

Supporting community action on AIDS in developing countries



Trainers' manual

COMMUNITY ENGAGEMENT FOR ANTIRETROVIRAL TREATMENT

Participatory tools and activities for civil society organisations
working with people with HIV

Acknowledgements

This training manual draws on the experiences of the International HIV/AIDS Alliance and its partners in developing approaches to community engagement for antiretroviral treatment.

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This manual is aimed at providing accurate information for lay people and is not intended to be used as a manual for clinicians. Any of the treatments mentioned in this manual must only be prescribed and used in accordance with standard treatment guidelines authorised in the country of use. While the advice and information in this book are believed to be true and accurate at the date of going to press, the International HIV/AIDS Alliance will not, to the maximum extent permitted by any relevant law, have any responsibility or liability for any errors that may have been made.

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Front cover photo: ACER Project Team, International HIV/AIDS Alliance in Zambia (left to right) Upper row: Mauld Maila Inaka, Catherine Samiselo (not ACER team but Alliance Zambia staff member responsible for PLHA involvement), Miriam Banda, Ruth Siabwacha, Harry Sakanya. Below: Paul Yengwe, Eric Nachibanga

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"HIV is seen in the clinics, but it lives in the community."

*Alliance community ARV workshop participant,
Lusaka, 2004*

In June 2006, the United Nations General Assembly affirmed its commitment to the goal of universal access to comprehensive prevention programmes, treatment, care and support by 2010. They called upon international and national bodies, the public and private sectors, civil society, people with HIV and communities affected by HIV/AIDS to work closely together to achieve this. By the end of 2005, only two million people were able to access antiretroviral (ARV) treatment out of a total of six million people estimated to be in need of treatment.¹

As well as the urgent need to increase treatment access, there is a growing awareness of the critical need for communities to be involved in education, preparation and support for ARV treatment. People need to learn about ARV therapy so that they understand the full range of issues involved and can accurately pass on information to those who need it in their communities. This includes not only people who are taking, or will need to take, ARV treatment themselves but also all those within the community who have a role in informing, supporting and advocating for treatment.

The success of ARV treatment depends on achieving high levels of adherence, sustaining protective behaviours and reducing stigma at the personal and community levels. Inadequate adherence to treatment can compromise a person's health by enabling a rapid increase in the amount of HIV in the blood and allowing the virus to change in ways that make ARV treatment less effective or stop working.

However, sustaining adherence to lifelong treatment, reducing HIV/AIDS-related stigma and sustaining protective behaviour will all require much more than reliable provision of ARV medicines. There must also be effective community and individual education about ARV treatment, including how to take and adhere to treatment; how to manage drug side effects; how to prevent HIV transmission; and how to access supportive care. Communities also need information on issues such as equity of access and criteria for enrolment into ARV treatment programmes. All of these will increase community knowledge and understanding of HIV and ARV treatment, help to increase uptake of voluntary counselling and testing (VCT) and ARV treatment, and will support individuals with their treatment and help to reduce stigma and discrimination.

Key community leaders and structures can provide vital support for successful provision and use of ARV treatment. This includes:

- treatment education
- working with service providers
- developing community referral mechanisms for VCT, treatment and psychosocial support
- involving people with HIV
- strengthening mechanisms to support and promote adherence, prevention and stigma reduction.²

Successful community engagement in ARV treatment programmes and support will result in increased social capital among people with HIV and the wider community, and will play a unique role in the continuing efforts to combat HIV/AIDS.³

¹ www.who.int/hiv/universalaccess2010/en/; www.unaids.org/en/Coordination/Initiatives/default.asp; www.who.int/hiv/fullreport_en_highres.pdf

² International HIV/AIDS Alliance (January 2005) 'What is community engagement for ARV treatment?' at: www.aidsalliance.org/sw7427.asp

³ There are various definitions of 'social capital'. The frequently used World Bank one defines social capital as processes that establish networks, norms and social trust between people, and facilitate co-ordination and co-operation for mutual benefit.

Abbreviations

®	registered trade mark
ACER	ARV treatment Community Education & Referral project (Zambia)
AAS	Association African Solidarité
AIDS	acquired immunodeficiency syndrome
Alliance	International HIV/AIDS Alliance
ANCS	Alliance Nationale Contre le SIDA
ART	antiretroviral treatment or therapy
ARV	antiretroviral drug(s)
CBO	community-based organisation
CD4	white blood cells, also called T4 cells
CNLS	Comité National de Lutte Contre le SIDA
HAART	highly active antiretroviral therapy
HIV	human immunodeficiency virus
HIV-1	the most common strain (version) of HIV in Africa
HIV-2	the less common strain of HIV, which is less easily transmitted and mostly found in West Africa
IEC	information, education and communication
IGA	income-generating activity
INN	international non-proprietary name
ISAARV	Senegalese Initiative for Access to ARVs
NGO	non-governmental organisation
NI	nucleoside inhibitor
NNI	non-nucleoside inhibitor
NNRTI	non-nucleoside reverse transcriptase inhibitor
NRTI	nucleoside reverse transcriptase inhibitor
PCP	pneumocystis pneumonia
PCR	polymerase chain reaction
PI	protease inhibitor
PMTCT	prevention of mother-to-child transmission
Q&A	question and answer session
STI	sexually transmitted infection
T4	white blood cells, also known as CD4 cells
TB	tuberculosis
UNAIDS	Joint United Nations Programme on HIV/AIDS
VCT	voluntary counselling and testing
WHO	World Health Organization

Founded in 1993, the International HIV/AIDS Alliance (the Alliance) is an international non-governmental organisation (NGO) based in the UK. The Alliance aims to support communities in developing countries to play a full and effective role in the fight against HIV/AIDS. It has ongoing programmes in over 20 countries and has provided technical and financial support to more than 2,000 NGOs and community-based organisations (CBOs) in over 40 countries.

The Alliance supports NGOs, CBOs and the communities they represent to be actively involved in the care and support of people with HIV and their families. Activities are carried out alongside and in collaboration with public and private sector health professionals. A number of projects supported by the Alliance have a special focus on ARV treatment:

- **Burkina Faso** Association African Solidarité (AAS) is a long-term Alliance partner NGO that has developed a community-based ARV treatment model, *Projet Orange*. Through this initiative, 300 people are accessing life-saving ARV treatment. *Projet Orange* has enabled development of specific adherence and prevention support strategies in which communities are directly involved.
- **Cambodia** The Khmer HIV/AIDS NGO Alliance (KHANA), an Alliance partner, is supporting ARV treatment pilot projects implemented by *Médecins Sans Frontières* that focus on community-based support for ARV treatment. KHANA brings to these projects its rich experience in community-based care, prevention and support, as well as its history of supporting greater involvement of people with HIV in its work.
- **Caribbean** The Alliance is a partner in the Caribbean HIV/AIDS Regional Training initiative (CHART) with the role of ensuring that the voices of people with HIV are heard and their needs addressed by health service providers, developing an innovative participatory feedback process to incorporate into CHART's work with providers.
- **Côte d'Ivoire** The Alliance has a comprehensive PEPFAR-supported HIV/AIDS programme that includes a programme supporting community engagement for ARV treatment. It has a specific focus on involving people with HIV in the delivery and support of ARV treatment.
- **India** The Alliance is conducting a formative assessment of the community support needs of people on ARV treatment. The results of this study will be used to develop models for involving CBOs, NGOs and people with HIV in the national scaling up of ARV treatment.
- **Nigeria** The Network on Ethics, Human Rights, Law, HIV/AIDS Prevention, Support and Care (NELA) is an NGO that has been providing support to many local organisations engaged in care, support and treatment for people with HIV. Training and support are given to ensure development of strong community engagement for ARV treatment.
- **Ukraine** The Alliance is the principal recipient of funds from the Global Fund to Fight AIDS, Tuberculosis and Malaria for a national programme enabling 4,000 people throughout the country to access ARV treatment. The Alliance is also planning operations research on the impact of ARV treatment on the Ukrainian health system.

- **Zambia** The Alliance's ACER project provides community education, treatment support and a community referral system for people using government ARV clinics. A team of people with HIV work as treatment educators and adherence counsellors, providing a living witness to the effectiveness of ARV treatment and the real possibility of living a full and healthy life with HIV.

Drawing on experience from these projects, the Alliance has been involved in the development of many tools and resources on ARV treatment. Some of these are listed in the 'Useful resources' section. A complete list of Alliance care and treatment resources can be found at: www.aidsalliance.org/sw7418.asp

Why was this manual developed?

A rapidly growing number of people with HIV are gaining access to ARV treatment. AIDS service organisations and other civil society actors, including religious organisations, have played an important role in the medical and psychosocial care and support of people with HIV for many years. Many of these key civil society actors work in collaboration with each other and have built partnerships with public and private sector health professionals. Staff and volunteers of CBOs and NGOs are a valuable human resource, working alongside doctors, nurses, social workers and psychologists who are often far too few in number to cope with the high volume of patients. All those involved in delivering, supporting or taking ARV treatment should be trained and informed about the range of issues related to ARV treatment.

Recognising the essential need for NGOs and CBOs to learn more about ARV treatment and how it affects people with HIV and their communities, the Alliance has developed an ARV training course targeted primarily at NGO and CBO staff and volunteers. This training course enables essential aspects of ARV treatment to be explained in layperson's terms to those who have had no medical training. Its aim is to raise awareness and prepare CBOs and NGOs for greater involvement on a number of levels:

- supporting people with HIV who are on ARV treatment, and their families, particularly in terms of facilitating treatment adherence
- preparing people with HIV who are not yet on ARV treatment but who might need it in the future
- providing information on ARV treatment to the general population through community education and promotion of HIV testing and prevention
- advocating for ever-greater access to ARV treatment, particularly for the most disadvantaged, along with high-quality comprehensive care for people with HIV
- designing, delivering, monitoring and evaluating ARV treatment programmes.

Although a lot of important information on ARV treatment is included in this manual, this is only an initial training course. CBOs and NGOs who wish to provide support for treatment adherence and prevention, for example, would need to provide additional training to their members, particularly on one-to-one and group psychosocial skills.

The course does not provide medical training and it is not aimed at health professionals. Nevertheless, health professionals may find some of the tools included in the manual helpful, as they can be used in treatment education for patients and their families or other supporters. Some front-line health workers who have been participants in Alliance ARV training workshops have found the participatory approach helpful in revising and supplementing training that they have received within the health system.

The manual is designed to be used by CBOs and NGOs in training activities. It is also a useful resource for national and international organisations or consultants providing technical support to CBOs and NGOs in English-speaking countries. A French version of the manual is also available from the Alliance.

How was this manual developed?

The original French version of the training manual was field tested in Senegal and Côte d'Ivoire during 2004 at pilot training workshops attended by representatives of local AIDS CBOs and NGOs:

- CBOs/NGOs involved in caring for people with HIV, some of them already implementing activities directly related to ARV treatment at community level
- CBOs/NGOs without any experience in ARV care or treatment
- national networks of people with HIV.

Workshop participants included people with HIV, many of whom were on ARV treatment, as well as health professionals, social workers and educators. The participants' knowledge about ARVs was very varied. However, all participants had very good experience of working at community level.

The content and methodology of the training activities in the manual were either amended or validated depending on participant reactions and comments during the two pilot workshops.

The training workshops were led by multidisciplinary teams of Alliance consultants and staff, doctors, heads of AIDS CBOs/NGOs or networks of people with HIV, social workers and pharmacists. As well as facilitating the workshops, team members also contributed to improving the manual.

Activities developed in the French-speaking workshops were adapted and developed for use in English-speaking settings, with the addition of traditional healers and professional front-line health workers among the participants. Additional activities on stigma, prevention and the 'treatment journey' were tested in Zambia and the Caribbean.

What is in the manual?

The manual is divided into thematic modules:

1. Basic information on HIV and ARV treatment
2. Starting ARV treatment – who needs it and when?
3. ARV treatment information and how to provide it
4. Adherence to ARV treatment
5. ARV treatment follow-up
6. Changing ARV treatment
7. ARV treatment – differences between men and women
8. Living with ARV treatment – new horizons
9. ARVs and the prevention of mother-to-child transmission
10. ARV treatment for children
11. The role of CBOs/NGOs in supporting people on ARV treatment.

Each module contains one or more participatory activities plus additional information, suggestions for materials to use in the activities and examples of activity results from trainings in various countries.

The modules are designed to be used in the order in which they are presented. However, the manual may also be used in a more flexible way so that the training schedule can be shaped to meet the needs of the participants. For participants with little knowledge of ARV treatment, it would be essential to begin the training with the first two modules in the manual. In other settings, with more experienced participants, one should still review the basic information on ARV treatment before continuing with other modules.

The manual also includes a number of annexes that contain information for photocopying and distributing to participants at different stages throughout the training:

Annex 1 Tables of ARV medicines⁴ available at the end of 2005 The list is subdivided according to categories (types) of ARVs. Each entry gives the generic name, the commonly-used abbreviation, the brand name and the names of producers of the drug (including both generic and originator companies).

⁴ Throughout this manual, the word "drug" generally refers to a specific substance (chemical) that has a clinical use in treatment. The word "medicine" generally refers to the form in which the drug is made available for use (for example, as a tablet or capsule). However, in daily use the two words are often interchanged or taken to mean the same thing.

Annex 2 Fact sheets on ARV medicines available at the end of 2005 Each sheet contains the following information on each of the available ARVs:

- the category of ARV to which the medicine belongs
- the presentation (for example, as tablets, capsules, syrup)
- the daily dose
- food restrictions, where appropriate
- the main side effects
- the main interactions with other drugs
- interactions of this drug with other ARVs
- storage requirements.

Annex 3 Examples of prescriptions for ARV triple combinations, with doses relating to weight of patient

During the training course there are many activities based on 'fictional' prescriptions (lists of drugs for a particular patient). Participants are asked to use these to develop case studies or role plays about individuals using these prescriptions. The list in the annex provides a range of common ARV combination therapies, and includes the weight of the 'patient', the name of each drug and the way in which each must be taken – just as a prescription would in real life. This list is not an exhaustive one, and facilitators should choose prescriptions that are typical for their country for use in training activities.

Annex 4 Fact sheets on the main side effects of ARVs

Each sheet contains the following information on a particular type of side effect:

- an explanation of how the side effect is experienced
- the ARVs that cause this side effect
- action that should be taken to deal with this side effect
- advice on how to prevent or reduce this side effect.

Annex 5 Example of an agenda for a training workshop

If all the modules are used, a training course will require five days. An example of a five-day training workshop is given in this annex. However, it is also possible to group the modules into a series of mini-workshops of one, two or three days. Also, some modules can be used independently to provide the basis for a one-day training event.










Annex 6 Wall chart headings These can be photocopied onto card or paper for use in the activities described in modules 1 and 2.

How should this manual be used?

Each module is made up of one or more training sessions. Each session is generally broken down into different activities using a wide range of methodologies. For each of the sessions, the manual provides a fact sheet offering guidance for carrying out the session.

The training session fact sheets

For each training session, the fact sheet provides the following sections:

-  The **aim of the session**. This is what the participants will be capable of doing by the end of the session. It is also what the trainers will be able to evaluate, primarily by asking questions.
-  A summary of the **methodology** used in the session. For example, whether it will involve group work, making a presentation or carrying out a role play.
-  The **time required** for the session. This gives the estimated time based on field tests. However, the length may vary according to the number of participants. The trainers can decide whether to adapt the methodology in order to shorten or extend the time.
-  A list of the **materials needed**, including a list of **documents for distribution to participants** during the session (for example, information on locally available ARVs). The documents will be found at the end of the session fact sheet or in an annex for photocopying.
-  A step-by-step **outline** of the **activity**, including the different activities to be carried out during the session.
-  **Essential information** To provide to participants during the session. This is information that the participants must be able to understand fully and remember. The trainers must ensure that all the information is covered during the activity. At the end of the activity, or at least by the end of the training course, the trainers must check that participants have remembered and understood the information.
-  **Additional information** This is information that is not absolutely essential but may be useful for answering participants' questions. It is based on questions raised during field tests. Trainers should not feel obliged to cover this information if participants do not ask for it. However, it may be worth asking participants some questions and providing this information if there is time available and the participants are likely to benefit from it.
-  **Notes for the facilitator** To draw attention to important aspects of the training session.
-  **Preparation** This section informs trainers about the materials they will need to prepare before the session starts (for example, posters or photocopies to be made). Careful preparation is essential, both before the workshop and before each session.

For most sessions, the fact sheet is followed by additional information and examples to help the trainers facilitate the training successfully:

- The content of posters presented during the session, particularly on ‘essential points to remember’ from the session. If trainers choose to use these posters, they must be prepared before the session and be shown to participants at the end of the session in order to recap the information that participants should remember from the session. The trainers can ask questions to check that participants have understood the information provided.
- Some examples of what participants produced during workshops in Senegal, Côte d’Ivoire and Zambia are included.

To ensure that the manual is used properly and that the training course is successful, trainers are advised to read it through carefully and make sure they understand it fully before using it. This will enable them to research any content they may be unsure of, to adapt the methodology where appropriate and to decide how to divide up the training sessions between the different trainers.

What training methodology is used?

The training methodology used in this manual is highly participatory. We have favoured an interactive approach that takes the existing knowledge of the participants as its starting point, so that they are truly involved in the learning process. As far as possible, the training should be enjoyable and entertaining, making serious information accessible and easily understood. We have avoided using lectures followed by question and answer sessions, since these can be too academic and would not be sufficient to help participants learn and make use of new information within a short space of time.

The trainers’ attitude is crucial in this kind of training. Some participants may start the training feeling that the issue is a complicated one and that they will not be capable of understanding it because they are not health professionals or because they are not ‘educated’. Openness and willingness to share, based on respect for the participants and their experiences (whatever these may be), will encourage them to learn. An arrogant attitude on the part of the trainers will block the learning process.

Some practical advice for trainers

- Ask participants to sit in a circle or semi-circle, never in rows or behind tables like at school or university.
- Move any tables out of the way so that participants and trainers (therefore ideas and learning) can move freely.
- Never start to explain something new without checking first if any of the participants can explain it. Encourage group dynamics by asking participants to correct and supplement each other’s responses. You will be surprised at how much knowledge the participants already have.
- You are not there to tell the participants how little they know. On the contrary, you are there to show them how much they know and to add to their existing knowledge.

The activities deliberately favour the use of materials that can be reproduced at low cost by organisations in their community work. We have therefore avoided presentations that require overhead projectors or computers, since many CBOs/NGOs do not have easy access to such equipment.

Using colour codes as a training tool

Participants are expected to take in a lot of new information during this training. The methodology aims to make this as easy as possible. Colour coding, which means associating a specific colour with a specific type of information, is part of this methodology. Consistent use of colour codes will make it easier for participants to identify types of information and to retain what they have learned after the training is completed.

Colour codes are used in the activities on the actions of HIV and ARVs in the human cell and in the activities that include names and categories of ARV drugs.

Six contrasting colours are required, but they do not have to be exactly the same ones used in this manual. The important thing is to be consistent. For example, if yellow is chosen for protease inhibitors, they must be associated with yellow throughout the training. Thin card is best, but coloured paper can be used. If neither are available, white card or paper can be used, with writing in coloured marker pen.

You can facilitate the training without colour codes, but coding will make your job much easier.

- Call on the practical experience that some participants may already have, whether they are health professionals, people on treatment or carers. Concrete examples given by participants will have far more impact than long, theoretical explanations.
- You are a trainer not a teacher. You are not there to impress the participants with your knowledge but to facilitate their learning.
- The materials you use are there to help you provide better explanations. If these are not going down well with the participants, use your imagination and create different support materials.
- Use your sense of humour.

Introduction

Who should be involved in the facilitation of training?

A multidisciplinary team experienced in ARV treatment issues should facilitate the training. The minimum number of trainers is two, but three would be best. All trainers should be present throughout the training course because the modules are all linked to each other.

