which is chosen by the manufacturer or distributor. Drugs that are sold by a generic name are often cheaper than drugs sold under a brand name.

Many countries need to update their essential drugs lists to include drugs for common HIV-associated infections.

managed to convince IPC that an HIV programme that could not offer treatment would not get community support, and therefore could not be effective. IPC eventually agreed to fund drugs as a pilot project.

The second strategy that La Bergerie - FUC adopted was to look at ways of reducing the cost of drugs. The volunteers looked at the most common HIV-associated illnesses and symptoms in their area, and asked people with HIV which drugs were most effective. The result was a list of essential drugs for HIV-associated infections (see box).

IPC decided to develop La Bergerie - FUC's list to use with other organisations. A doctor, who was chair of the Care and Support Committee of the National AIDS Programme, approved the list. Then IPC circulated this list to community-based organisations providing counselling and palliative care. The organisations created a national network to improve the delivery of community-based care and support services in Burkina Faso. Recently the National AIDS Programme has asked this network to help them change the national essential drugs list to include essential drugs for treating common HIV-associated infections.

Association La Bergerie - FUC, 04 BP 8346 Ouagadougou 04, Burkina Faso.

With thanks to Christophe Cornu, International HIV/AIDS Alliance, UK.

Drugs for HIV-associated infections in Burkina Faso

This is an example of a drugs list developed with people with HIV in Burkina Faso. It includes drugs for common HIV-associated diseases in that country. Lists developed in other countries will vary according to local needs and availability.

COMMON HIV-ASSOCIATED ILLNESSES/SYMPTOMS	DRUGS
Gastroenteritis Diarrhoea Vomiting	Anti-diarrhoeal drugs, such as loperamide hydrochloride Oral rehydration salts Anti-nausea drugs, such as metoclopramide
Intestinal parasites (worms) Intestinal parasites (micro-organisms such as giardiasis, amoebiasis)	Mebendazole Metronidazole
Chest infections (excluding tuberculosis)	Cough linctus, antibiotics according to local needs, such as ampicillin, co-trimoxazole
Skin problems (itching, herpes zoster, pus-producing infections)	Gentian violet, antiseptic solution, antihistamines such as chlorpheniramine, antibiotics such as flucoxacillin
Fever (malaria) Fever (general)	Anti-malarials, such as chloroquine, quinine Anti-pyretics, such as aspirin, paracetamol
Candida (thrush)	Anti-fungals, such as nystatin, ketoconazole, miconazole
Haemorrhoids	Anti-haemorrhoidal suppositories (such as the brand Anusol)

Introducing antiretroviral therapy



Many people want to know about antiretroviral therapy, and some people even have access to it, so information on it is important.

What is antiretroviral therapy?

Antiretroviral (ARV) therapy is treatment with drugs called antiretrovirals (ARVs) that fight the HIV virus. ARV therapy can help people with HIV stay healthy. But at present, ARVs have to be taken for life, are expensive, often difficult to take and can cause severe side effects. Also, ARVs are becoming increasingly available in many countries, but many people are not using them properly. This is dangerous as resistance (see definitions) can develop quickly and side effects are common.

Monotherapy (treatment with only one ARV) is used to reduce the risk of HIV transmission, for example, from needle-stick injuries, or from mother to child. Monotherapy is not used to treat people with HIV, because resistance soon develops.

Combination therapy (treatment with two or more different ARVs) is used to treat people with HIV. This is because different ARVs fight HIV in different ways, and are therefore more effective when used together; it is also harder for HIV to develop resistance to ARVs when they are used in combination.

Three main types of ARVs are currently in use in combination therapy: nucleoside analogues, non-nucleoside reverse transcriptase inhibitors, and protease inhibitors (see table). There are many possible combinations of ARVs, but some should not be used together because they react with each other.

ARV therapy for children also appears to be effective, but the dosages vary for each child and more information is needed about side-effects of therapy for children.

Starting therapy

ARV therapy should only be given to people who have tested HIV positive. Some doctors prefer people to start therapy early, when the immune system is less damaged and viral load is still relatively low. (Viral load can be very high immediately after infection with HIV, but it usually drops after a few weeks.) Other doctors prefer to start therapy later because of the cost of ARVs, and because resistance is more likely to develop the longer someone is taking the drugs.

Using antiretroviral therapy

Following instructions This is also known as adherence or compliance. Antiretrovirals must be taken according to strict instructions. These can be difficult to follow. Several different pills must be taken each day at different times, with different food or drinks. The pills can cause unpleasant side effects. ARVs are expensive (three drugs in combination can cost US\$8,000-20,000 per year). Many people cannot afford ARVs regularly or do not have a regular supply, so that they have to stop treatment while they wait for more ARVs. Sometimes people give their drugs to family members or friends because they think they need them more. Multi-drug resistant HIV is already appearing, largely as a result of non-adherence. The tuberculosis experience has highlighted the need for community-based support for people who are taking long-term treatment. A similar approach might help improve adherence for people on ARV therapy, although it is more complex.