At least one trainer (but preferably all trainers) must be experienced in using participatory methods. It is advisable that at least one trainer should also be a person with HIV who is on ARV treatment. One trainer with clinical experience in ARV treatment is essential, but you could also have facilitators who have already been involved in adherence support or treatment education (for example, staff or volunteers of CBOs/NGOs, a nurse, a psychologist or a social worker).

It is important to demonstrate that good training can enable NGO and CBO members who are not health professionals to gain a good grasp of information and issues relating to ARV treatment. Ensure that different training modules are facilitated by the different members of the training team so that it becomes clear that medical information can be accessible to lay people, not only to trained health workers. The job of the trainers is to demystify the information and make it accessible to participants so that they in turn can pass on the correct information and advice in appropriate language to people with HIV and community members.

Thorough preparation is vital for this type of training. It is important to have all materials and information ready to use. It is also essential that trainers should work together to prepare for all the sessions and to make sure that everyone understands their role and has a good understanding of the information and activities that are needed.

Example: Introductory session for an ARV treatment training workshop

ARV treatment training for organisations working with HIV-affected communities can be provided in a variety of ways: a workshop of several days or several mini-workshops of one or two days. How the training takes place will depend on the availability of participants and trainers and on the local context. An example is shown opposite of an introduction for a full workshop over several days. The stages shown in this introduction remain the same whatever training format is chosen. However, the methodology and contents of this session can be adapted according to the time available for the training.

Aims of the workshop

To build skills relating to ARV treatment for NGOs and CBOs providing care and support for people with HIV

- inform participants about issues linked to ARV treatment
- to adapt and develop practical tools and methods for information and training on ARV treatment issues, relevant to the needs of organisations and communities.

To reflect on strategies for integrating ARV treatment issues into NGO and CBO programmes, including:

- care and support for people with HIV on treatment, and their families (including support for treatment adherence)
- information and awareness for people with HIV who are not yet on treatment but who might be in the and how to get access)
- information on ARV treatment for the general public associated with prevention work and promotion of HIV testing (integration into information, education and communication (IEC) campaigns, prevention outreach work)
- advocacy for increased access to ARV treatment and ensuring delivery of acceptable quality treatment (choice and quality of drugs, quality of follow-up care).

The workshop does *not* provide

Medical training

By the end of the workshop you will not be able to prescribe drugs as a doctor would.

Complete training on ARVs

- You will not be an ARV treatment specialist at the end of the workshop
- You will require extra training in order to provide effective care for people on treatment
- Information on ARVs is continually being updated, so it is necessary to keep up to date on a regular basis.

Training for adult educators

- This manual does not provide a 'training of trainers'
- The activities in the manual, however, can be used as elements in a training course for trainers.

The workshop will familiarise you with the key issues relating to ARV treatment

It will provide you with a realistic understanding of the problems and risks, and a clearer definition of your potential role and that of the organisations involved in this area.

Example: Introductory session for an ARV treatment training workshop

Introduction to the workshop



Aim of the session

- Ensure that the trainers and participants all get to know each other
- Explain to the participants what the training workshop involves
- Explain the aims of the workshop
- Define the ground rules for group work during the training
- Allow participants to express what they expect to get out of the training
- Discuss expectations for the workshop highlighting those that will be met and those that cannot be met during the training
- Gain the commitment of participants to take part in the learning process.



Methodology

- Presentations
- Q&A session led by the facilitators



Time

1 hour 40 minutes



Materials needed

- Large post-it notes
- Flip chart with instructions for presentations and ground rules for working
- Photocopies of the workshop programme – what will be covered and when (Annex 5)
- Posters 'Aims of the workshop' 'The workshop does *not* provide' (see page 8)
- A4 paper sheets, cut in half.



Activity

Presentation of participants

- Give each participant a post-it note. Ask them to write on the post-it (in large letters) the first word that comes into their head when they hear the word 'antiretroviral'. Ask them to stick the post-it on their chest
- Ask participants one by one to give their name, organisation, job, place of work, to say briefly how ARV treatment relates to their work, and to explain why they thought of the word on their post-it.

Presentation of the aims of the workshop

- Present the aims of the workshop, referring to the flip charts prepared beforehand
- Answer any questions from the participants.

Presentation of the agenda and the methodology used

- Give participants a copy of the workshop agenda and go through it with them.

Ground rules for working in groups during the workshop

- Ask the participants to suggest workshop ground rules
- Write these ground rules on a flip chart and keep it visible on a wall throughout the workshop.

Expectations of participants

- Give each participant a half sheet of A4 and ask them to write one question on ARV treatment that they would like to be answered by the end of the workshop
- Ask all participants to stick their sheets on the flip charts provided
- Read the questions one by one and say if each expectation will be met during the workshop.



Preparation

- Prepare posters 'Aims of the workshop', 'The workshop does *not* provide' (see page 8) on flip charts
- Prepare flip charts with headings 'Ground rules' and 'Presentations'.

Basic information on HIV and ARV treatment

Effect of HIV on the human immune system



Aim of the session

At the end of the session participants will be able to explain:

- the effect of HIV on the human immune system (CD4 cells, also sometimes called T4 cells).



Methodology

- Q&A session led by the trainer(s)
- Interactive presentation explaining the effect of HIV on the human immune system, using stick-on drawings/diagrams on flip charts



Time

35 minutes



Materials needed

- Flip chart with drawing of CD4 cell
- Card cut-outs in different colours representing three elements – HIV viruses, reverse transcriptase enzyme and protease enzyme (see Figure 1, page 14)
- Blu Tack or fixing tape to attach the cut-outs to the flip chart.



Notes for the facilitator

- Even if you think that participants already understand the essential information, it is important to use this activity as a preparation for the following activity. It is impossible to understand how antiretroviral drugs work unless you first understand how HIV affects the immune system
- Limit the use of scientific terms or technical jargon as much as possible. If you use technical words, always check if participants understand them, and explain them in plain language before you continue. Do not intimidate participants or make explanations too confusing. Encourage them to ask for an explanation if there is something they do not understand.
 - There is no need to explain in detail what a retrovirus is. Only the name is important to be able to explain the term 'antiretroviral'
 - There is no need to explain that transcriptase and protease are enzymes. It is enough to say simply that they are parts of the cell



Activity

- Ask participants what they understand by the terms 'HIV' and 'AIDS'.
- Ask participants to explain how HIV attacks the immune system. For example: 'Who can explain how HIV attacks the immune system?' When they have responded, go on to explain and ask: 'This is a simplified drawing of CD4 cells. Who can show us how HIV enters the cells, what it does inside the cell and how it moves out of the cell?'
- Based on the explanations already given by participants, use the coloured cut-outs to show in stages on the flip chart how HIV gets into the CD4 cells, enters the nucleus and multiplies. For example, start with how HIV breaks through the cell membrane, then explain how HIV uses the nucleus etc. (see 'Essential information'). Before explaining, always check at each stage what participants already know and ask volunteers to explain this visually using the cut-outs on the flip chart. The trainer should then correct misunderstandings or add more information as appropriate.



Essential information

What is HIV?

Human Immunodeficiency Virus is the virus that causes AIDS. The virus affects only humans; it is transmitted from human to human, not from human to animal or animal to human.

HIV is one of a group of viruses called retroviruses, which is where the name of the group of drugs used to treat HIV comes from – **antiretroviral** drugs (also often called ARVs).

What is AIDS?

Acquired	=	something that happens during your lifetime, not inherited or transmitted by genes
Immune	=	the body's defence system
Deficiency	=	lack or reduction in strength
Syndrome	=	signs or symptoms that appear in the body and are due to the same cause

In other words, AIDS is the effect of various illnesses that appear when HIV has seriously reduced the ability of the body to defend itself against infections and other diseases.

The effect of HIV on the immune system

HIV enters the body and attacks the body's defence cells – the **CD4 cells**. This is why we say that it attacks a person's immune system. It enters these cells by breaking through the cell membrane.

The virus needs to move into (infect) the nucleus of the cell so that it can make new copies of itself (reproduce). In order to do this, after it enters the CD4 cell, it needs to 'adapt' or to change itself in order to survive. It requires help to do this, which it gets from a part of the cell called **reverse transcriptase**.

Then, the virus copies itself to make many new, small viruses that need further help to grow to full size. This help is provided by **protease** in another part of the cell, which allows the viruses to become fully grown (mature) before leaving the cell to infect other CD4 cells.

Explanation with use of the images on the flip chart HIV re-enters the body and attacks the 'soldier' cells that defend the body (T4 or CD4). As the HIV virus multiplies, it kills more soldier cells, the number of soldier cells falls and the body loses its natural defences, allowing AIDS illnesses to develop.

Effect of HIV on the human immune system

- If a participant or facilitator uses a scientific term, they should be asked to explain what they mean in simpler language
- If complex terms or words cannot be avoided, write them up on a flip chart while you explain what they mean.
- Use cut-outs made from coloured card rather than just drawings to show how HIV acts on the immune system. This is because:
 - this method makes it easier to explain how the different elements interact, since you can move them around on the flip chart
 - it allows participants to see better what you are explaining – drawings on flip charts are not always easy to see, especially if participants cannot get close enough to them
 - you can leave the flip charts on the walls of the room throughout the training and can re-use them to support learning during other activities.
- In order not to waste time during the session, make sure that all the materials for this session are prepared in advance.



Preparation

- Prepare two flip charts with simple drawings of a CD4 cell, including the nucleus and the cell membrane (see Figure 1, page 14)
- Make colour cut-outs of HIV viruses (large and small), reverse transcriptase and protease. Write the name of each element in large capital letters using a marker. It is important to have a clear colour coding system so that participants do not get confused.



Additional information

Why do we say that HIV is 'acquired' and not inherited, yet it can be transmitted from a mother to her child?

We can say that the virus is not inherited by the child from its mother because HIV is not in the mother's genes. Transmission happens through the placenta during the last few weeks of pregnancy, during labour when the baby is in contact with the mother's blood, or in breast milk after birth.

If HIV is only a human virus, why are tests carried out on animals?

Micro-organisms such as HIV can live in certain animals, but they do not develop in the same way as in humans. It is only in humans that these micro-organisms can develop.

What is the difference between a person with HIV and a person with AIDS?

An HIV-positive person is someone who is infected with the virus. He or she can be described as **asymptomatic** if no signs or symptoms of HIV-related illness have yet appeared. A person who has a weakened immune system and has signs and symptoms is described as **symptomatic** – this stage is described as AIDS. If a person with symptoms gets effective ARV treatment and becomes asymptomatic again, he or she can no longer be described as having AIDS, but will still be a person with HIV infection.

How long does it take for the HIV virus to establish itself in the cell?

Immediately, as soon as it is in contact with the cell membrane.

How long does it take for the HIV virus to start to multiply?

As soon as a person becomes infected with the HIV virus, multiplication (replication) of the virus begins. Even if a person is asymptomatic, the virus is still multiplying.

Why do HIV screening tests not detect the virus immediately after infection?

Currently HIV screening tests detect antibodies that the human body produces when it is attacked by the HIV virus. The time between infection and when the body starts to produce its antibodies to HIV is called the **seroconversion period** – sometimes called a **window period**. This period can be up to three months. This is why people are told to wait three months from when they thought they might have risked infection until being tested. However, during the seroconversion period the HIV virus is already multiplying.

Is it possible to have HIV-1 and HIV-2 at the same time?

There are two main types of HIV: HIV-1 and HIV-2. A person can be infected with HIV-1 and HIV-2 at the same time. HIV-1 is the more aggressive type and is the most common; HIV-2 is less common but is sometimes present in people in or from West Africa.

Basic information on HIV and ARV treatment

Effects of ARV drugs on HIV



Aim of the session

At the end of the session, participants will be able to:

- name the categories of ARVs that are available in their country
- explain their respective roles in HIV treatment
- explain why a person must take several types of ARV medicines at the same time, and explain what is combination therapy and triple therapy in particular
- explain the benefits of ARVs (a stronger immune system, less illness related to HIV/AIDS, return to normal weight, possibility of having a social life, ability to work, longer life expectancy)
- explain why ARV treatment must continue to be taken for life once it has been started
- explain what ARVs do not do (they do not make HIV disappear from the body)
- explain that a person who takes ARV treatment can still transmit HIV.



Methodology

- Q&A session led by the trainer(s)
- Interactive presentation on the effect of different categories of ARVs on HIV



Time

45 minutes



Materials needed

- Flip chart with drawing of CD4 cells used during the previous session
- Thin card cut-outs in different colours representing HIV, reverse transcriptase and protease used during the previous session
- Thin card cut-outs in different colours representing the three main categories of ARVs – nucleoside reverse transcriptase inhibitor (NRTI), non-nucleoside reverse transcriptase inhibitor (NNRTI) and protease inhibitor (PI). Use a different colour for each ARV category and maintain the colour code throughout the workshop (see page 7 and Figure 2, page 14)
- Blu Tack or fixing tape to attach the cut-outs to the flip chart



Activity

1. Interactive presentation on the effect of different categories of ARVs on HIV. Ask participants: 'Do you know how ARVs act against HIV?' Check if some participants already understand that different types of ARVs act in different parts of the cell, and ask them to use the cut-outs and the flip charts to explain it visually to the others. The trainer should then correct misunderstandings or add more information as appropriate (see the poster 'Essential points to remember about the effect of ARV drugs on HIV', page 15).
2. Using the flip chart diagrams with their cut-outs as a basis, present other important issues using Q&As. For example, the questions -
 - Why must a person take several categories of ARVs at the same time?
 - How many must they take?
 - Which combinations are available in this country?
 - What is the approved first-line treatment in this country?
 - Why must a person take this treatment for life once it has been started?
 - What are the benefits of ARVs for patients taking this treatment?
 - What do ARV drugs *not* do?
3. Review the key points while asking the questions, using the poster 'Essential points to remember about the effect of ARV drugs on HIV', page 15).



Essential information

How do ARVs act against the virus?

In very simple terms ARVs prevent the virus from entering the CD4 cells, from developing inside the cells and from leaving the cells.

In slightly more detail There are three ways in which existing drugs work:

- Some prevent or inhibit fusion (combining) of the virus with reverse transcriptase, so preventing or restricting adaptation of the virus in the cell. Two families of drugs do this: **nucleoside reverse transcriptase inhibitors** (NRTIs or nukes) and **non-nucleoside reverse transcriptase inhibitors** (NNRTIs or non-nukes)
- Some inhibit protease and therefore stop the new virus particles from growing. These are called **protease inhibitors** (PIs).
- Recently, another type of drug has been developed that can prevent HIV from breaking into the CD4 cell. These are called **attachment or fusion inhibitors**. By mid 2006 only one of these drugs was available, but it has limited use because it must be given by injection and is very expensive.

Why do several ARVs have to be taken at the same time?

Different categories of ARVs have different and complementary effects in their action against HIV. The different groups or families of drugs stop the virus from multiplying (replicating) at different stages within the CD4 cell. At least three drugs, preferably from at least two categories, must be used together. This is known as **triple therapy** or **HAART** (highly active antiretroviral therapy)

Note: During the presentation, illustrate the explanations by using the flip chart and showing what can happen when one or other type of drug is removed.

How many drugs must patients take?

A person must use at least three drugs from two families in order to act at both stages of HIV replication at the same time and be truly effective in fighting HIV. This is called triple therapy.

Note: Make sure that participants do not confuse the number of ARV drug groups that must be used together for treatment with the number of tablets or capsules that a person must take each day.

Effects of ARV drugs on HIV

- Poster listing the ARV treatment protocols currently used in the participants' country
- Poster with 'Essential points to remember about the effect of ARV drugs on HIV' (see page 15)

Notes for the facilitator

- Explain carefully that the various ARVs work in different ways. It is important for participants to understand that different types of ARVs must be combined for effective treatment
- In order to illustrate the possible combinations of ARVs, trainers can fix A4 cards (see Annex 5) with the name of each category of ARV to the wall, arranged in the main combinations of ARVs (see Figure 2, page 14). The visual impact is stronger if different colours are used for each category of ARV (using the same colours as in the activity described above). If coloured paper is not available, white A4 paper with coloured lettering can be used
- Pay close attention to the vocabulary used by the participants. Remind them that they cannot use the term 'cure' when talking about ARVs as this is inaccurate. Instead, words such as 'control' or 'manage' can be used
- It is essential to prepare all the materials for this session in advance, preferably before the workshop starts, as this will take some time.

Preparation

- In advance, cut out different coloured card or paper for:
 - NRTIs
 - NNRTIs
 - PIs
- Use distinctive colours that remain the same throughout each activity of the training. For example, blue can be the colour for NRTIs, yellow for PIs and so on, depending on local availability of materials
- Prepare several A4 sheets with the name of each category of HIV
- Think through the activity in advance to make sure you have enough copies of each name/card.

Why do different ARVs have to be taken at different times of the day?

Each drug is dealt with in a different way inside the body. This depends on the special characteristics of each drug. Some drugs pass out of the body quite quickly; others stay around longer. Each dose needs to be taken at a time when the previous dose is already passing out of the body. Taking a dose too soon will increase the risk of side effects. Taking a dose too late allows the virus to start reproducing again before the next dose arrives to stop it. Some ARVs can be taken once a day, many have to be taken twice a day, a few have to be taken three times a day.

Which combinations of drugs are available?

Patients are usually given three drugs from two families of ARVs:

- two nucleoside inhibitors (NRTIs) plus one non-nucleoside inhibitor (NNRTI)
- two nucleoside inhibitors (NRTIs) plus one protease inhibitor (PI)

Note: An entry inhibitor is used only for people whose HIV has become resistant to other ARVs.

Standard or typical combinations of ARVs are agreed to be the most effective by international and national authorities, and have been published as standard treatment protocols or guidelines.

Which combinations are used in this country?

Show the available combinations on a summary flip chart (see the poster 'Standard first-line ARV treatment protocols', page 15).

What is a 'first-line' treatment protocol?

A **first-line** treatment protocol is the standard combination of ARVs that should be prescribed for a person with HIV who has never had ARV treatment before. Such a person is also sometimes called a 'treatment-naïve' patient.

Why must this treatment be taken for life once it has been started?

If the treatment is stopped, the HIV virus begins to re-establish itself in the cells and multiply. **Note:** This can be easily illustrated on the flip chart by taking away the NRTI, NNRTI and PI stick-on cards, at the same time asking participants what happens when this occurs in real life. If NRTIs or NNRTIs are not used, the virus continues to enter CD4 cells and adapt itself ready for replication. If PIs are not used, the virus starts to multiply (replicate) again.

What are the benefits of ARVs for patients taking this treatment?

- Less illness, return to a more normal lifestyle (patients are able to work again).
- An HIV-positive woman can have a child with a reduced risk of transmission.

What do ARVs not do?

- ARVs are not a cure. The treatment does not remove the virus. The drugs only inhibit the viral replication cycle, but the HIV virus remains in the body
- A person on treatment is still infected and can infect someone else, even if the viral load is low or undetectable (cannot be found using laboratory tests).

What happens if a person is treated with only one ARV drug (monotherapy)?

The treatment will be ineffective and drug resistance will develop, which will make further treatment more difficult.

Basic information on HIV and ARV treatment

Effects of ARV drugs on HIV

Additional information

What treatment is available for people who are infected with both HIV-1 and HIV-2?

The same protocol is used for people with both types of HIV as for people who have HIV-2: two NRTIs and one PI (NNRTIs are ineffective against HIV-2).

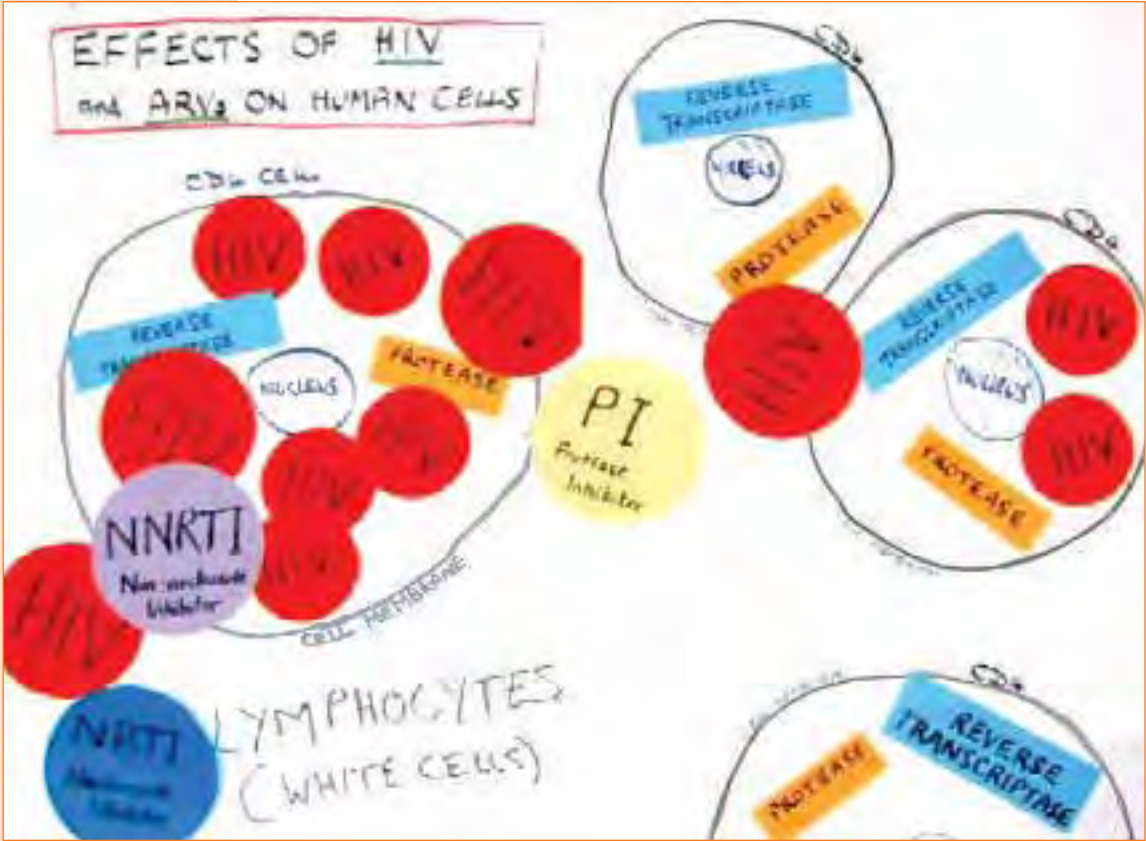


Figure 1 Flip chart for explanation of actions of HIV and of ARVs in human cells, with coloured card cut-outs to show viruses, drug types and so on

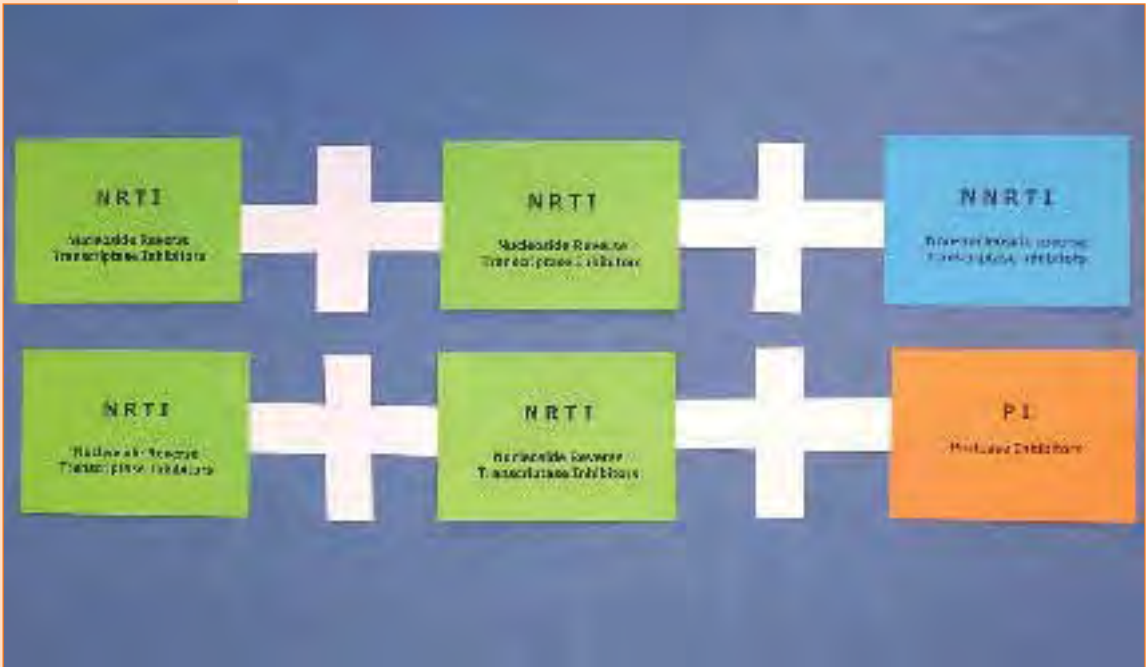


Figure 2 Wall cards showing different combinations of drug types for ARV treatment

Effects of ARV drugs on HIV

Notes (Figure 1)

- When you introduce the various items during the interactive talk, place them (or make sure they are placed) in the correct positions on the flip chart while you give your explanations
- Move the different items around as much as possible; for example, while explaining how HIV changes in the CD4 cell, how it multiplies and how it goes on to infect other cells
- Try to use locally relevant ways of explaining what happens; for example, in many situations, CD4 cells are described as 'soldiers' defending the body. Another way of explaining is that the nucleus of the CD4 cell is like a house, with fences and walls that the virus (a 'thief') tries to break into. The ARVs are the security guards: the NRTIs and NNRTIs try to stop the thief entering right into the nucleus; the PIs try to stop the thief escaping. Work with local facilitators to develop these ways of explaining.

Notes (Figure 2)

- Although this activity might seem simple, it is a very useful way of enabling participants to memorise the combinations of ARV categories, especially for those who rely more on their visual memory
- The trainers can also remove the sheets during the activity and ask the volunteers to put them back up to show the different combinations. This is a way of checking that the participants have understood and can remember the explanations
- No fusion/entry inhibitor appears on the photograph because it is not currently available in many countries. Most ARV treatment programmes cannot use it because of its very high cost and the need for daily injections.

Standard first-line ARV treatment protocols

Adults who have HIV-1

Three ARVs (triple therapy): **2 NRTI + 1 NNRTI or 2 NRTI + 1 PI**

Two nucleoside reverse transcriptase inhibitors (NRTI) and one non-nucleoside reverse transcriptase inhibitor (NNRTI)

or

Two nucleoside reverse transcriptase inhibitors (NRTI) and one protease inhibitor (PI)

Adults who have HIV-2

Three ARVs (triple therapy): **2 NRTI + 1 PI**

Two nucleoside reverse transcriptase inhibitors (NRTI) and one protease inhibitor (PI)

Note: NNRTIs are excluded because HIV-2 has natural resistance to these drugs

Children

Same approach, depending on the availability of paediatric forms of the drugs

Essential points to remember about the effect of ARV drugs on HIV

- The HIV virus attacks the cells that help a person to defend against infections.
- HIV is a retrovirus, so anti-HIV drugs are called antiretroviral drugs (ARVs).
- There are several categories or families of ARV drugs, which have different effects on the HIV virus.
- It is necessary to take several ARV drugs at the same time – at least three drugs from two different families – because they act in a complementary way (they achieve different things at the same time). This is why we call it **triple therapy**.
- Standard triple therapy uses either 2 NRTIs + 1 NNRTI or 2 NRTIs + 1 PI. The exact combination will be decided by the doctor, based on national protocols or guidelines.
- There are two main types of the HIV virus: HIV-1 and HIV-2. Some people have HIV-1 and HIV-2 at the same time.
- ARVs improve the length and quality of life of people with HIV. They can have less illnesses, a chance to lead a normal life and the possibility of having a baby with reduced risk.
- These drugs do not kill the HIV virus nor do they cure people living with the virus. For this reason, the drugs must be taken for life.
- If you are taking these drugs you can still infect other people.

Basic information on HIV and ARV treatment

Names of ARV medicines



Aim of the session

At the end of the session participants will be able to:

- explain the difference between generic/international non-proprietary names (INN), chemical names and commercial names of drugs
- identify different drug names on packages of ARVs and know which is the generic name
- explain and demystify drug names that frequently confuse patients and health workers.

The session also aims, where possible, to allow the participants to handle the drugs and their packaging so that they can familiarise themselves with their appearance (colour, form, size etc.) and their packaging. Encouraging familiarisation through direct contact with the drugs is one way of supporting adherence.



Methodology

- Activity in pairs, including handling drug packages and identifying drug names
- Q&A session led by the trainers



Time

- 60 minutes



Materials needed

- A range of different drug packets or bottles relating to ARVs available in the country or at the place of training
- Five A4 sheets each with the name of one category of ARV – nucleoside reverse transcriptase inhibitors (NRTI), non-nucleoside reverse transcriptase inhibitors (NNRTI), protease inhibitors (PI), fusion/entry inhibitors, fixed (double or triple) combinations (see Annex 5)
- For each of the three categories of ARVs, three more A4 sheets to use as headings, one with generic/INN name, one with chemical name or abbreviation, and one with commercial or brand name (see Annex 5)
- For each ARV, A4 sheets of coloured paper, each with one of the various names for one ARV – first the generic/INN name, then the chemical name or abbreviation, and finally the commercial or brand names. If available, you can also stick the relevant tablet or capsule to each sheet to show participants what it looks like



Activity

1. Stick on the wall the five A4 headings with the categories of ARVs.
2. Present participants with definitions of chemical, generic and brand names of drugs (see 'Essential information') and stick the A4 sheets with these headings under each of the ARV categories. Check that participants understand your explanation of them, using a flip chart to summarise.
3. Ask people sitting next to each other to work in pairs.
4. Give one example of a drug to each pair. Ask them to look at it and identify the generic and brand names of the drug, plus any chemical name or abbreviation. Ask: 'Are there several names on the same box? If so, please note them down.'
5. Depending on available time, ask the pairs to hand their packet, container or label to the next pair when they are ready to look at it. They should be able to look at two or more different ones during the time allowed.
6. After ten minutes or so, bring participants back together and ask some of the pairs to tell the group the generic and brand names and any abbreviation on the packet that they are holding. If they can only give one name, ask the rest of the group if they can say the others. For example, if a pair has a box labelled 'Videx', they give the name 'Videx'. If they say that this is a brand name, place the sheet 'Videx' in the 'trade' names column. If participants give the name 'didanosine', you ask where that goes and they should be able to answer that it goes in the 'generic' (INN) names column. When participants give the name 'ddl', the trainer once more asks where this goes. The participants should indicate that it goes in the column 'chemical name or abbreviation'.
7. When everyone is clear that each ARV often has two or three different names, note these different names in three columns on the flip charts on the wall. Stick up a sheet headed 'generic (INN)' name, another headed 'chemical name or abbreviation' and finally one headed 'trade' name.
8. Then ask participants to explain why each drug has several names, and provide further clarification if necessary (see 'Essential information').
9. Continue for the other drugs. The corresponding tablet(s) can be attached to the generic/INN sheet (see Figure 3, page 17) The names of the drugs should remain on the wall for the duration of the workshop.
10. At the end of the activity, give each participant a copy of the summary table of ARV drugs available in their country (see page 21), and a photocopied extract of pages 66-67 of the *Handbook on Access to HIV/AIDS-related Treatment – A collection of information, tools and resources for NGOs, CBOs and PLWHA groups* (International HIV/AIDS Alliance/UNAIDS/WHO, 2003) (see page 20).



Essential information

- When a new drug is launched onto the market, it usually has three different names:
 - a **chemical name** or its abbreviation (because chemical names are long and complicated, the use of the corresponding abbreviation is often preferred)
 - a **generic or international non-proprietary name (INN)** – usually simpler and often designed to indicate which family of drugs it belongs to
 - a **commercial or brand name** that belongs to the producer or patent owner.
- The inventor of a new drug can take out a **patent**, which is a legal document that gives them exclusive rights over the product for a fixed time – usually 20 years. The drug is given a generic/INN name by the World Health Organization (WHO) and the manufacturer gives it a brand (trade or proprietary) name that is used for marketing and advertising. For example, zidovudine (generic name) is often called by its abbreviations ZDV or AZT, but is marketed by the producer GSK (GlaxoSmithKline) using the trade

Names of ARV medicines

- Blu Tack or fixing tape
- Photocopies of the summary table of ARV drugs available in the country. Use Tables 1 to 5 in Annex 1 as a reference, but check in advance which drugs are actually in use in the country at the time of the workshop
- Photocopies of extracts from pages 66-67 of the *Handbook on Access to HIV/AIDS-related Treatment – A collection of information, tools and resources for NGOs, CBOs and PLWHA groups* (International HIV/AIDS Alliance/UNAIDS/WHO, 2003) (see pages 20).

name Retrovir®. When the patent on a drug expires, other manufacturers have the right to produce the same drug. These copies are known as **generic drugs** and must have the same effects and doses and be as safe to use as the original.

- It is important to use the generic/INN name for purchasing and for prescribing. National supplies of ARVs are usually purchased through a process called **tendering** in order to ensure the best possible price. Different suppliers (laboratories) compete with each other each time a new purchase tender is announced. A different supplier might win the tender each time, so brand names can change although the actual drugs and their generic names remain the same. If brand names are used to prescribe ARVs, people on treatment might worry that their treatment has been changed if they receive a different brand, although it is actually the same drug and has the same generic name.



Figure 3 Visual tool to illustrate families and names of common ARVs

Basic information on HIV and ARV treatment

Names of ARV medicines



Preparation

- Gather together packaging for all ARVs available in the country, as far as you can. It is best to have different forms of the same drug (tablets, capsules, soluble powder), where these exist.
- If possible, try to get containers with real tablets and capsules in them. This is not always possible because they are expensive, so pharmacists and doctors are sometimes not willing to allow them to be taken away from the clinic or pharmacy. The activity will still work well if you can only get empty packets; it is the drug names that are the most important
- Prepare a sufficiently large space on a wall in the room to stick all the different names of drugs in their ARV families
- Group together the three sheets for each drug – generic/INN name, chemical name/abbreviation and commercial name – in order to be ready to stick them on the wall without wasting time when the participants give the names they have found on the boxes (see Annex 5)
- Photocopy the summary table of ARVs available in the country (see page 21) and the extract from pages 66-67 of the *Handbook on Access to HIV/AIDS-related Treatment – A collection of information, tools and resources for NGOs, CBOs and PLWHA groups* (International HIV/AIDS Alliance/UNAIDS/WHO, 2003) (see pages 118-19).



Additional information

What is the difference between generic names of drugs and generic drugs?

- The generic name is the INN
- Generic medicines are copies of a medicine that was previously patented (owned by the producer) and has its own INN. The generic copies are not allowed to use the same brand name as the original but they must use the same INN. So a generic medicine has the same INN as the original but will be marketed (sold) with different brand names (or sometimes just the generic name). For example, 'zidovudine' is marketed under the names 'Zidovir[®]', 'Zido-H[®]', 'Viro-Z' or just 'Zidovudine'.
- '3TC', 'ddl', 'D4T' etc. are abbreviations of ARV chemical names. Before a drug is ready for the market, it is first tested for effectiveness and safety. During this testing stage only the chemical name is used, but it is often abbreviated to make it easier to say and write.

Why are the abbreviations 'TM' or 'R' used after certain drug names?

'TM' is the abbreviation for trade mark and 'R' is the abbreviation for registered. This means that the commercial or brand names of these medicines have been registered with the authorities by the companies that produce them. Therefore no other company can use the same commercial name. Packaging designs for medicines are also registered to prevent others from copying them.



Notes for the facilitator

- This activity requires the handling of a lot of material. It therefore needs to be facilitated by at least two trainers. One trainer who is very familiar with the names of the drugs should lead the discussion, while one or two other trainers should help by passing around the packages and then placing the names of the drugs on the sheets on the wall
- You can use different coloured sheets for each category of ARV, keeping the same colour code as used in the previous activity on ARV drug combinations (see Figure 3, on page 17)
- When you come back into plenary after the pairs of participants have looked at the packaging, do not try to go through every one of the drugs if there are a lot of them as the activity can become long and boring. The main thing is to see all the generic/INN names and a number of brand names for some of them in the full group, so that the participants clearly understand that there are often several brand names for one generic name. The remainder of the A4 sheets with individual ARV names should be put up by the facilitators during or just after the rest of the session. They should be left on the wall for the rest of the training to help participants memorise at least some of the names
- The trainers can ask further questions about some of the packaging to ensure that the participants fully understand. Rather than giving the answers themselves, the trainers should always rely on the group's knowledge and use a Q&A activity. For example:
 - Q Why are there different boxes for Videx if it is the same brand?

A The medicines come in different forms (tablets, capsules, soluble powder) and doses (400mg, 250mg, 200mg and 125mg doses) so that doctors can prescribe the right amount according to the weight and age of the patient.
 - Q Can you have one single INN with several commercial names?

A Yes, because different producers can use the same drug to make their own

versions, and each producer gives its own commercial name to its own product.

- **Q** Why are there two INNs, zidovudine and lamivudine, on the Combivir® box?

A Some ARVs such as Combivir® combine two drugs because this allows the person on treatment to reduce the number of tablets or capsules they have to take, even if they are still on tritherapy. Taking fewer tablets or capsules every day can enable greater adherence.

- **Q** Are there some ARV medicines that combine more than two drugs?

A Yes, for example Trizivir®, Triviro®, Triomune®, all of which contain three drugs in one tablet

- Reassure participants that they do not have to memorise all the drug names they have seen. The activity is intended to demystify ARV medicines and help people to understand why there are different names. Advise them always to have their summary tables of ARVs (see page 21) close to hand so that they can check which names are which. Explain that those who are supporting others with their ARV treatment will soon become familiar with the different names
- It is important to explain to participants that allowing patients to handle their medicines, as done by the participants during the session, is an important part of adherence support, and will be discussed later in the training course
- It is better not to include medicines that are not yet available in the country, unless you are sure that they will be available very soon.

Basic information on HIV and ARV treatment

Names of ARV medicines

Drug names

It is important to know and remember the names of drugs, even when they are long or difficult to say. Simply saying the white tablets or the pink syrup can result in serious mistakes. Drugs which look the same may contain very different ingredients, and some that look different may actually be the same.

The name of a drug must appear clearly on the label. You should never accept a drug without a name. A person who cannot read should at least know that every drug has a name and that different drugs must not be mixed together or kept without a label. All drugs have at least one or two names. These include:

- A **chemical name** – the scientific name of the drug chemical. This is mainly used by researchers, but is sometimes shortened and used by health workers instead of the generic or brand name
- A **generic name** – the name that is adapted from the chemical name and is shorter and easier to say. This is decided by the WHO and is also called the international non-proprietary name (INN)
- A **brand or proprietary name** – the name chosen by the producer of the drug. This is short and easy to remember, to encourage people to ask for the drug by that name. The same manufacturer may have several different brand names for the same drug.

One way to reduce confusion about drug names is to use only generic names. For example, paracetamol is a generic name, but it also has many brand names. In addition, it is often combined with other drugs in many hundreds more brands for joint pains, fevers or coughs. A person might use two or three of these brands for different reasons and not realize that they are taking an overdose of paracetamol, which can cause serious liver damage.

Generic drugs are products that have only the generic name on the label. They are usually available if there is no valid patent (or legal ownership) on the drug. Mostly, there is little practical difference between using generic or branded versions of the same drug.

Branded or proprietary drugs are products that have a brand name. They are often advertised using this name, to encourage people to be loyal to that one company's product. This can lead to people prescribing or asking the brand even when cheaper generic products are available.

Generic drugs are usually cheaper than brand-name drugs, often by a large amount. When a generic drug arrives on the market, there is usually competition between companies. This drives the prices down and, sometimes, can even lead to the original drug becoming much cheaper.