Side effects Many people experience unpleasant side effects when they start antiretroviral therapy, such as vomiting, diarrhoea, and fever. Some side effects, such as diabetes and pancreatitis, may be life-threatening. People who experience these may need to change the drugs in their combination.

Reactions with other drugs Some antiretrovirals also react with other drugs and stop them working as well. For example, protease inhibitors react with the tuberculosis drug rifampicin.

Close monitoring Antiretroviral therapy must be monitored closely to

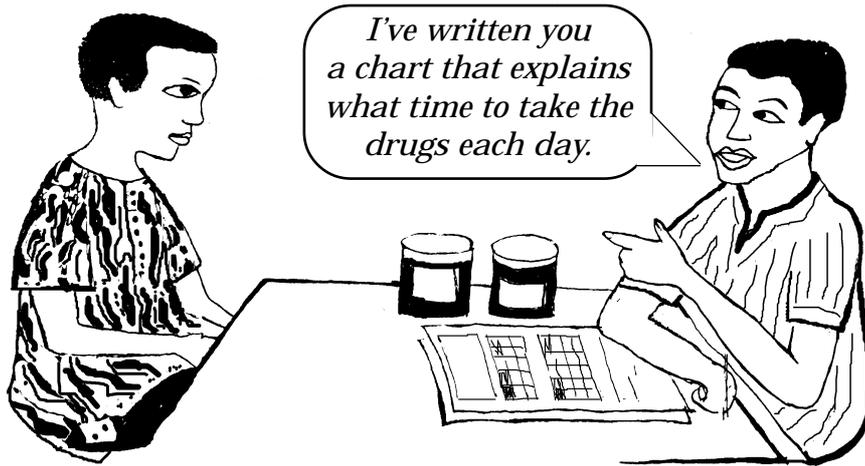
DEFINITIONS

CD4 count is the number of CD4 cells in a cubic millimetre of blood. CD4 cells help to protect people from getting infections. HIV attacks and destroys CD4 cells. A CD4 count in a healthy, HIV-negative adult is usually 600-1200 CD4 cells per cubic millimetre of blood. The CD4 count of most people with HIV usually falls over time. If the CD4 count drops below 200 cells per cubic millimetre of blood, there is a high risk of serious infection.

Viral load is the amount of HIV that can be measured in the blood. If the person has not developed symptoms, a viral load higher than 100,000 per millilitre of plasma (the fluid part of the blood) is considered to be high, and below 10,000 is considered low. An **undetectable viral load** means that it is too low for the test to be able to measure it with standard techniques.

Resistance to an ARV means that HIV in the body has changed so that the drug no longer works against it. People often develop resistance to ARVs because they stop using them, do not take them regularly or in complete doses.

Cross resistance means that HIV is resistant to more than one ARV. This can include drugs that the person has not used. For example, if someone develops resistance to indinavir, they will also be resistant to ritonavir.



make sure that it continues to be effective and that HIV in the body is not developing resistance to drugs in the combination. The best way to do this is to take CD4 and viral load counts at least every 3-6 months. These tests are expensive and are not available in many places.

Changing therapy

Therapy should be changed if the person has severe side effects to one or more of the drugs. If they only react to one drug, only that drug

should be changed. Therapy should also be changed if the CD4 count is falling or the viral load is not being reduced or maintained. In this case, all drugs in a combination should be changed if possible.

Information about ARVs, the long-term effects, negative effects and drug interactions, is being updated and changed all the time, and new drugs are being developed. Guidelines on using ARVs are listed in Resources on page 8.

Antiretroviral drugs	
NUCLEOSIDE REVERSE TRANSCRIPTASE INHIBITORS (NRTIs)	
Generic name	Brand name
Zidovudine (ZDV)	AZT or Retrovir
Lamivudine (3TC)	Epivir
Zidovudine and lamivudine combined (ZDV+3TC)	Combivir
Zalcitabine (ddc)	Hivid
Didanosine (ddl)	Videx
Stavudine (D ₄ T)	Zerit
1592U89	Abacavir, Ziagen
NON-NUCLEOSIDE REVERSE TRANSCRIPTASE INHIBITORS (NNRTIs)	
Generic name	Brand name
Nevirapine	Viramune
Delavirdine	Rescriptor
PROTEASE INHIBITORS	
Generic name	Brand name
Saquinavir	Invirase
Ritonavir	Norvir
Indinavir	Crixivan
Nelfinavir	Viracept

✓ CHECKLIST FOR HEALTH WORKERS

Before prescribing antiretroviral therapy

- ✓ Check the national drugs policy. Are ARVs licensed in your country?
- ✓ Make sure you have up-to-date information on ARVs – this information changes very frequently.
- ✓ Make sure the patient has tested positive for HIV.
- ✓ Make sure the patient will have access to a long-term supply of the drugs in their combination.
- ✓ Discuss with the patient how they will pay for ARV therapy. Can they afford it? Will there be enough money for food for other household members? Do other household members have HIV and need ARVs?
- ✓ Discuss the various combinations available in detail with the patient. What combinations will they use if they develop resistance to the first combination of drugs?
- ✓ Explain clearly the importance of adherence. Discuss some of the problems people have with adherence. Spend as much time as possible with the patient to help them decide the best time to take the tablets each day. Write or draw a drug and diet chart showing when and how to take the drugs, food and drinks. Ask the patient to practise using this chart before actually starting to take the ARVs.
- ✓ Talk to the patient about side effects associated with the drugs. Discuss how to make it easy to start treatment, such as taking time off work in case side effects occur.
- ✓ Discuss a nutritious diet.