Example

Generic drugs and brand-name products contain the same active drug but have different names. The following example is of a drug often used to treat tuberculosis (TB):

Chemical name (12Z,14E,24E)-(2S,16S,17S,18R,19R,20R,21S,22R,23S)-1,2-dihydro-5,6,9,17,19-pentahydroxy-23-methoxy-2,4,12,16,18,20,22-heptamethyl-8-(4-methylpiperazin-1-yliminomethyl)-1, 11, 13-trienimino) naphtho (2,1-b)-furan-21-yl acetate

Generic name rifampicin

Brand name Rifadin, Rifampin, Rimactane

Some generic drugs are combined together in the same medicine. These combinations are often given a **compound generic name**. For example:

<i>trimethoprim</i>	+	<i>sulfamethoxazole</i>	=	<i>cotrimoxazole</i>
(generic name)		(generic name)		(combined generic name)

International non-proprietary names can vary slightly according to language. For example:

Generic name in English: amoxicillin
 Generic name in French: amoxicilline
 Generic name in Spanish: amoxicillina
 Generic name in Latin: amoxicillinum

Some countries use **non-international generic names**. For example:

International generic name used in most countries: paracetamol
 Non-international generic name used in the USA: acetaminophen

Source *Handbook on Access to HIV/AIDS-related Treatment – A collection of information, tools and resources for NGOs, CBOs and PLWHA groups* (International HIV/AIDS Alliance/UNAIDS/WHO, 2003), pages 66-67. www.aidsalliance.org/sw7421.asp

Fact sheet: ARVs available in 2006

There are three main categories or families of ARVs available for use in 2006:

- Reverse transcriptase inhibitors (Tables 1 and 2)*
- Protease inhibitors (Table 3)
- Entry inhibitors (Table 4).

Some medicines are **combinations of more than one reverse transcriptase inhibitor** (see Table 1).
Other medicines are **combinations of more than one ARV from different categories** (Table 5).

Reverse transcriptase inhibitors

These are divided into two main sub-categories:

- Nucleoside reverse transcriptase inhibitors, also known as nukes or NRTIs
- Non-nucleoside reverse transcriptase inhibitors, also known as non-nukes or NNRTIs.

This is the oldest category of ARVs and forms the longest list of drugs.

Action against HIV

They block HIV as soon as it enters the CD4 cells by acting on the reverse transcriptase which helps the virus to adapt in the cells.

Protease inhibitors

This category of ARVs revolutionised treatment for HIV during the 1990s when they started to be combined with reverse transcriptase inhibitors to work at different locations within the CD4 cells.

Action against HIV By acting on the protease that HIV needs in order to develop, protease inhibitors prevent the normal development of new HIV viruses in the CD4 cells. The new HIVs can then no longer infect new CD4 cells.

Entry inhibitors

In 2006 this category included only one available drug, enfuvirtide (T20), sold under the trade name Fuzeon®.

Action against HIV It prevents HIV from entering CD4 cells.

In 2005 a new category of ARV was being studied, **anti-CCR5**, which prevents HIV from attaching to the cell membrane. Scientific research will continue to discover new categories of ARV. It is therefore important to remain up to date with developments and constantly check what new ARVs have come into use.

*See Annexes 1 and 2 for the tables mentioned here.

Starting ARV treatment – who needs it and when?



Aim of the session

At the end of the session participants will be able to explain:

- why a person does not always need to start treatment as soon as HIV is diagnosed
- why it is necessary for the doctor to use both clinical checks and laboratory tests in order to decide when to start treatment
- what are the clinical checks and laboratory investigations (tests) that are used for deciding when to start treatment
- what are the different stages of HIV infection that are used for deciding when to start treatment.



Methodology

- Q&A session led by the facilitators (whole group)
- Presentation of explanations and recap to check that participants have understood



Time

- 45 minutes



Materials needed

- Information on the clinical and laboratory investigations recommended for use in the country where the training is taking place. For example, different countries use different CD4 levels for starting treatment, and it is important not to give participants incorrect information for their country.
- Posters prepared in advance, showing the clinical indicators and laboratory investigations that are used for deciding when to start ARV triple therapy.



Notes for the facilitator

- It is important that participants understand clearly that there are two types of criteria for putting people on ARV treatment: clinical checks and laboratory tests.
- In places where laboratory tests are not easily available, participants should understand that clinical criteria are sufficient for deciding whether people should be started on ARV treatment.



Activity

1. Ask the group: 'In your opinion, who should take ARVs?' 'How should the decision be made – what criteria are used?' Write the answers on a flip chart, separating the clinical criteria from the laboratory tests so that participants can see how they are different. Correct any inaccurate answers and explain further where necessary.
2. Invite participants to ask more questions and provide answers using the poster 'Criteria for prescribing ARV treatment' (see page 25) to recap and ensure people have fully understood.
3. The session can finish with the trainer asking participants a series of questions about practical examples of a patient discussing starting ARV treatment with their doctor. These questions could include (depending on national guidelines about CD4 levels and symptoms):
 - Doctor, I've come to see you because my skin has started to itch. What stage is my HIV at now? (symptomatic)
 - I am getting a few symptoms. What do you need to find out before I can start on ARV treatment? (a CD4 blood count)
 - What should my CD4 level be before you will prescribe ARVs for me? (less than 350)
 - If you are asymptomatic and your CD4 is 500, should you be put on treatment? (no, because there are no symptoms and the CD4 count is more than 200)
 - You have some symptoms but your CD4 is 600, might you be put on ARV treatment? (no, because it is not necessary unless the CD4 is less than 350)
 - You are ill, you have an opportunistic infection but your CD4 is 400, should you be put on ARV treatment? (yes, because you have reached the AIDS stage, when the CD4 level does not affect the decision to start treatment)



Essential information

Does everyone with HIV need ARV treatment?

Not all people with HIV need ARV treatment. A person must meet certain criteria before starting treatment.

Two key sets of criteria are taken into account: **clinical examinations** and **laboratory investigations**. The list of clinical criteria includes health problems that can also happen to people who do not have HIV. The doctor will be able to judge a person's HIV stage after a positive HIV test, by assessing the number, type and seriousness of the health problems.

Clinical criteria for adults and adolescents with confirmed HIV infection

The WHO guidelines are being revised in 2006. When finalised, new versions will be available on the WHO website at www.who.int/hiv/pub/guidelines/en/

The WHO defines four clinical stages of HIV infection:

Clinical stage 1:

- A person usually has no symptoms (is 'asymptomatic') and can do normal activities
- Sometimes the person has swollen glands that continue for some time; for example, in the armpits or neck (persistent generalised lymphadenopathy).

Starting ARV treatment – who needs it and when?

- For the practical examples in the last part of the activity, you can split participants into small groups and give each group one of the examples to discuss and then present to the full group. This depends on the time available. Small group work always takes longer than one expects!



Preparation

- Prepare a poster 'Criteria for prescribing ARV treatment' (see page 25).

Clinical stage 2:

- The person has some symptoms (is 'symptomatic') but can still do normal activities
- Moderate weight loss (less than 10 per cent of body weight) with no obvious cause
- Frequent infections in the face (sinuses), tonsils, chest, ears or throat
- Shingles (herpes zoster) within the last two years
- Splits or cracks in corners of mouth, caused by fungus infection (angular cheilitis)
- Frequent mouth ulcers (more than twice in six months)
- Itchy, raised skin spots (not scabies)
- Itching, scaly patches on skin (dermatitis), especially scalp, face, upper body or genitals
- Nail infections caused by fungus.

Clinical stage 3:

- The person develops opportunistic infections, is ill more often and needs more support
- Tuberculosis infection in the lungs – especially if the person has been carrying an old (latent) TB infection
- Severe weight loss (more than 10 per cent of body weight); the person is noticeably thinner
- Frequent (chronic) diarrhoea with no obvious cause, for more than one month
- Fever with no obvious cause, for more than one month (can be irregular or persists all the time)
- Mouth infection caused by fungus (thrush); swallowing food may be difficult due to pain
- Tongue develops unusual white coating (oral hairy leucoplakia)
- Infections caused by bacteria in various parts of the body
- Insufficient red or white cells in the blood, with no obvious cause.

Clinical stage 4:

- The person is seriously ill most of the time and needs constant care
- HIV wasting syndrome – severe weight loss, plus frequent diarrhoea and/or fever
- Severe lung infections (pneumonia) caused by pneumocystis (a parasite) or by bacteria
- Herpes simplex infection in or around mouth, genitals, anus or rectum, for more than one month
- Fungus infections in the throat, chest or lungs
- Tuberculosis infection outside the lungs, in various parts of the body
- Other unusual infections in the eyes, brain, nerves or other parts of the body
- Cancers, such as Kaposi's sarcoma, cervical carcinoma or lymphoma
- Brain and nerve problems caused directly by HIV infection.

Laboratory investigation criteria for adults

Laboratory tests are used to confirm that the person is HIV positive, to find out how much damage has been done to the immune system and to estimate how much virus is in the person's blood.

Damage to the immune system can be measured by counting the number of CD4 cells in the blood (the CD4 count), since these are the cells targeted by the HIV virus. Specific CD4 levels (CD4 thresholds) are used for deciding whether to prescribe ARVs for someone who has been confirmed as HIV positive.

Starting ARV treatment – who needs it and when?

Well-resourced laboratories can also measure the amount of virus in the blood (the viral load). A viral load test helps the doctor to know how active the virus is in the person's body. When ARV treatment is successful, the viral load is usually 'undetectable', which means that there is hardly any virus in the blood. However, the virus is present throughout the body and a person with an undetectable viral load can still transmit HIV to another person.

The CD4 count and the viral load are different methods for finding out about HIV infection. A person who is ill and needs to start treatment will usually have a high viral load and a low CD4 count. However, a person who has just become infected with HIV will also usually have a high viral load, even though HIV has not yet damaged the immune system.

Clinical and laboratory criteria are both used for deciding if a person with HIV should start ARV treatment:

- Does the person show symptoms? If yes, what are they? Is the person ill? Is the person suffering from any opportunistic infections? What are they?
- Is the person's immune system weak or strong?
 - If the person has no symptoms (asymptomatic) they will only start ARV treatment if their immune system is weak and the CD4 count is less than 200
 - If the person is showing symptoms (symptomatic) they will start ARV treatment if their immune system is weak and the CD4 count is less than 350
 - If the person is ill due to opportunistic infections, they will start ARV treatment even if the CD4 count is high, because the presence of one or several opportunistic infections proves that the immune system is already damaged.

Note: Even if the CD4 count increases, the person must continue with the treatment for the rest of their life.

HIV and tuberculosis – a special case

If an HIV-positive person has a CD4 count of less than 200 and develops active TB, then ARV and TB treatment can be taken at the same time. If the person is very ill, it is possible to start both treatments at the same time. However, if the person is not too ill, the TB treatment is started first to allow the body a few weeks to get used to it. Then ARV treatment is started when the intensive phase of TB treatment is complete. When the CD4 count is greater than 350, the TB treatment should be completed before ARV treatment is considered.

Typical TB treatment can last for nine months, although this varies depending on a country's national TB treatment guidelines. During the first two months, the patient takes an intensive course of four anti-TB drugs. If the intensive treatment has been successful, the patient then goes on to the **consolidation treatment** phase, which involves taking two drugs for the remaining months.

TB infection makes the CD4 count fall very quickly. When the TB is treated, the CD4 count usually rises. The CD4 count is checked after the two months of intensive treatment. If after the intensive TB treatment phase the CD4 count is still less than 350, it is usually assumed that this is because of HIV, and ARV treatment can start. For some people, the CD4 count rises to more than 350 after two months of TB treatment, and it is therefore not necessary to start ARV triple therapy.

Starting ARV treatment – who needs it and when?



Additional information

Normal CD4 count for a person who is well

A normal CD4 count is approximately 500-1000/mm³, but the count can fall if the person has any kind of infection. The count increases when the infection is removed, either naturally or with the help of treatment.

Why wait until the CD4 count falls before prescribing ARVs?

Would it not be helpful to give ARV treatment to everyone with HIV to prevent viral replication as soon as possible? No. ARV treatment is difficult to take, it sometimes causes side effects and once started must be taken for life. Moreover, the HIV virus can develop resistance to certain ARVs and the drugs stop having the desired effect on the HIV virus after a period of time. It is therefore better to wait until the person really needs the drugs before prescribing them.

People who are sick and bedridden

Are ARVs still useful if a person with HIV has already reached a specific stage of the illness? If the doctor sees an HIV-positive person who is already very ill (WHO clinical stage 4) and bedridden, it is very helpful if they can first have a good level of nutrition and recover slightly before starting ARV treatment. ARV treatment can be very effective, even for those with extremely low CD4 counts (less than 10) or classed as being at the terminal stage (about to die).

If ARV treatment is working well and the person is able to have good nutrition, recovery is often seen within a few months, although it can take longer to become fit enough to return to a full normal life.

Accidental exposure to HIV in blood (for example, injection through a needle) or in semen (for example, due to a split condom or rape)

Accidental infection with HIV can happen, although the risk is low. In these cases, it is possible to use ARVs to prevent the virus from starting to multiply in the body (seroconversion). This is called **Post-Exposure Prophylaxis (PEP)**. Health care workers should all be trained in how to prevent accidental infection using standard precautions. However, they, and people who might be infected through accidental sexual exposure, can benefit from PEP when it is made available.

Procedures:

- **Start PEP within two to four hours after exposure** to have the best chance of success, or in any case as quickly as possible. **Do not delay** while waiting for an HIV test or other investigation
- If possible, following the exposure the person must have a rapid HIV test to check if they were already HIV positive before the accidental exposure to HIV
- If the person is already HIV positive, it is not necessary to give them ARVs for PEP. However, a doctor can check to see if the person requires ARV treatment according to the criteria above
- If the person's status is unknown, or they are HIV negative, a special course of triple ARV therapy is started. National guidelines are usually available on which drugs to use and for how long
- The treatment must be taken for one month
- The person must be followed up for six months to check if the treatment has been effective. It is therefore important not to risk exposure to HIV during that time
- At the end of six months, the person must have another HIV test. If the result is negative (and if the person has not been at risk during this period) this means that either they were not infected through accidental exposure or that the PEP treatment has prevented seroconversion.

Note: Triple therapy for PEP does not always prevent seroconversion.

Criteria for prescribing ARV treatment (adults and adolescents)

If a CD4 test is available, WHO recommends offering ARV treatment to patients with:

- WHO stage 4 disease, irrespective of CD4 count
- WHO stage 3 disease, with CD4 cell counts less than 350/mm³
- WHO stage 1 or 2 disease, with CD4 cell counts less than 200/mm³.

If a CD4 test is not available, WHO recommends that a simple white blood cell test (total lymphocyte count) is used and ARV treatment is offered to patients with:

- WHO stage 4 disease, irrespective of total lymphocyte count
- WHO stage 3 disease (including but not restricted to HIV wasting, chronic diarrhoea of unknown etiology, prolonged fever of unknown etiology, pulmonary TB, recurrent invasive bacterial infections or recurrent/persistent mucosal candidiasis), irrespective of the total lymphocyte count
- WHO stage 2 disease with total lymphocyte count of less than 1200/mm³.

ARV treatment information and how to provide it

Making an ARV treatment plan



Aim of the session

At the end of the session participants will be able to:

- describe some of the important elements of ARV treatment and be able to explain them to people taking ARVs – the number of drugs, how many doses need to be taken, when to take the drugs, intervals between doses, how the drugs should be taken
- explain the essential characteristics of a good treatment plan.

In addition, the session must enable the participants to familiarise themselves further with the names of ARVs by working with examples of prescriptions for ARV treatment.



Methodology

- Working in groups
- Role plays



Time

- 1 hour 40 minutes



Materials needed

- Photocopies of 'Things to remember when explaining how to take ARV treatment (treatment plan or calendar)' (see page 28)
- Sample prescriptions for ARV triple therapy based on the list of possible combinations (see Annex 3)
- Flip charts
- Marker pens of various colours
- Several pairs of scissors
- A4 sheets of coloured and white paper
- Sticky labels in various colours
- ARV capsules and tablets available in the country where the training is taking place (if possible)
- Example of an ARV treatment plan



Notes for the facilitator

- Insist that explanations of how to take ARVs should be based on taking the drugs over a whole week and not just one day. Encourage participants to think about what will happen when a person's routine changes due to holidays, journeys and so on.



Activity

1. Divide the group into smaller groups with a maximum of five people per group. Give each group a sample 'prescription' for ARV treatment, based on what would be prescribed in the country.
2. Ask participants to imagine that they have to explain to a person who is about to start treatment how they should take their medication. This person does not know how to read. It might be necessary to create a visual aid and to use symbols that the person will be able to understand. Each group should have a flip chart that they can use to create this tool
3. The explanations must be based on taking the treatment for an entire week (seven days) and not simply one day. The groups must use the prescription, which shows the doses, the number of doses, the form (tablet, capsule etc.), the daily dose, advice about food (for example, 'take after food'). Explain to participants that they can use their own experiences. Use another sample prescription to illustrate your instructions. Provide about 40 minutes for this activity
4. When each group has created a support tool for taking ARVs, explain to the participants that some of the tools will now be tested on participants from other groups by means of role plays
5. For the role plays, one participant plays the role of the treatment counsellor, while another person from a different group plays the person who is going to start the treatment. At the end of the role play, ask the participants who played the role of the person starting treatment if they found that the visual support and explanations were helpful, and why
6. Next, with the full group, analyse the advantages and disadvantages of the tools presented
7. Then ask groups who have not presented their visual supports in role plays to now present them to the group. Analyse the advantages and disadvantages of the visual supports presented with the rest of the group
8. When all of the presentations have been given, explain that this type of tool is usually called a **treatment plan** or **treatment calendar**
9. With the whole group, make a summary of the things to remember when making a treatment plan.



Essential information

What should you remember when making a treatment plan?

- It is important that the patient is fully aware of the following (especially when symbols such as images and stickers are used to help explain):
 - form of the drugs (tablets, capsules)
 - colour of the drugs (tablets, capsules)
 - number of different drugs to take and the number of tablets or capsules of each drug
 - times of day (or night) when the drugs must be taken
 - length of time between one dose and the next
 - special requirements for taking the drugs (for example, with food or drink).
- If symbols and images are used, it is much better if they show the drugs as they are in real life to prevent confusion. Above all, make sure that the person does not confuse the different drugs that they have to take
- Symbols must be extremely clear. For example, if a drawing of a tablet above a cup is used to show that the tablet should be taken with a drink, the person might think instead that the tablet must be placed in liquid. Always check that the drawing or symbol has been understood correctly by asking the person to repeat back what they have understood.
- For people who cannot read easily, avoid written instructions or information. Instead, use symbols and spoken explanations
- Whenever possible, try to encourage direct contact with the drugs during the explanations, so that the person becomes familiar with them.

Making an ARV treatment plan

- The small group work is not aimed at developing perfect, complete or totally correct treatment plans. The main aim is to encourage participants to think about the various elements that need to be discussed when developing a treatment plan with a person who has to take ARVs.



Preparation

- Make photocopies of 'Things to remember when explaining how to take ARV treatment (treatment plan or calendar)' (see page 28).
 - Prepare prescriptions of possible ARV combinations (see Annex 3).
 - Prepare enough packages of materials necessary for the small groups to prepare treatment plans.
 - Provide examples of any available treatment plans, bearing in mind the national treatment context (see Figure 4, page 28).
- A treatment plan should be drawn up with the patient based on their daily schedule and lifestyle. This includes the times that they wake up, eat, go to sleep and all other daily activities that form their regular timetable (for example, work, household tasks, prayer)
 - When these daily events have been recorded, try to associate the doses of drugs with the events in the timetable and establish a routine for taking the drugs
 - It is best to make a treatment plan for several days and not simply one day, since a person's timetable can vary throughout the week. Think of the best strategies for taking the drugs both during the week and on days off (like the weekend) as these can be different. For example, a person may choose to take their treatment during the week at times when they are on their own, but they might be with family at corresponding times during the weekend. This could make their treatment difficult to take and require a change of plan to allow for this
 - There is no ideal form of visual support. Above all, a treatment plan must be adapted to each individual depending on their ability to understand and remember. Making a treatment plan involves a dialogue that requires active listening on the part of the counsellor
 - Always check that the person has understood at each stage and ask them to repeat and summarise what has been discussed at the end.

ARV treatment information and how to provide it

Making an ARV treatment plan

Things to remember when explaining how to take ARV treatment (treatment plan or calendar)

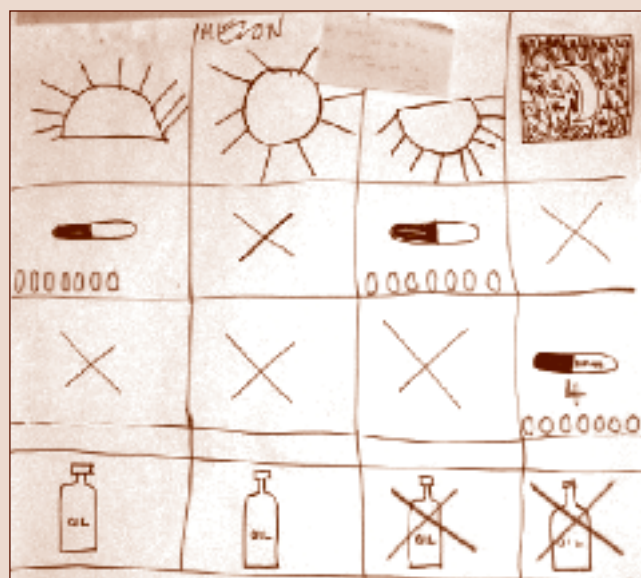
- Whenever possible, try to encourage **direct contact with the drugs** during the explanations
- Treatment plans should be produced through **dialogue with the patient**, based on their routine and lifestyle. The times that the patient wakes up, eats, goes to sleep and everything else that they do on a regular daily basis (for example, work, household tasks, prayer) must all be noted
- Once these events have been noted, it is important to try to fit the taking of drugs around these events in the plan – in other words, to **establish a routine** for taking the drugs
- It is best to draw up a treatment plan **covering several days** and not just one, since a person's routine can vary over a week. For example, consider the best strategies for taking medication both during the week and on days off (like the weekend) as these can change. For example, a person may choose times to take their treatment during the week when they are on their own, but might be with family at corresponding times during the weekend. This could make their treatment difficult to take and require a change of plan to allow for this
- Always check that the person has understood by asking them to **repeat and summarise** what has been discussed.

When to use a visual aid

It is important that the patient is fully aware of the following (especially when symbols such as images and stickers are used to help explain):

- the **form** of the drugs (tablets, capsules)
- the **colour** of the drugs (tablets, capsules)
- the **number** of different drugs to take and the number of tablets or capsules of each drug
- the **times of day** (or night) when the drugs must be taken
- the **length of time** between one dose and the next
- the **special requirements** for taking the drugs (for example, with food or drink).
- **Symbols must be extremely clear.** For example, if a drawing of a tablet above a cup is used to show that the tablet should be taken with a drink, the person might think instead that the tablet must be placed in liquid
- If symbols and images are used, it is much better if they **show the drugs as they are in real life** to prevent confusion. Above all, it is important to make sure that the person does not confuse the different drugs that they have to take
- For those unable to read, it is necessary to avoid anything written and instead use symbols and good verbal explanations
- There is no ideal form of visual aid. A treatment plan must above all be **adapted to each individual** according to their ability to understand and remember. Making a treatment plan involves a dialogue, which requires active listening on the part of the counsellor.

Figure 4 A treatment plan from a training workshop in Zambia.



Notes

ARV treatment information and how to provide it

Side effects of ARVs



Aim of the session

At the end of the session participants will be able to understand and explain:

- people's common fears about possible ARV side effects and why it is important to discuss them with a person who is already taking or is about to start ARV treatment
- some of the most common ARV side effects
- some scientific terms in simple language – lactic acidosis, peripheral neuropathy, lipodystrophy.



Methodology

- Q&A
- Interactive explanation and summarising by the facilitators



Time

- Maximum 1 hour 40 minutes



Materials needed

- Photocopies of fact sheets on ARVs (Annex 1)
- Flip charts
- Marker pens of various colours
- Flip chart, with headings, on 'Side effects of ARV treatment' (see page 33)



Notes for the facilitator

Stress that at community level, gaining knowledge about side effects does not allow people to make a diagnosis themselves. You should always consult the doctor who is looking after the person on ARV treatment. If you do not know or are not sure what is happening, it is much better to consult a professional person who has the right knowledge.



Preparation

- Prepare in advance a flip chart showing the 'Classification of side effects according to frequency and seriousness' (see page 32), which can be completed with the participants.



Activity

1. **Q&A** Introduction. Ask the participants:
 - What is a side effect?
 - When do side effects happen if a person is taking ARVs?
 - Which people can get side effects when taking ARVs?
2. **Q&A** Explain that the group and facilitators will look together at different side effects caused by ARVs. They will talk about which side effects are common or less common, and what effect they might have on a person's health. Show them the flip chart already prepared and ask them to name side effects they know about. For each side effect, ask where it should be written on the flip chart. When participants are not sure or run out of answers, the facilitator should add other side effects and explain them. The facilitator should also point out side effects that are specific to one drug or one group of drugs, and note them on the flip chart.
3. **Q&A** What else can we say about side effects? (see 'Essential information')
4. **Q&A** Why is it important to talk about side effects with people on treatment or people close to them?

Finish by telling participants that the following sessions will help them to make more detailed explanations about side effects and how to prevent or reduce them, especially when planning for food and healthy living in general.



Essential information

Definitions: side effects and toxicity

- For every drug, there is a risk of some unwanted effects. These are known as **side effects**.
- Distinguish between:
 - **side effects** that are symptoms experienced by the patient; they can be mild and will disappear when the drug that causes them is stopped
 - **toxicity or toxic effects** that are more serious and cause damage within the body that is sometimes severe or cannot be reversed.

When do side effects start?

- Undesirable side effects (sometimes called **adverse reactions**) often appear at the start of treatment but gradually disappear when the body gets used to the drugs. Some side effects, however, can continue for a long time
- Toxicities are usually more progressive, becoming worse as treatment continues.

Who gets side effects from ARVs?

It is impossible to say in advance who will get side effects. Some people can get side effects from a particular drug but other people do not. Certain people often suffer from side effects, but others are rarely affected. There is no known method of predicting this yet.

What side effects are caused by ARVs and how can I know if they are rare, frequent, dangerous or not?

See poster 'Classification of side effects according to frequency and seriousness' (page 32) and the information about individual ARVs in Annex 1.

What else do we need to know about ARV side effects?

- Side effects can appear after taking a drug for some time. Side effects that appear at the beginning of treatment usually disappear after a short time (days or weeks)
- You can take steps to reduce or prevent ARV side effects (see page 34)
- It is important to know how to recognise ARV side effects because symptoms can have other causes, such as HIV itself or another illness. Sometimes symptoms can have a psychological cause.



Additional information

Meanings of scientific terms related to ARV side effects

Lactic acidosis A build-up (accumulation) of toxic products in the blood (see Annex 3) – this toxicity is very rare but it is dangerous and the person must see a doctor urgently.

Cholesterol A type of fat found in the blood.

Flatulence Digestive problems, gas, bloated stomach.

Peripheral neuropathy Nerve inflammation that causes feelings of 'pins and needles', tingling, 'walking on cotton' or losing your shoes without realising.

Lipodystrophy A change in the distribution of fat in the body, which can lead to a change of appearance such as developing a large stomach or very thin cheeks.

- It is usually more dangerous to stop taking ARVs than to continue taking them when side effects appear. The exception is when a severe allergic reaction or lactic acidosis occur. These are rare and a doctor should be consulted immediately if they happen.
- Whatever the cause of a side effect, consult with the doctor responsible for the ARV treatment as soon as possible in case it is something serious or it has another cause.

Why do some people get sick again soon after starting ARV treatment?

- This can happen when the immune system starts to recover. When the viral load is very high and the immune system is so damaged that it cannot fight any infections, symptoms of opportunistic infections (for example, TB) do not always develop. When treatment starts, the viral load drops, the immune system starts to recover and starts to produce symptoms, which are a sign that the body is fighting an infection. Any symptoms that appear must therefore be treated at the same time as continuing ARV treatment to support the immune system and help it recover.
- This is sometimes called **immune reconstitution** or **IRIS** (immune reconstitution inflammatory syndrome).

Why is it important to spend time talking about side effects, both with the person on treatment and with those who are supporting them to take their treatment?

- Many people in communities affected by HIV have heard that ARVs are very strong drugs. They may even believe a myth that says ARVs will kill them, especially if they know of some people who start treatment too late and have died from opportunistic infections soon after starting treatment.
- Some people are discouraged by side effects and stop taking their treatment in the way it was prescribed, or even stop taking it altogether. So it is important that everyone fully understands what to do about taking the medicines and informing the doctor if something happens which might be a side effect or the result of immune reconstitution (see the module on adherence pages 46-58).
- In some rare cases side effects are dangerous and people must be able to recognise them and urgently consult a doctor, who can change or stop the treatment in a safe way.

Discussing possible side effects is not intended to scare the person on treatment. It is meant to enable them to:

- be prepared if they occur (so there are no surprises) – the information enables the person to have greater control over their treatment
- talk about them with their doctor
- in some cases take a number of simple steps to limit side effects and the way they affect a person's quality of life on ARV treatment (see page 00)
- achieve good adherence – instead of stopping treatment when side effects appear, the person will be more comfortable with continuing treatment and speaking about side effects with their doctor.

Awareness of side effects is part of a person's right to information about their treatment. It enables civil society organisations to provide good information to those already on treatment or to those about to start treatment. It also enables them to encourage people to see their doctor for follow-up and, if necessary, medicines to reduce side effects or a change of treatment if the side effects are more serious.

ARV treatment information and how to provide it

Side effects of ARVs

Classification of side effects according to frequency and seriousness

To complete with the participants

Side effects of ARVs	Effects on health
Common	
Less common	

For facilitators to refer to

Side effects of ARVs	Effects on health (always consult a doctor about side effects)
Common	<p>Less serious:</p> <ul style="list-style-type: none"> • nausea, bloating/gas, vomiting • fatigue • headache • diarrhoea • vertigo, insomnia, bad dreams (Efavirenz) • loss of libido. <p>Sometimes serious:</p> <ul style="list-style-type: none"> • allergic skin rashes (very common in early stages of treatment, often not serious but if getting worse, involving eyes or mouth, or spreading across the body, can mean a serious and life-threatening reaction – see a doctor urgently) • lipodystrophy (after long-term treatment with some ARVs). <p>Serious:</p> <ul style="list-style-type: none"> • anaemia • neuropathies (ddl, d4T) • hepatitis (NNRTIs).
Less common	<p>Serious – see a doctor urgently:</p> <ul style="list-style-type: none"> • kidney stones (Indinavir) • severe vomiting • severe diarrhoea • lactic acidosis.



Aim of the session

At the end of the session participants will be able to explain:

- some nutritional issues related to side effects, such as what a person should or should not eat or drink if certain side effects occur (for example, diarrhoea, bloating, nausea)
- some nutritional issues related to taking specific ARVs, such as what a person must or must not eat or drink and at what times of the day
- the effects of using substances such as alcohol and tobacco on ARV treatment
- some recommendations about healthy living when on ARV treatment
- the importance of consulting the doctor when experiencing ARV side effects, and of not using other medicines to control side effects without the doctor's advice.

In addition, the activities suggested will enable the participants to:

- realise that they already have some knowledge and experience of giving nutritional advice to people on treatment
- combat myths and misinformation on the benefits of certain foods or methods for dealing with side effects.



Methodology

- Working in small groups
– case studies
- Feedback and discussion in plenary



Time

- 1 hour 15 minutes



Materials needed

- Photocopies of Annex 3 (examples of ARV combinations in prescriptions)
- Photocopies of Annex 4 (fact sheets on the main side effects of ARVs)
- A4 sheets or flip charts with pre-prepared scenarios for case studies (see page 35).



Preparation

- Make photocopies of the sheets in Annex 2 and of the 'side effects' sheets in Annex 4, if not already given to participants.
- Write the case study scenarios on A4 sheets or flip charts (one case study per sheet).



Activity

1. Divide participants into several small groups. Give each small group a case study describing a person on ARV treatment, the drugs they are taking and examples of side effects. Each case study must be written either on an A4 sheet or on a flip chart. Ask each group to make a summary of the advice they would give this person to prevent and reduce the side effects of the ARVs they are taking. The advice should relate to what the person should or should not eat or drink, points about healthy living and medication to take. The advice should be written on an A4 sheet or another piece of flip chart. It is also helpful to provide the instructions for the activity on a flip chart that everyone can see (see 'Instructions for case studies', page 35).
2. Ask each group to produce a role play that involves the following characters:
 - a community counsellor explaining the side effects and giving advice to prevent and alleviate them
 - a person who is on ARV treatment and/or
 - one or more members of their family.
3. After each role play, ask the members of the other groups to comment and suggest how the advice could be improved or changed. If there is not enough time for all the groups to act their role plays, ask just one or two groups to perform their role plays and then ask the other groups to describe briefly what their role play would show and the key issues they would portray.
4. Give each participant two sets of fact sheets: one on individual ARVs (Annex 2) and the other on ARV side effects (Annex 4). Ask them to read each sheet individually and check whether the advice they gave in their role play was correct. Using the sheets on ARV side effects, the trainers should also comment and make sure participants are clear which advice was correct and which was incorrect. If time is too short for this, you can instead distribute the fact sheets at the end of the session, ask participants to read them that evening and provide time for questions in the agenda of the following day.



Essential information

- A person on ARVs can use strategies to reduce or even eliminate most of the undesirable side effects of ARVs.
- Some symptoms are not necessarily the side effects of drugs. They may be linked to the effects of the HIV virus itself.
- It is always important to tell the doctor about particular symptoms that could be linked to taking ARVs. The doctor can establish whether the ARVs are really the cause of these side effects and take the necessary steps to deal with them.
- At a community level, you should not be offering advice on which medicines should or should not be taken to reduce side effects. You must **never take the place of a doctor in terms of prescribing drugs**. Taking certain drugs at the same time as ARVs can be extremely dangerous (see page 40).
- You must always **check that the patient is taking their medicines correctly**, as side effects occur more easily when a person takes doses that are too high.



Notes for the facilitator

- The question 'What advice should be given about taking or not taking medicines to reduce side effects?' is a trick. People who are not trained health workers should never diagnose side effects and certainly should not prescribe medication
- Trainers should correct any wrong or misleading advice and any false beliefs given by participants during the session. They should make sure that everyone has understood the correct advice.

Case studies for the session

Case 1

Mary is taking the treatment **Abacavir + d4T + Indinavir**

Mary has been taking this treatment for two years. She complains that her skin is like 'snake skin'. In addition, she has pains in her lower back but she thinks this is because she sits in an office all day. However, what bothers her most is her flatulence, which she is unable to control.

Case 2

Robert is taking the treatment **ddl + d4T + Kaletra**

Robert has been taking his treatment correctly for six months. One of his problems is that he has ulcers in his mouth. He also has diarrhoea several times a day and that bothers him a lot, particularly when he is at work. Another thing that concerns him all the time is a strange 'tingling' sensation in his feet.

Case 3

Gertrude is taking the treatment **Combivir + Nevirapine**

Gertrude has been taking Combivir and Nevirapine for more than a year. She is itching all over. She complains of a loss of appetite and she feels sick, particularly in the morning.

Note: Case studies must be adapted to the local context: first names, drug combinations and so on.

Instructions for case studies

Advice to give on reducing side effects:

- what you should eat
- what you should drink
- what you should not eat
- what you should not drink
- how you should look after your general health
- what drugs you should or should not take.

ARV treatment information and how to provide it

Managing ARV side effects – nutrition and daily living

Examples from a training workshop in Côte d'Ivoire

Case 1

Side effects:

- Bloating, flatulence
- Pain in the lower back*
- Dry skin

Problem	What should be done	What not to do
Dry skin	Continue treatment See the doctor	Stop treatment Use other medication without the advice of the doctor
Back pain	Drink plenty of water during the day See the doctor Eat well Activity Massage	Stop treatment Avoid seeing the doctor Sit for too long
Severe flatulence	Eat plenty of fruit Eat a balanced and healthy diet Rest	Stop ARV treatment Self-medicate Consume alcohol, tobacco or other stimulants

Advice:

***Note:** Back pain is probably linked to kidney stones, which are sometimes caused by indinavir. If this is the cause, massage will be useless as the problem is in the kidneys and not the joints or muscles of the back. Instead, advise drinking plenty of water (two to three litres per day) to prevent development of stones.

Case 2

Side effects:

- Diarrhoea
- Ulcers or sores in the mouth
- Tingling sensation in the feet and numbness around the mouth (peripheral neuropathies)

Advice:

Sensations and symptoms	Eat more	Drink more	Eat less	Drink less	Hygiene	Medication
Mouth ulcers	Porridge or gruel Purée Bland, soft foods	Plenty of plain water	Spices	Alcohol Ginger juice	Don't smoke Clean your teeth Use mouth washes	See your doctor
Diarrhoea	Bread Biscuits Banana	Plenty of plain water	Spices Dairy products Cakes	Alcohol Ginger juice	Drink clean water, use clean utensils Have good personal hygiene	Oral rehydration salts See your doctor
Tingling sensation in the feet					Wear roomy leather shoes Stand and walk upright	See your doctor

ARV treatment information and how to provide it

Managing ARV side effects – nutrition and daily living

Case 3

Side effects:

- Nausea
- Itching
- Loss of appetite

Advice:

Problem	What you should do	Do not
Nausea	<p>Eat a balanced diet: protein (meat, fish); fats (butter, oil); carbohydrates (maize, yam, rice)</p> <p>Drink plenty of water, along with fruit juices containing vitamin C</p>	Eat foods that you are allergic to or that are badly stored or stale
Itching	Develop good personal, environmental and food hygiene	Drink alcohol or fizzy drinks (sodas)
Loss of appetite	Refer patient to the doctor, who may prescribe medication against nausea and allergies, as well as vitamins	Self-medicate

Notes

ARV treatment information and how to provide it

ARV treatment and taking other medicines – drug interactions



Aim of the session

At the end of the session participants will be able to explain that:

- drug interactions can be dangerous and stress the dangers of self-medication
- the concentration of certain drugs in the blood can become stronger or weaker due to the presence of other drugs, and explain why this is a problem.



Methodology

- Q&A session led by the facilitator
- Presentation



Time

- 35 minutes



Materials needed

- Pre-prepared poster 'Essential points to remember on interactions between ARVs and other drugs' (see page 41)



Notes for the facilitator

- None



Preparation

- On a flip chart, prepare the poster 'Essential points to remember on interactions between ARVs and other drugs' (see page 41).



Activity

1. Ask participants to define the term 'drug interaction'. Correct and clarify, based on the definition given below.
2. Clarify the following concepts by using interactive Q&A:
 - concentration (level) of drug in the blood
 - relationship between the drug blood levels and the time intervals between drug dosages.
3. Ask if drug interactions are always a problem, and introduce the concept of 'booster' drugs such as ritonavir that improve the effects of other drugs.
4. After the Q&A session, put up the poster 'Essential points to remember on interactions between ARVs and other drugs' and recap using the points on the poster, checking that participants have understood.



Essential information

What is a drug interaction?

A drug interaction happens when a person takes two or more medicines at the same time and one of the drugs changes the effects of another one.

Interactions with other drugs

Certain drugs can:

- increase the concentration of ARVs in the blood, making them toxic
- decrease the concentration of ARVs in the blood, making them less effective.

For these reasons:

never take drugs without consulting a doctor first
= no self-medication when taking ARV drugs

What is the concentration of a drug in the blood?