Managing antiretroviral therapy

- ✓ Monitor patients regularly for side effects and for resistance to the antiretrovirals, preferably using tests for CD4 and viral load counts.
- ✓ Change the combination if side-effects are severe or if CD4 and viral load indicate that resistance is developing.
- ✓ Do not add an antiretroviral drug to a treatment that is failing. It is preferable to change at least two of the drugs.
- ✓ Promptly treat HIV-associated infections.
- ✓ Encourage patients to ask questions and tell you how they are feeling. Inform them of any support groups or other forms of support that are available.

Source: 'Towards the healthy women counselling guide' UNDP/WHO

RESOURCES

Care at home for patients with AIDS in resource-poor countries discusses treatment and care options. Available free from Medical Mission Institute (MMI), Salvatorstrasse 7, D-97074 Würzburg, Germany.

Developing essential drugs policies: a guide for NGOs includes information on HIV-related drugs. Available free from the Essential Drugs Project, 77 Lee Road, Blackheath, London, SE3 9EN, UK.

Guidelines for the use of antiretroviral agents in HIV-infected adults and adolescents is a book that is continually updated to include new information on antiretroviral drugs. Available free from International Association of Physicians in AIDS Care (IAPAC), 225 West Washington, Suite 2200, Chicago IL 60606, USA.

Guidelines for the use of antiretroviral agents in paediatric HIV infection is aimed at health workers who have access to ARVs. Available from the HIV/AIDS Treatment Information Service, PO Box 6303, Rockville MD 20849-6303, USA. E-mail: atis@hivatis.org

Guidance modules on antiretroviral treatments (WHO/ASD/98.1 UNAIDS/98.7) provides information for health planners and policy makers, including safe and effective use of ARVs, laboratory requirements, and ethical and social issues. Available for Sw.fr.19.60 (developing countries) or Sw.fr.8 (elsewhere) from WHO, CH-1211, Geneva 27, Switzerland. Fax: +41 22 791 4834. E-mail: publications@who.ch Order no. 1930139.

HIV prevention and AIDS care in Africa: a district level approach is a useful manual for health planners at district level and discusses health service delivery issues. Available for Dfl.49 from KIT press, PO Box 95001, 1090 HA Amsterdam, The Netherlands.

Implications of antiretroviral treatments (WHO/ASD/97.2) discusses issues that health planners and policy makers may need to consider. Available for Sw.fr.10.50 (developing countries) or Sw.fr.15 (elsewhere) from WHO, CH-1211, Geneva 27, Switzerland. Order no. 1930112.

Provision of pharmaceuticals in home-based care programmes is aimed at pharmacists and health planners. Available free from Medical Mission Institute (MMI), Salvatorstrasse 7, D-97074 Würzburg, Germany.

Sexual health and health care: care and support for people with HIV/AIDS in resource-poor settings includes basic information on setting up care and support programmes. Available from IFH, Parchment House, 13 Northburgh Street, London EC1V 0AH, UK.

ELECTRONIC RESOURCES

If you have full Internet access, websites offer some of the most up-to-date information on treatment issues.

The **AIDS Treatment News Internet Directory** provides a starting point for finding HIV treatment information on the web (and elsewhere) at: <http://www.aidsnews.org>

Background materials and outputs from an on-line conference on 'Anti-retroviral (ARV) treatment in developing countries: Questions of economics, equity and ethics' are available at:

<http://www.worldbank.org/aids-econ/arv/>
For information on care of children with HIV go to: <http://www.pedhivaid.org>

AF-AIDS DISCUSSION FORUM ON HIV/AIDS

If you have access to e-mail, you can join the AF-AIDS discussion forum on HIV/AIDS in Africa free of charge by sending an e-mail to: af-aids@hivnet.ch with the word 'join' in the subject line.

Each day members discuss regional HIV issues, share their experiences about what works and what does not work in response to the epidemic, share news from the region and forthcoming events such as conferences and workshops. The forum is also linked to the discussion forum SEA-AIDS in Asia.

For further information contact:
E-mail: info@hivnet.ch
Website: <http://www.hivnet.ch/fdp>

Ways to work with men

Men's sexual health matters is a new publication from Healthlink Worldwide that provides practical information for people who are working with men on sexual health or intend doing so. It looks at ways of involving men in discussions about sexual health and sexual responsibility at different ages and in many settings. It contains exercises, role plays, illustrations and suggested resources.

Single copies free to individuals and indigenous organisations in developing countries; £10/US\$20 elsewhere.



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Contact: hnet@usa.healthnet.org

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