- The concentration means the level that is reached in the blood after taking a drug by mouth, injection and so on
- The correct concentration is the level that is required to achieve the best effects from the drug; that is, the **correct dose of ARV**
 - If the level of a drug in the blood is too low, the drug is not effective
 - If the level of drug is too high, it can be toxic and the body might be unable to eliminate it correctly.
- The quantity of a drug decreases gradually after taking it because we eliminate it naturally in sweat or urine, or through chemical reactions in the liver. As soon as the amount of drug in the blood drops to an ineffective level, another dose must be taken
- This is why there are **strict intervals between drug doses** in order to ensure that the concentration in the blood is at the best level. Different drugs require different intervals between doses because they are removed from the body at different speeds. Some drugs are removed very slowly (for example, after 12 hours), which is why the medicine is only taken twice a day, while others are eliminated much faster and so have to be taken three or four times a day.

Interactions between ARVs are not always negative. Some ARVs can boost the concentration of other ARVs and improve their effectiveness. For example: ritonavir (RTV) boosts the effectiveness of saquinavir (SQV), indinavir (IDV) and lopinavir (LPV).



Additional information

Traditional and herbal medicines

Traditional and herbal medicines should not be ignored because many of them have real effects on the body. Some of them may interact with ARVs, but very little research has been done to find out about interactions with pharmaceutical medicines such as ARVs. Providing traditional healers with training on ARVs will help them to understand what can happen and change how they use herbal remedies for people who are taking ARV treatment.

Essential points to remember about the effect of ARV drugs on HIV

Essential points to remember on interactions between ARVs and other drugs

- Taking certain other drugs when on ARV treatment can be very dangerous.
- These drugs can increase the concentration of ARV drugs in the blood and make them toxic.
- ARVs can also increase the concentration of these drugs in the blood so they become toxic.
- Some drugs can reduce the concentration of ARV drugs in the blood and make them ineffective.
- Drug interactions can sometimes be useful. For example, a small dose of ritonavir (a protease inhibitor) can improve the effects of some other protease inhibitors.

**Never take drugs without consulting a doctor first
= no self-medication when taking ARV medicines**

ARV treatment information and how to provide it

ARV treatment and prevention



Aim of the session

At the end of the session participants will be able to explain:

- why prevention is necessary even when a person is taking ARV treatment
- why prevention messages and support must be an integral part of an ARV treatment plan.



Methodology

- Presentation and brainstorm
- Role play



Time

- 1 hour 30 minutes



Materials needed

- Photocopy of role play scenario or
- Poster with scenario written on it



Notes for the facilitator

- Ensure that participants are clear about the modes of transmission.
- Refer to other modules on prevention of mother-to-child transmission (page 86), healthy living (page 82) and stigma (page 52).
- In the role play, try to choose a participant for the role of treatment support worker who already knows something about prevention for people on ARV treatment. Ensure that awareness of the following points are addressed in the role play:
 - the need for ongoing prevention
 - the risks of re-infection
 - views about disclosure of HIV status, taking ARVs and the link to prevention
 - the gaps in people's knowledge
 - the kinds of activities that can reduce these knowledge gaps
 - what can help people with prevention when they are on ARV treatment.



Preparation

- Prepare photocopies or poster of the role play scenario (see page 45)



Activity

1. Introduce the session and ask participants to brainstorm what they think about prevention for people taking ARV treatment. Ask them to explain their statements and to discuss what needs to be prevented and how. Note answers on a flip chart.
2. Divide participants into two groups (one of men and one of women) and ask them each to prepare a role play in which the women act as men in one group and the men act as women in the other.
3. Give each group the role play scenario and give them 15 minutes to prepare. See 'Notes for the facilitator' (on this page) for guidance on what the groups should include in their discussion.
4. Ask each group to present their role play, allowing for 10-15 minutes of discussion after each group's presentation.
5. Summarise the main points from the brainstorm and role plays, correct any misconceptions, highlight any gender differences and emphasise the aims of the session.



Essential information

Prevention of HIV infection or re-infection

- **Prevention of HIV re-infection while on ARV treatment** There are different versions (strains) of HIV. A person who is infected with one strain, and receiving treatment for it, can become infected with another, different strain of HIV that may be resistant to those ARVs. Consistent condom use and safer sex practices can help to prevent this
- **Prevention of drug resistance** Drug resistance develops when inadequate doses of ARVs are taken (for example, because of poor adherence or treatment interruptions). A person on ARV treatment can reduce the chances of drug resistance by good adherence to treatment, avoiding treatment interruptions and avoiding re-infection with other strains of HIV
- **Prevention of mother-to-child transmission** HIV infection can pass from mother to child in the womb, at childbirth and through breastfeeding. To reduce the chance of transmission, the mother can take ARV drugs near the end of pregnancy and the child can be given them after birth. If the mother herself needs and receives ARV treatment, this will reduce the risk of transmission even more. People on ARV treatment should receive clear advice on reproductive choices and how to reduce the risks of HIV transmission to the child (see the module ARVS and the prevention of mother-to-child transmission (PMTCT), page 86).
- **Prevention of HIV transmission to sexual partners** People on ARV treatment can still pass HIV to their sexual partners, even if they have a very low or undetectable viral load. Couples where one person is HIV negative and the other is HIV positive (a sero-discordant couple) should practice safer sex and consistently use condoms. Even if both are HIV positive, it is possible that each has a different strain of HIV that can infect the other partner. It is important for the couple to understand that ARV treatment does not eliminate the chance of HIV transmission. Negotiating safer sex can be very difficult, especially for women, and advice may be needed on how best to do this
- **Preventing non-sexual HIV transmission** Sharing needles, razor blades or tattoo instruments can also pass on HIV infection. Instruments should be sterilised if they have to be shared. Injecting drug users should know how to reduce risks of sharing and know whether needle exchange services are available.

Prevention of other infections

- **Avoiding cross-infection** Where sexual partners are both HIV positive, they can risk passing some HIV-related infections to each other; for example, TB or sexually transmitted infections (STIs). Early detection and treatment of infections, along with safer sex, can help to avoid this

- **Prevention of sexually transmitted infections** STIs such as herpes put a further strain on the immune system. STI symptoms can be more severe in people who have HIV and can also be more difficult to treat. STIs can also increase the risk of HIV transmission
- **Prevention of TB** People with HIV are at greater risk from TB. In high TB-prevalence situations, a course of isoniazid (INH) might be prescribed to prevent active TB infection
- **Prevention of pneumocystis pneumonia (PCP)** The drug co-trimoxazole in low dose is a useful method of preventing this chest infection, which is much more common in people with HIV. However, there are problems of drug resistance to co-trimoxazole in some countries
- **Prevention of other health problems** Good nutrition, hygiene and physical activity, and social and emotional support can help a person taking ARV treatment to live healthily and to prevent further infections.

Safer sex

Below is an example of guidance for counsellors on the risks of STIs and HIV transmission in different sexual activities, taken from *Programme Guidance on Counselling for STI/HIV Prevention in Reproductive Health Settings* (International Planned Parenthood Federation, 2002).

There are many different sexual activities that men and women, men and men or women and women may engage in to express their sexuality. Sexual intercourse involving penetration is only one of these. There are many more. When you help clients to assess their risk and make a risk reduction plan, you need to help them to talk about what activities they engage in. In this way, your clients will be aware of the risk level of all potential activities and will have many pleasurable possibilities to consider.

Safe sex	Safer sex	Unsafe sex
<p>These are sexual activities with no risk of HIV transmission. They include:</p> <ul style="list-style-type: none"> • all activities between two people who are not infected with HIV • all activities that do not and could not involve semen, vaginal fluids or blood going from one person into another 	<p>These are sexual activities with a low risk of STI and HIV transmission. They include:</p> <ul style="list-style-type: none"> • activities involving a person with an HIV infection if there is no semen, vaginal fluid or blood going from one person into another • activities that have not been proved so far to be a route for infection 	<p>These are high-risk sexual activities. They include:</p> <ul style="list-style-type: none"> • any activity with a person who might have an HIV infection that allows blood, semen or vaginal fluid inside the body through the mouth, vagina, penis or anus, or through broken skin
<p>These include:</p> <ul style="list-style-type: none"> • massage • hugging • solo masturbation • body-to-body rubbing (not genitals) • sex talk, sexy dancing • sharing sexual fantasies • body kissing • showering together • using sex toys without sharing them 	<p>These include:</p> <ul style="list-style-type: none"> • masturbation of each other if there are no cuts on the hands and people don't touch their own genitals afterwards • open mouth kissing if both partners do not have cuts or bleeding gums in the mouth • vaginal intercourse with a condom • gentle anal intercourse with a condom and plenty of water-based lubricant • oral sex (see below) 	<p>These include:</p> <ul style="list-style-type: none"> • vaginal and anal intercourse without a condom • any type of blood contact, including menstrual blood, semen or vaginal fluid entering wounds in the skin • sharing sex toys without cleaning them between partners • any type of sex that damages the delicate tissues in the vagina, head of penis or rectum. For example, dry sex, rough sex, abrasive substances in vagina, sex when one and/or both partners has sores in areas of contact

ARV treatment information and how to provide it

ARV treatment and prevention



Additional information

HIV and oral sex (mouth to genital contact)

Research shows that transmission of HIV through oral sex is rare. As far as we know, receiving oral sex is safer than giving oral sex. The risk of HIV transmission through oral sex is greater if the person or partner has an untreated STI such as gonorrhoea or syphilis. Untreated STIs are easily transmitted through oral sex.

- **Oral sex on a woman** is risky during menstruation or when the person doing the oral sex has bleeding gums, mouth ulcers or open sores in the mouth or throat. Oral sex on a woman with HIV is less risky than oral sex on a man who has HIV. A barrier called a **dental dam** (a square piece of latex or plastic film) can be used during oral sex with a woman
- **Oral sex on a man** is safer if the man wears a condom. It is risky to do it without a condom if the person doing the oral sex has bleeding gums, mouth ulcers or any open sores in or around the mouth.

Why does someone using ARV treatment need to prevent and treat opportunistic infections?

ARV treatment reduces the amount of HIV in a person's body and allows the immune system, and their health, to recover. It dramatically reduces the incidence of opportunistic infections among people with HIV who have received the drugs.

However, prevention and treatment of opportunistic infections continue to be essential. Early treatment of opportunistic infections can mean that a person does not need to start ARV treatment until some time later. Unfortunately, many people still do not have an HIV test until they are already seriously ill with opportunistic infections. This often means that they need to begin ARV treatment immediately. For some people, it is better to delay ARV treatment and just treat the opportunistic infection first, especially if drug interactions or drug toxicities might be a problem.

For example, most people with acute TB will receive curative treatment for this before they start ARV treatment. Only people who are seriously at risk of dying will receive both at the same time, and the choice of drugs will be restricted in order to avoid interactions or toxicity.

People who have already started ARV treatment may require other treatment if opportunistic infections appear after the beginning of ARV treatment. This can happen when the immune system starts to recover because the body's defences start to work again and symptoms of infection appear that were hidden before. These may require specific treatment while ARV treatment continues.

Measures to prevent and treat opportunistic infections become essential if ARVs stop working because of poor adherence, drug resistance or other factors.

Prevention and treatment of opportunistic infections not only helps people with HIV to live longer, healthier lives, it can also prevent TB and other transmittable opportunistic infections from spreading further among the population.

How can we prevent HIV-related opportunistic infections?

people with HIV can reduce their exposure to certain health-threatening germs. They should be especially careful about uncooked meat, domestic animals, human excrement and lake or river water. However, there is no easy way to avoid exposure to such things as candida, bacterial pneumonia and other diseases because they are common in the environment.

Several HIV-related infections (including TB, bacterial pneumonia, malaria, septicaemia and PCP) can be prevented using drugs. This is known as **drug prophylaxis**. One particular drug called co-trimoxazole (also known as Septra, Bactrim and SMX-TMP) is effective at preventing a number of opportunistic infections. This drug is cheap and widely available. WHO recommends that co-trimoxazole should be offered to the following people in Africa:

- HIV-positive adults with symptomatic HIV disease or a CD4 count below 500
- HIV-positive pregnant women after the first trimester
- infants born to HIV-positive women
- any child identified as HIV infected who has HIV-related clinical signs or symptoms.

Some have suggested that WHO should recommend co-trimoxazole to all Africans with HIV, regardless of CD4 count. However, there are concerns that widespread use of co-trimoxazole may encourage drug resistant bacteria and malaria parasites.

Drug prophylaxis (preventive treatment) is sometimes recommended for those receiving ARV treatment if they have very weak immune systems or are considered to be especially vulnerable. They may be advised to stop taking the drugs if their immune system recovers.

Ongoing (or secondary) prophylaxis may be necessary for people who have been successfully treated for an opportunistic infection, to prevent it happening again. This applies to diseases such as TB, salmonella, cryptococcosis and PCP.

Scenario for a role play

A treatment support worker from the local network of people with HIV comes to a newly formed treatment support group. The group includes people preparing to start treatment and people who are already on treatment. At least one has been on treatment for two years or more. The support group members ask the treatment support worker some questions about prevention (why, what, how) and sex, and the treatment support worker provides information.

Adherence to ARV treatment



Aim of the session

At the end of the session participants will be able to:

- give a practical definition of adherence
- list the main methods to check if a person is taking their treatment correctly
- explain the effects of poor adherence to ARV treatment.



Methodology

- Q&A session led by the facilitators
- Presentation of summary



Time

- 45 minutes



Materials needed

- Posters 'Taking treatment correctly means...' and, for the last part of the session, 'What not to do when taking ARVs' (see page 47)



Notes for the facilitator

- The small differences between the word 'adherence' and other similar words such as 'compliance' are not important for this type of training. It is better to say simply that they mean the same thing.



Preparation

- Prepare the two posters 'Taking treatment correctly means...' and 'What not to do when taking ARVs' (see page 47)



Activity

1. Discussion with whole group: 'What is adherence?', 'What does it mean when you say that someone is or isn't taking their treatment correctly?', 'What rules should you follow?'
2. Summarise the explanations given by the participants on a flip chart (see 'Essential information').
3. To recap, go through points on the poster 'Taking treatment correctly means...' (see page 47).
4. Then present the poster 'What not to do when taking ARVs' (see page 47).
5. Ask what might happen if someone does not do these things (Q&A).



Essential information

What does it mean when you say that someone is or is not taking their treatment correctly? (see the poster on page 47).

Adherence is a word used to describe how faithfully a person 'sticks' to the prescribed treatment. 'Poor' adherence implies that person does not take the treatment as prescribed; for example, forgetting doses, taking too many tablets or even stopping treatment for a 'holiday'. ARV treatment requires very high levels of adherence. For example, a person taking doses twice every day must not miss more than one dose per month in order for the treatment to be successful.

What other words are used when talking about adherence?

- Compliance
- Concordance
- 'Observance' in French

Adherence is the cornerstone of successful ARV treatment

- Even slight non-adherence can lead to a drop in the levels of drugs in the blood and the development of drug-resistant HIV. The treatment will therefore cease to be effective.
- Missing doses is risky; it is better to aim for 100 per cent adherence. Some people want to take 'treatment holidays', either because they get tired of taking the drugs, or because they don't like the side effects. However, breaks in treatment are not recommended because research has shown that people who do this do not survive well, even if they resume treatment again.
- Resistance does not appear suddenly. A patient can seem well even if they have poor adherence. The virus will continue to multiply in the body and eventually the viral load will rise and the risk of illness will increase.



Additional information

Non-adherence: is it a choice or the effect of difficulties?

- Non-adherence can be a decision taken by the person on treatment who, for example, interrupts their treatment because they no longer want to take it
- Non-adherence can be forced upon the person on treatment; for example, if they do not have the financial means to buy the drugs or if it becomes too difficult to take them due to stigma and discrimination
- It is always important to work with the person on ARV treatment in a non-judgemental way to work out the reasons why doses are not being taken correctly and find a way to resume good adherence.

Non-adherence: is it occasional or regular?

- Non-adherence may be a very rare occurrence; for example, when a person forgets to take their drug at the correct time on a certain day because they had an unexpected visitor
- Non-adherence may be something that happens regularly. For example:
 - a person changes their routine for taking the drugs because the timetable given by the doctor was not suitable
 - a person decides never to take their drugs on a Friday because that is when they go to the mosque
 - a person simply stops their treatment for several days, weeks or even months.
- You must always check whether the non-adherence happens only rarely or on a regular basis in order to understand the reasons and assess the consequences
- **Adherence is not always consistent.** It can change as time passes for each person, depending on a variety of factors and circumstances

Taking treatment correctly means...

- Sticking to the doses prescribed by the doctor. Not taking more or fewer drugs than those prescribed
- Sticking to the method of taking the drugs; for example, tablets or syrup
- Sticking to the number of doses per day, and not reducing or increasing the number of doses
- Sticking to the timetable for doses and the intervals between the advised doses
- Following the advice given regarding diet, fasting and drinking, as these can influence the effectiveness of the treatment
- Not taking any other drugs that were not prescribed without talking to the doctor
- Not taking any substances that can influence the effectiveness of the treatment
- Making sure that you understand what each of your drugs are for, and which ones are the most important

What not to do when taking ARVs

- Do not take more or less tablets than those prescribed by the doctor
- Do not take your drugs in syrup form if you were prescribed tablets. Do not open up capsules and mix the contents with food or drink
- Do not reduce or increase the number of daily doses
- Do not change the timetable for doses or the intervals between them
- If the drugs must be taken on an empty stomach, do not eat just before or just after taking them
- Do not take other drugs without talking to the doctor
- Do not use any substances that can affect the success of the treatment

Adherence to ARV treatment

ARV treatment – barriers to adherence

Aim of the session

The aim of this session is to enable participants to understand that everyone has some difficulties in adhering to ARV treatment, through reflecting on the situation of persons who are on ARV treatment. At the end of the session participants will be able to:

- explain the different factors affecting adherence to treatment, including factors linked to:
 - the individual
 - the context in which they live or their social situations (family, work, etc.)
 - the ARV treatment itself
 - health care workers and health services
- describe some examples for each category.

Methodology

- Case study activity in pairs
- Sharing the results with the rest of the group
- Reading a fact sheet on barriers to adherence
- Discussion based on the fact sheet.

Time

- 45 minutes

Materials needed

- Fact sheet 'Barriers to adherence' (see page 49)
- Sample prescriptions for ARV treatment, based on the list of possible combinations (Annex 3)

Notes for the facilitator

For the activity in pairs, it is important for participants to really think of themselves as a person with HIV. If there is a person on ARV treatment in the group, the facilitator can ask them to share the problems they have encountered with adherence. However, it is important not to force a person with HIV to share their personal experience, and their wishes must be respected.

Preparation

- Make photocopies of the fact sheet 'Barriers to adherence' (see page 49-50)
- Prepare enough sample prescriptions of ARV treatment so that each pair has one

Activity

1. Divide the participants into pairs. Give each pair a sample prescription. Ask the pairs to imagine that they are a person on ARV treatment and that they must follow the treatment protocol as outlined on the prescription.
2. Ask the participants to imagine honestly and sincerely how this treatment fits into their lifestyle (when to take the doses, food, etc.). They should take into account their current work, social and family situations. They should discuss when and why they think they would find it difficult to adhere, as well as the difficulties that could arise, and note them down.
3. Go around the group and ask each pair to list the difficulties they noted in being adherent on a daily basis. Why do these difficulties arise when taking the treatment? What reasons would result in skipping a dose or reducing doses (not being adherent)? Note down these obstacles on a flip chart.
4. Present the fact sheet 'Barriers to adherence' (see page 49), show the different categories (personal, social, linked to treatment, linked to health care professionals and services) and discuss any other factors that have not been mentioned already by the participants.
5. Discuss any other important obstacles that have not come out of the discussions in pairs.

Essential information

- There are different types of barriers to adherence:
 - personal barriers
 - social and economic barriers such as family, work, income, etc
 - barriers related to treatment
 - barriers related to health care workers and the health services.
- These barriers can be occasional or regular, and will vary from person to person
- Some people will experience a lot of barriers, but others might experience very few.

See the fact sheet 'Barriers to adherence' on page 49.

Example: results of activity from a training workshop in Senegal

What difficulties would you face in adhering to your treatment if you were on ARVs?

- Forgetting doses
- Difficult during fasting periods such as Ramadan
- Not easy to have three regular meals
- Sleep
- Difficulty in taking drugs when away on a trip
- Too many drugs to take
- Professional activities prevent taking the drugs – workload, lack of time
- Side effects are a nuisance
- Not always easy to conceal the drugs
- Illness
- Difficult to maintain confidentiality, in particular when with the family
- Consumption of alcohol
- Laziness
- Interrupted supply of the drugs
- Difficult to accept HIV and the treatment
- Interruptions to the water supply prevent taking the treatment correctly.

Fact sheet: Barriers to adherence

Individual barriers for a person on treatment, based on different types of challenge:

Emotional/psychological factors

- Depression, emotional breakdown
- Guilt at having survived the death of a loved one (survivor's syndrome)
- Level of self-esteem
- Denial – if a person wants to forget that they are infected by the HIV virus, they might not want to take drugs as they remind them of HIV/AIDS

Mental factors

- Inability to understand and remember prescriptions, dosage schedules etc. (these can be linked to the level of literacy and education)
- Lack of belief in the effectiveness of the treatment (can be related to perceptions of drugs in general)

Behavioural factors

- Possible difficulties in organising and managing personal time (for example, in relation to work schedules)
- Reactions to side effects and other related constraints of the treatment
- Consumption of substances such as alcohol or drugs, which can affect the memory or make someone unwilling to take a dose of the treatment

Physical factors

- For someone who is HIV positive and asymptomatic, the treatment can be perceived as the start of illness – the side effects of ARV drugs are believed to be the first signs of AIDS
- For a symptomatic HIV positive person, the disappearance of opportunistic infections and other pathologies can give the impression of being cured and no longer requiring the treatment

Social factors (environment)

- Situations in which the person taking the treatment must take their drugs secretly (in the family, at the workplace, with friends etc.)
- Stigma, discrimination, fear, rejection, social isolation
- The level of support from the family in general and when taking the treatment
- Lack of financial resources and greater priorities for survival
- Caring for other sick people, children in particular
- The failure of treatment for another family member can affect a person's belief in the effectiveness of their own ARV treatment

Fears associated with ARV treatment

- | | |
|--|--|
| • Not being able to control the side effects | • Social stigmatisation |
| • Feeling that the drugs are too strong and might be fatal | • Unsuccessful treatment |
| • Physical discomfort, pain, tiredness | • Doubts about its long-term effectiveness |
| • Physical changes | • The illness arising or returning |
| | • A fatal side effect occurring |
| | • Uncertainty about life expectancy |

continued over...

Adherence to ARV treatment

ARV treatment – barriers to adherence

Fact sheet: Barriers to adherence (continued)

Factors linked to the treatment

- The larger the number of doses, the more complicated it is to take the treatment, especially when taking other medication (preventive and/or curative treatments for opportunistic infections and other problems). More than two doses of drugs per day often leads to poor adherence
- The greater the number of side effects or adverse reactions, the more difficult it is to take the treatment
- If a person thinks that the 'illness is progressing' despite the treatment, they are less motivated to take the drugs
- If the person is given treatment for other illnesses at the same time as ARVs, lack of information or understanding can lead to confusion about which drugs are ARVs and which are given for other reasons.

Factors linked to health workers and health services

- A lack of knowledge and training for health care workers in relation to HIV, ARV treatment and adherence
- Failure to observe confidentiality for patients using health services or disclosing the patient's HIV status unnecessarily or without the patient's consent
- Perceived or actual stigma and discrimination by health care workers against people with HIV, which deters patients from starting treatment or returning for follow-up appointments.
- Failure to provide the patient with clear information on:
 - dosage
 - the scheduling of doses
 - effects and effectiveness of the drugs
 - possible side effects
 - possible interactions with other drugs or substances such as alcohol, and the risks incurred
 - food requirements associated with the treatment
 - risks of stopping treatment or incorrect doses of the drugs
- Failure to adapt the treatment to the personality and lifestyle of the person on treatment; for example, to fit in with their schedule
- Lack of time and lack of active listening to the person on treatment
- Refusal to take into account side effects suffered by a person on treatment and the effects of the treatment on the person's life (work, family life, emotions, sexuality, etc.)
- Attitudes of health care professionals about a person's ability to take their treatment correctly. If a doctor thinks that their patient is not able to follow the treatment, this can influence the patient
- Distance and costs for the person on treatment in accessing the clinic to see the doctor, visits to the laboratory for tests, getting drugs from the pharmacy
- Clinic opening time is unsuitable for clients to attend for consultations

Notes

Adherence to ARV treatment

Stigma and ARV treatment



Aim of the session

At the end of the session participants will be able to explain:

- how stigma relates to ARV treatment
- how stigma affects a person's ability to take ARV treatment
- what can help to reduce the effects of stigma on ARV treatment.



Methodology

- Discussion
- Case studies
- Reporting back in plenary
- Stop-start drama
- Discussion



Time

- 4 hours



Materials needed

- Photocopies or flip chart posters of 'Health workers and stigma', case studies 1 to 5 (see pages 55-57)
- Photocopies or flip chart posters of 'Stop-start drama – religion, stigma and ARV treatment', scenarios 1 and 2 (see page 57)



Notes for the facilitator

One of the causes of stigma is a lack of knowledge, so it is essential that participants are clear about how HIV is transmitted. You should review this with them as part of the activity, unless this has been done earlier in the workshop.

The case studies and stop-start drama should be adapted to your local context.



Preparation

Either:

- photocopy 'Health workers and stigma', case studies 1 to 5 (see pages 55-57) and 'Stop-start drama – religion, stigma and ARV treatment', scenarios 1 and 2 (see page 58) as handouts for participants

or

- write the posters on flip charts: 'Health workers and stigma', case studies 1 to 5 (see pages 55-57) and 'Stop-start drama – religion, stigma and ARV treatment', scenarios 1 and 2 (see page 58)



Activity

1. Introduce the session.
2. Ask participants to volunteer any examples of stigma that they themselves may have experienced and how this made them feel – this does not have to be HIV related.
3. Ask participants to brainstorm on how they think stigma relates to ARV treatment and note their answers on a flip chart.
4. Explain that the aim of the first activity is to look at health workers, stigma and ARV treatment.
5. Divide participants into groups and give each group one of the case studies on health workers and stigma, either on photocopied sheets of paper or on a poster.
6. Ask each group to discuss their case study and answer the questions.
7. Ask the groups to come back together to report back in plenary.
8. Ask the large group to summarise how stigma is affecting the person taking ARVs in the different case studies and note answers on a flip chart.
9. Ask the large group to summarise how the effects of stigma on the individuals can be reduced and note answers on a flip chart.
10. Explain that the second activity is a stop-start drama (or, if time allows, two stop-start dramas) on religion, stigma and ARVs.
11. Ask for volunteers to start the role play, giving the outline of the characters.
12. Let them role play a little, stop the action and ask the audience to say what has happened and give some ideas for what should happen next.
13. Write these ideas on a flip chart and vote or decide which option to try – then try it.
14. Ask participants to identify the issues raised by the drama and review some of the ways of reducing HIV-related stigma.



Essential information

Experience in different settings on different continents shows that stigma is one of the greatest challenges for most people with HIV, especially when they need access to services. Stigma is also one of the main reasons why uptake of services does not reach expected levels, even when communities know they are available and accessible. The close links between stigma, care, treatment and prevention therefore need to be examined and understood in order to plan improvements in uptake and quality of prevention, care and treatment services.

Internalised or self-stigma

- Since HIV-positive people share the same belief and value systems as the rest of the community and are often subjected to cruel, thoughtless and hurtful finger-pointing and stigmatising actions by others, it is not surprising that they also stigmatise or blame themselves
- HIV-positive health workers in particular can feel that they 'should have known better' and blame themselves for becoming infected
- This can lead to loss of hope and feeling worthless (even suicidal) and inferior. These result in some HIV-positive people isolating themselves from society, friends and family. In terms of ARV treatment, such feelings can have a negative impact on adherence.

Secondary stigma

- Friends, families, children and care-givers of people with HIV, including health workers or NGO workers, are also stigmatised 'by association'
- For example, parents are blamed for their child's 'bad' behaviour, which led to them becoming HIV infected
- As a result, secondary stigma can also cause loss of reputation and livelihood.

How does stigma relate to ARV treatment?

- Stigma and discrimination are still among the biggest challenges for people with HIV
- Stigma prevents people from accessing HIV testing, care, support, treatment and prevention
- Preventing and reducing stigma and discrimination is vital so that people are not discouraged from using or helping others with ARV treatment
- ARV treatment that is effective and easily accessible and affordable for everyone who needs it, is a powerful way to reduce stigma and discrimination in affected communities.

How can stigma affect a person's ability to take ARV treatment?

- When stigma stops a person from accessing services for HIV testing, care, support, treatment and prevention, it also reduces their access to ARVs.
- Stigma causes psychosocial problems, such as anxiety, depression, guilt, shame and loss of hope. This can cause problems for a person starting or adhering to ARV treatment
- Taking ARVs may make someone afraid that they will be identified as having HIV
- Secrecy and not being able to disclose their HIV status may make it difficult for a person to keep ARV medicines at home or carry them around during work or recreation time
- Stigma can isolate a person with HIV from their family, friends and community. This means the loss of important sources of support for ARV treatment
- Women, young girls and children are often more stigmatised than men. Women, young girls and children with HIV might therefore have greater difficulties in getting access to or adhering to ARV treatment
- Stigma can also extend to carers of people with HIV, including health workers. This can prevent them from offering support to people taking ARVs, or from getting ARV treatment if they need it themselves.

What can help to reduce the effects of stigma on ARV treatment?

- Increasing people's knowledge about HIV and encouraging them to recognise that stigma and discrimination exist
- Raising awareness of the benefits and availability of ARV treatment
- Including prevention in messages about ARV treatment. This means showing people that prevention is still necessary for people taking treatment and that it is possible to avoid opportunistic infections such as TB by taking drugs to prevent them
- Ensuring that people already on ARV treatment receive good support from their family, friends and community
- Providing safe and confidential spaces for people to discuss their issues about HIV and ARV treatment
- Providing psychosocial support services as a part of ARV treatment support, such as counselling and support groups
- Involving people with HIV, especially those taking ARVs successfully, in providing support and information. In this way, those who need ARV treatment can see the positive results of treatment, and experiences can be shared with the community and with health workers who are responsible for referring people for ARV treatment
- Involving a wide range of people to provide a supportive environment for ARV treatment, such as health workers, families, communities, NGOs, community groups, traditional healers and faith-based organisations
- Developing treatment-friendly communities by using community education, support and referral strategies. This means helping people to understand better about HIV and its transmission, about prevention and treatment, and about how to support people with their ARV treatment.

Adherence to ARV treatment

Stigma and ARV treatment

- Ensuring that people who are stigmatised or vulnerable – women, children, sex workers, men who have sex with men, injecting drug users – can assert their rights and have access to ARV treatment.



Additional information

Ways to reduce HIV- and AIDS-related stigma

- It is important to look at and address the social context in which HIV-related stigma occurs.
- A good understanding of what HIV is and how it is transmitted is essential so that people are equipped to make correct assessments of actual HIV risk in any given life situation
- Values, norms and moral judgments that contribute to stigma need to be understood and addressed. This includes using non-stigmatising language, without moral judgements, to describe behaviours with a high risk of transmission. Faith-based organisations and community leaders must be engaged in this
- HIV-positive people have an important role in reducing HIV-related stigma, especially if they are active members of HIV/AIDS programmes

Forms of stigma and some strategies for reducing it in specific settings

Examples of forms of stigma	Examples of strategies to combat stigma
Health centres	
<ul style="list-style-type: none"> • Clinic creates gossip by isolating chronic patients • Limited physical contact with chronically ill clients because of fear of contracting disease – demoralises patients, makes them feel unwanted and may destroy their will to live • Nurses make assumptions about client's sexual history and judge them for 'having had many partners' • Health care workers stigmatise each other if they think a colleague is HIV positive. 	<ul style="list-style-type: none"> • Allow health care workers to talk about their own attitudes, feelings, fears and behaviour. Help them deal with fears about their status and burnout • Teach skills in sensitively handling patients • Develop codes of practice • Update health workers on HIV and stigma through in-service training • Get feedback from clients (community walk through clinic to identify stigma points).
Community	
<ul style="list-style-type: none"> • HIV-positive people and families face isolation, insults and discrimination • In some cases they are kicked out of rented accommodation or their businesses suffer – people stop buying from them. 	<ul style="list-style-type: none"> • Involve community leaders and CBOs in promoting anti-stigma work • Use people with HIV as role models and facilitators • Organise community meetings, peer group meetings and home visits • Organise drama performances • Make links between clinic and community • Inform community members what is involved in caring for people with HIV – physical care, counselling, etc.
Home-based care workers	
<ul style="list-style-type: none"> • Home-based care (HBC) workers face stigma by association – rejected by the community who say they carry AIDS • HBC workers are rejected by patients when they make home visits • HBC workers wearing uniforms triggers stigma towards family (by neighbours) • Visits are seen as a 'death warrant' 	<ul style="list-style-type: none"> • Stop wearing uniforms during home visits • Raise awareness by providing correct information on HIV, ARV treatment, TB and stigma.
Church/faith groups	
<ul style="list-style-type: none"> • HIV status associated with sin – promiscuity, adultery, immorality, many sexual partners • Gossip and condemnation • Silence and fear • Lack of adequate knowledge about HIV/AIDS and ARV treatment among church leaders (pastors, deacons) – results in silence • No proper preparation for marriage 	<ul style="list-style-type: none"> • Use churches/mosques as places to discuss stigma • Get the faith group to recognise that they stigmatise: blame and judge people for getting HIV • Educate faith group leaders on stigma and help them play a lead role in anti-stigma action • Encourage them to become counsellors in a non-stigmatising way; and role models for treating HIV-positive people in non-stigmatising ways.

Source: *Understanding and Challenging HIV Stigma: Toolkit for action* (Change Project and ICRW, 2003)

Adherence to ARV treatment

Stigma and ARV treatment

Examples of case studies from a training workshop in Zambia

(to be adapted to local context and used as posters or photocopies)

Health workers and stigma

Case study 1 Mrs Mulenga

Mrs Mulenga is 47 years old and is the sister-in-charge at the clinic. She has four children who are all grown up, and she is well respected in the community. Mrs Mulenga is HIV positive and gets ARVs from a private clinic, spending nearly 50 per cent of her salary on treatment. Recently when she went to the clinic to collect her monthly prescription, Mrs Mulenga met a colleague from her workplace. The colleague guessed that she was positive and told others at work. Mrs Mulenga is aware that there is a lot of gossip about her, especially among junior colleagues, and she has started hating going to work.

Discuss the case study and answer the questions below:

- Why do you think Mrs Mulenga went to the private clinic for her treatment?
- Why do you think colleagues are gossiping about her at work?
- What can be done to:
 - support someone like Mrs Mulenga?
 - address the problem of stigma in the clinic?

Case study 2 Viola Malambo

Viola Malambo is a voluntary counselling and testing counsellor at the local clinic. She is 27 years old and is engaged to be married. She has a good reputation as a hard worker and gets on well with her colleagues at work. Viola tested herself last year and found out that she is HIV positive. She knows about ARVs but does not know whether she wants to start treatment yet. She feels well but has begun to lose weight. She has overheard some colleagues talking about her, saying that they suspect she is HIV positive and that she 'should know better'. She has not talked to anyone at work about her situation.

Discuss the case study and answer the questions below:

- Why do you think Viola has not started on ARVs yet?
- Why do you think colleagues are gossiping about her at work?
- What can be done to:
 - support someone like Viola?
 - address the problem of stigma in the clinic?

Case study 3 Gilbert

Gilbert is a male nurse on the surgical ward. He is 30 years old and married with two children. Gilbert is HIV positive and was getting his ARVs from a clinic in Kabwe. He did not want anyone at work to know about his status. Last month, the clinic in Kabwe ran out of Triomune, so he went to the clinic at the hospital. Since then, nearly all his colleagues have avoided him, they whisper names and have stopped asking him to come for a drink after work. Gilbert feels depressed and begun taking sick leave as he cannot face the situation at work.

Discuss the case study and answer the questions below:

- Why do you think Gilbert was going to Kabwe to get his ARVs?
- Why do you think colleagues are treating him like this at work?
- What can be done to:
 - support someone like Gilbert?
 - address the problem of stigma in the hospital?

Case study 4 Dr Banda

Dr Banda is 40 years old and works in the hospital. He has a good reputation and is well respected. His wife died two years ago and he has four children. Dr Banda has known he is HIV positive for the last two years and has been taking ARVs, which he obtains secretly from the hospital. Sometimes the supply of ARVs does not come through and he has to go to a private clinic where his friend works to buy them. Dr Banda has not told anyone at work about his status and he lives in fear of anyone finding out.

Discuss the case study and answer the questions below:

- Why do you think Dr Banda does not want people to know his status?
- What can be done to:
 - support somebody like Dr Banda to be more open?
 - address the problem of stigma in the hospital?

Case study 5 Mrs Mundia

Sibeso Mundia is a home-based carer in one of the compounds outside of town. She got involved in home-based care through her church and looks after a lot of people who have AIDS-related illnesses. Mrs Mundia also helps community members set up support groups for people with HIV. Mrs Mundia is HIV positive herself, but travels to the clinic in town to get her ARVs so that no one will see her. She has told her family but they have asked her not to tell anyone else, especially people in the home-based care team. Recently her husband lost his job and there is a shortage of money. Her family are putting pressure on her to access the cheaper ARVs at the local clinic nearby.

Discuss the case study and answer the questions below:

- Why do you think Mrs Mundia has been getting her ARVs in town?
- Why do you think her family do not want her to tell others about her status?
- What can be done to:
 - support someone like Mrs Mundia?
 - address the problem of stigma in the home-based care team?

Adherence to ARV treatment

Stigma and ARV treatment

Stop-start drama

Religion, stigma and ARV treatment: Scenario 1

A young couple have been to get an HIV test together, as recommended by the pastor at their local church. The man has tested positive, the woman is negative. They have discussed the situation and still wish to get married.

Pastor	Young man	Young woman
<ul style="list-style-type: none"> You are a pastor at the Church of New Life and believe that HIV is a punishment sent from God to teach people to stop sinning You will not tolerate anyone with HIV in your church 	<ul style="list-style-type: none"> You have been engaged to your fiancée for two years and have just been for an HIV test that your pastor insisted on before he would discuss arranging a wedding You have found out you are HIV positive, but your fiancée is negative You cannot believe that she still wants to marry you, but after talking things through she assures you that she will stand by you You want to discuss the forthcoming wedding with the pastor 	<ul style="list-style-type: none"> You have been engaged to your fiancé for two years and have just been for an HIV test together You are planning to get married in three months' time You are shocked that your fiancé is HIV positive, but you have talked things through and you still love him and are sure about marrying him.

Stop-start drama

Religion, stigma and ARV treatment: Scenario 2

Some members of the choir at the church are meeting for a rehearsal. One of the members comes late and is wearing a T-shirt promoting condoms. They are a community mobiliser at the local voluntary counselling and testing (VCT) centre.

Choir member 1	Choir member 2
<ul style="list-style-type: none"> You are a community mobiliser at the local VCT centre You have rushed from work to get to choir practice and you are wearing your new T-shirt with a condom promotion message, which you were given today. 	<ul style="list-style-type: none"> You are friends with the T-shirt wearer, although you believe that everyone should abstain from sex before they marry.
Choir member 3	Choir master
<ul style="list-style-type: none"> You recently lost your sister to AIDS. You do not know the T-shirt wearer very well, but you believe that everyone should know about condoms in order to protect themselves from HIV. 	<ul style="list-style-type: none"> You are quite new to the church and are trying to organise regular choir practices You are shocked to see the choir member wearing the condom T-shirt, especially in church You believe that condoms promote promiscuity and are against nature.

Notes

Adherence to ARV treatment

Supporting adherence to ARV treatment



Aim of the session

At the end of the session participants will be able to explain:

- several factors that can support a person for adherence to ARV treatment.



Methodology

- Work in small groups
- Presentations in plenary



Time

- 1 hour 30 minutes



Materials needed

- Fact sheet 'Barriers against taking treatment correctly' (see pages 49-50)
- Pre-prepared flip charts with the titles 'Individual (person on ARV treatment)', 'Social', 'Treatment', 'Health care'.



Notes for the facilitator

Trainers can present the strategies for overcoming obstacles to adherence or the factors encouraging adherence (see 'Essential information') as a supplement to the strategies identified by participants in small groups during the activity.



Preparation

Write on four flip charts 'Individual (person on ARV treatment)', 'Social', 'Treatment', 'Health care' so that one flip chart can be distributed to each small group.



Activity

1. Divide the participants into four groups and give each group one of the following flip charts: 'Individual (person on ARV treatment)', 'Social', 'Treatment', 'Health care'.
2. Each small group must start with the barriers presented in the previous activity for one of the following categories:
 - the individual
 - their social or economic situations (family, work, income etc.)
 - the treatment
 - health care workers and services.
3. Within the groups, ask participants to reflect on various strategies that could enable the barriers to be overcome; in other words, strategies that would enable a person to take ARV treatment correctly (to be adherent). Participants do not have to reach a consensus on strategies at this stage. All suggestions must be simply accepted and noted.
4. Each group lists their strategies on a flip chart for the category of barriers that they were assigned.
5. A representative from each group presents the results of their group's discussions to the rest of the participants.



Essential information

Factors supporting good adherence can be classified into the same categories used to define barriers to adherence:

- factors at a personal level
- factors related to the social environment
- factors related to the treatment
- factors related to health care professionals and services.

When providing adherence support, you must help the person on treatment to think about existing barriers as well as those that might arise during the course of treatment. This can then be used to help the individual to identify strategies to overcome the barriers.

Strategies at an individual level

- Undertake activities that contribute to increasing self-esteem
- Talk about their HIV-positive status and treatment with at least one close member of their family circle
- Never hesitate to seek moral support from their family and friends, NGOs/CBOs, health professionals and so on
- Obtain sufficient, good-quality information on treatment
- Maintain a good level of personal hygiene and care.

Strategies at a social level

It is important that at least one family member, friend or 'buddy' can support the person on treatment and knows how it should be taken. This person's support may take different forms. For example:

- reminding the person when it is time to take the drug
- providing encouragement to take or continue with their treatment
- accompanying the person to follow-up appointments
- helping to look after children, especially for women on ARV treatment
- helping with housework or shopping when the person on treatment is not strong enough.

Strategies related to treatment

- Providing treatment with as few unpleasant side effects as possible
- Providing treatment that is simple to take in terms of doses and scheduling
- Free treatment or treatment that is covered by different types of health insurance
- Support for costs of getting to clinic or pharmacy.

Strategies related to health care professionals and services

- Professionals who listen to people on treatment and give clear and full information in a way that their patients can understand
- Professionals who provide adherence support tools where necessary, such as pill boxes, written treatment plans etc
- Professionals who work in multi-disciplinary teams and are happy to involve families, 'buddies' and CBOs/NGOs
- Health services that are accessible to people on treatment in terms of distance, opening hours, waiting times and protection of confidentiality.

Adherence to ARV treatment

Supporting adherence to ARV treatment

Example from training workshop in Côte d'Ivoire

Strategies to overcome personal barriers to adherence

A person on treatment can:

- accept their status, live positively, take no notice of what other people think of them
- confide in someone
- be convinced of the effectiveness of the medication
- join a care and support community organisation
- accept the issues related to taking treatment
- look after their own health
- adopt responsible behaviour (do not have unprotected sex, do not be ashamed)
- have better self-esteem
- avoid re-infection.

Strategies to overcome social barriers to adherence

- Inform one's partner
- Inform one's family
- Raise community awareness and mobilise it around care
- Raise awareness and educate around traditional practices that may be harmful
- Train the medical profession
- Raise awareness and train community leaders, religious leaders and traditional healers

Strategies to overcome barriers to adherence related to the treatment itself

- Make combination ARV therapy available to patients
- The choice of ARVs should depend on the side effects
- Review the presentation of some ARVs (reduce the size of some tablets)
- Reduce the cost of medication
- Encourage studies into treatment interruption to give patients a break during their treatment (therapy fatigue)
- Availability and accessibility of ARVs
- Pill box
- Therapeutic timetable

Strategies to overcome barriers to adherence related to health workers and health services

- Training
- Incorporation of care for people with HIV into all health centres
- Increase sensitivity to a patient's daily concerns – lifestyle, work, family etc.
- Increase numbers and availability of health care workers for HIV-related care – doctors, nurses, community counsellors etc.
- Availability of ARV treatment in all health centres
- Free access to ARVs for all patients
- Local or regional production of generic ARV drugs
- Involvement of community workers in care centres
- Good collaboration between counsellors, social workers and doctors
- Development of community and home-based care to include ARV treatment

Notes

ARV treatment follow-up

Providing treatment counselling and support



Aim of the session

The main aim of this session is to enable participants to apply what they have learned during the previous modules:

- Basic information on HIV
- Starting ARV treatment – who needs it and when?
- ARV treatment information and how to provide it
- Adherence to ARV treatment



Methodology

- Explanation
- Role plays
- Analysis of role plays with the whole group



Time

- 1 hour 10 minutes



Materials needed

- Poster 'Supporting adherence – adherence counselling' (see below, right)
- Posters describing scenarios for role plays (see page 65)



Notes for the facilitator

- It is important to emphasise that the role plays are not a test of the counselling abilities of those participating in the role play
- If the observers make negative comments about the way the counsellors behaved in the role plays, it is important that the facilitators also point out the positive aspects
- Make it clear that these role plays are not aimed at training participants to become counsellors. They are intended to help revise the information participants have received in previous sessions in a practical and dynamic way. Stress that people who will be providing adherence counselling should always receive a basic training course in counselling techniques, whether they are professional care workers or members of the community
- Comment on the usefulness of having people with HIV who are on treatment themselves working as treatment counsellors: clients can identify with them and feel more free to ask questions. Mention also some of the challenges, such as over-identification with clients and wanting to 'rescue' rather than help people make their own decisions.



Activity

1. Explain the aim and the methodology of the session.
2. Explain when adherence counselling is needed, what it should focus on and who should provide it, using the poster 'Supporting adherence – adherence counselling' (see below)
3. Present the two scenarios for the role plays. These are situations involving counselling and ongoing support for adherence (show the posters to participants as you describe the scenarios):
 - a session with a patient about to start treatment (pre-treatment counselling)
 - a session with a patient who started treatment some time ago and is now experiencing difficulties with adherence.
4. Give instructions for the role plays:
 - 10 minutes to prepare each role play
 - 10 minutes to perform each role play
 - two volunteers for each role play – a man and a woman to play a counsellor and a person with HIV
 - the other participants are observers, staying silent during the role play. They should note the client's questions and the contribution made by the counsellor (supportive information). Ask them also to think about other questions and advice that could or should have been offered to the client.
5. At the end of each role play, allow the participants who played the roles of counsellor and person with HIV to comment first. Then ask the observers to make their comments.



Essential information

See Module 1: Basic information on HIV and ARV treatment; Module 2: Starting ARV treatment – who needs it and when?; Module 3: ARV treatment information and how to provide it; Module 4: Adherence to ARV treatment.

Supporting adherence – adherence counselling

When is adherence counselling needed?

- Before starting treatment (pre-treatment)
- When treatment has started (first day, first few months)
- After the first few months of treatment (adherence challenges can change)
- When a person needs to stop or to change treatment

What issues should be talked about?

- Aims of the treatment
- How to take the treatment
- Side effects
- Obstacles to adherence and strategies for overcoming these
- What will happen in terms of follow-up

Who can provide adherence counselling (after training)?

- Health care professionals
- Professionals from the social sector; for example, social workers
- Community members, including people with HIV who are on ARV treatment

Providing treatment counselling and support



Preparation

- Make the posters 'Supporting adherence – adherence counselling' (see page 64) and 'Role play 1' and 'Role play 2'
- Adapt the role plays to local circumstances, such as names, context, challenges faced with ART adherence

Role play 1

Person starting treatment	Counsellor
<ul style="list-style-type: none"> • Man called Albert • 45 years old • Shopkeeper • Married • Three grown-up children • His wife and children do not know he is HIV positive • Travels regularly • Drinks a lot of alcohol • About to start ARV treatment 	<p>The doctor has already explained to Albert how to take his treatment and the possible side effects</p> <p>During the interview, the counsellor will explore with him the possible obstacles that might prevent him from adhering successfully to his treatment</p>

Role play 2

Person having difficulties with adherence	Counsellor
<ul style="list-style-type: none"> • Woman called Hope • 27 years old • Married • Three children – six months, two years and five years • Husband is HIV positive, not on treatment, knows his wife is HIV positive • Lives with her mother-in-law who is unaware of her HIV status • On treatment for six months, taking lamivudine+zidovudine (fixed dose combination) and indinavir • Has side effects – diarrhoea, nausea, vomiting 	<p>During the interview, the counsellor:</p> <ul style="list-style-type: none"> • asks Hope how she is taking her treatment and checks if she is taking it correctly • works with her to identify the different barriers to adherence • checks if she is taking any other medication • works with her to identify strategies that will help her to improve adherence • asks questions about the six-month-old child to check if it is growing alright or has any illnesses, and if she is able to feed it properly.

ARV treatment follow-up

ARV treatment follow-up and monitoring treatment success



Aim of the session

At the end of the session participants will be able to explain:

- the frequency of medical follow-ups for a person on ARV treatment
- what is monitored during follow-up (ability to tolerate the treatment, drug side effects, effects of the treatment on the immune system)
- the need for taking blood samples for laboratory tests at follow-up appointments.



Methodology

- Q&A session led by the facilitator
- Explanation and provision of information sources by the facilitator



Time

- 50 minutes



Materials needed

- Summary table of tests and checks made at follow-up appointments. Use local protocols if available. If not, you can use information from the website at www.aidsinfo.net.org/factsheet_detail.php?fsnumber=120 where you will find helpful and regularly updated fact sheets on this and other issues (FAQs)



Notes for the facilitator

Information for participants on protocols for monitoring and follow-up must be adapted to the local context (for example, viral load testing may not be available outside the capital city). Treatment follow-up procedures can vary from country to country, especially in terms of which tests are available and the frequency of follow-up visits.



Preparation

- Trainers should find out in advance about the monitoring and follow-up protocols in the country where the treatment is taking place. To supplement this information, access the internet for further support; for example, www.aidsinfo.net.org/factsheet_detail.php?fsnumber=120 where there are helpful and regularly updated fact sheets on this and other HIV and ARV treatment issues (FAQs)



Activity

1. Ask participants the following questions, and note the important points on a flip chart, providing further information as appropriate:
 - What do you understand by medical follow-up for a person on ARV treatment? What does it consist of?
 - What is the purpose of such follow-ups?
 - How can you measure:
 - effectiveness of treatment?
 - ability to tolerate treatment?
 - adherence to treatment?
2. Discuss the practical aspects of follow-up in the country you are in: the frequency of visits to clinic, checks and laboratory tests that will be carried out, where these will be done etc.
3. Use the information below on the frequency of follow-up for treatment to recap and explain when and how follow-ups are done by the doctor throughout the course of ARV treatment.
4. Ask what role participants think NGOs/CBOs could play in supporting follow-up.



Essential information

What is follow-up? What does it include?

- Appointments with the doctor. These should be on a regular basis to ensure good follow-up. The patient should not just attend when they feel the need or have a problem
- Laboratory blood tests. These have to be done in a laboratory, so the patient might be sent from the clinic to the laboratory with a request for the necessary tests.

What is the purpose of treatment follow-ups?

Follow-ups are for checking the:

- effectiveness of the treatment
- patient's ability to tolerate the treatment
- patient's adherence to the treatment.

Checking the effectiveness of the treatment

- The patient's weight and CD4 count are checked. Although viral load is a more accurate test, since it measures that actual virus levels in the blood, it is expensive and unaffordable for many resource-limited situations. WHO (December 2003) states that CD4 levels and clinical check-ups are sufficient in these settings to monitor effectiveness of treatment
- If the treatment is effective, the CD4 level will have increased or, if it was already at a satisfactory level, it will have remained at a constant level. CD4 levels are expressed either as a number (for example, 400 per cubic millimetre) or a percentage of CD4 cells relative to the total number of white cells in the blood
- If the treatment is effective, the patient will have increased weight or will have stabilised at a satisfactory level.

Checking the patient's ability to tolerate the treatment

Ability to tolerate treatment is checked through:

- asking the patient questions, especially about possible side effects
- clinical examination of the patient
- laboratory tests, specifically checking for toxic effects (for example, in the liver – see Module 3: Side effects of ARVs, page 30).



Additional information

What can be done at community level to support follow-up?

Remind patients and their 'treatment supporters' that follow-up appointments and tests are important for people on treatment in order to measure the effectiveness of treatment and monitor side effects. Make sure they understand that:

- the person on treatment needs to know when and how often the tests and the necessary medical appointments must be done
- the tests are done on samples of blood taken from the patient at the follow-up appointment
- the tests are critical for measuring the effectiveness of treatment
- monitoring helps the doctor to know what is happening to the HIV infection in the person's body
- monitoring is important for managing side effects
- it is important to prepare before going to the doctor. The person on treatment should prepare a list of information to share with the doctor and a list of questions to ask. They should also prepare to take a friend or relative with them to the appointment if they feel the need for a 'supporter' to help them talk to the doctor and get questions answered.

Checking the patient's adherence to the treatment

- This is done through careful and non-judgemental questioning of the patient. Pill counts – checking how many pills the patient has remaining after a certain number of days – are not usually helpful, because patients do not always give a correct story about how many pills they have taken.
- The patient should prepare carefully for this discussion because doctors usually have little time to spend with each patient and, as well as discussion, also have to carry out a clinical examination, decide on diagnosis and establish how treatment should continue.

The frequency of follow-up for treatment

The frequency of follow-up depends on the available resources and the needs of patients for treatment support. Usually, a follow-up timetable is arranged so that the patient is seen more often in the early stages of treatment and can then be followed up every three or six months when it is clear that the treatment is working and the patient is recovering well.

- **Pre-treatment assessment (PI)** This assessment uses laboratory tests to decide if the person satisfies the criteria for starting treatment as laid down in national treatment guidelines. If the person has not already had an HIV test, one will be done during this assessment, since treatment cannot start without confirming a person's HIV status
- **Date of issue of the prescription (DO)** This is the standard assessment that is used to check the patient's health and provides a reference point as treatment goes ahead
- **14 days after the start of treatment (D14)** This assessment shows how the person is tolerating the treatment. It checks how the body is reacting to the treatment and that the drugs are not toxic, in particular for the liver and kidneys
- **One month after the start of treatment (M1)** This assessment is a further check on how the person is tolerating the treatment. It checks how the body is reacting to the treatment and that the drugs are not toxic, in particular for the liver and kidneys. If tests are available (affordable), viral load is also checked to measure the effectiveness of the treatment
- **Every six months** The patient continues to be monitored to check their tolerance to the treatment and to assess the effect of the treatment on their immune system (CD4 and viral load if necessary and possible).

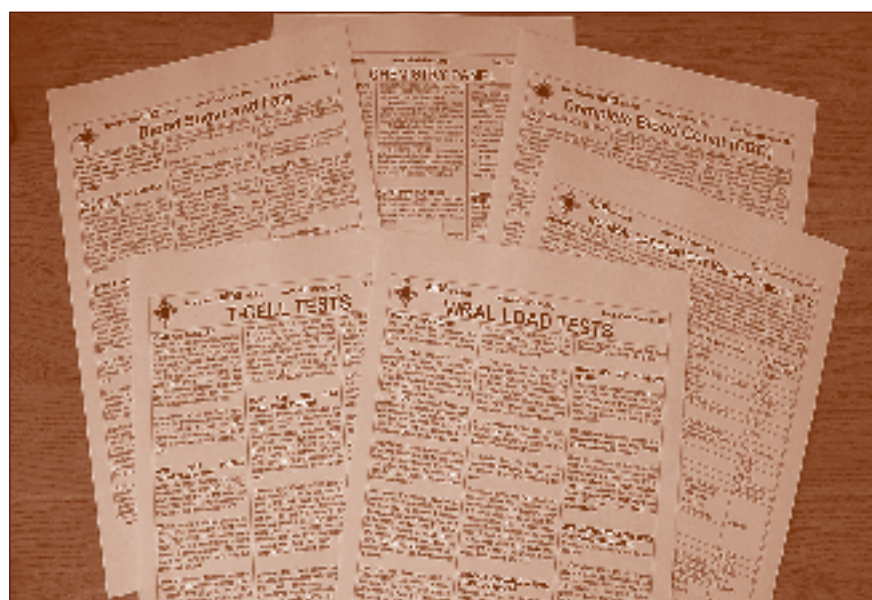


Figure 5 Fact sheets on laboratory tests, from www.aidsinfonet.org

ARV treatment follow-up

The role of the person on ARV treatment in follow-up



Aim of the session

At the end of the session participants will be able to give some examples of:

- the type of information that a person on ARV treatment needs and the questions that they can ask, especially from the doctor
- the type of information that the doctor, a community counsellor or a 'treatment supporter' (family or friend) might need from the person about the ARV treatment
- places and people who can provide resources and important (accurate) information about ARV treatment.

The aim of the session is to show that the person receiving treatment is not just a passive 'patient'. On the contrary, they should play an active role, especially in preparing for sessions with the doctor or counsellor, in getting help from treatment supporters and in becoming better informed about HIV and ARV treatment.



Methodology

- Plenary Q&A session led by the facilitator



Time

- 1 hour 10 minutes



Materials needed

- Flip charts prepared in advance



Notes for the facilitator

- Depending on the time available, the activity of looking at what information needs to be obtained and provided, and at sources of information can be done in small groups
- If the activity is done in a large group, it is best to have two trainers involved: one to lead the discussion and another to record the details on the flip charts.



Preparation

- Prepare the flip charts (see pages 70-71)



Activity

1. Ask the group: 'What are all the types of information that a person with HIV should have about treatment, both before they need treatment and when they start/are continuing with it?' Note the important points on a pre-prepared flip chart with two columns (see page 70).
2. Then ask: 'Where might a person look for and find information about their ARV treatment?' Use markers of different colours to record the different sources of information on a flip chart. If you use abbreviations, remember to make a note of what they mean on another flip chart.
3. Finally, ask: 'Who should the person on treatment share the information with? A parent or friend, a community counsellor, a doctor?' Note the responses on another flip chart divided into three columns (see page 71).
4. Conclude by showing that the amount of essential information to share with a doctor will differ from that needed by a community counsellor and, even more so, that needed by family or friends. Emphasise how useful it can be for the person on ARV treatment to have someone from the family or a good friend who they can confide in and talk with freely.



Essential information

- A person on ARV treatment must be prepared to give clear information to their doctor during a follow-up appointment. This includes:
 - the last doctor seen, if different
 - current ARV drugs and doses
 - any other medication, including traditional medicines
 - last CD4 count, and viral load count if available
 - health problems arising since the last appointment – What are the symptoms? When did they begin? How long did they last? What in particular could have caused them?
 - psychological state, related particularly to relationships with family and friends, depression or attitudes to treatment
 - treatment adherence – Have any doses been forgotten? How many? Were any doses delayed? Why?
- It is best for the person on ARV treatment to prepare their answers to these questions before the appointment, because doctors usually have only a short time to spend with each patient
- It is best if the person on ARV treatment can also give some information to people within their circle of family or friends so that they can provide support for treatment. This information includes:
 - name and address of doctor and/or centre that provides the ARV treatment
 - form of treatment (names of drugs, presentation, role etc.)
 - patient registration or medical file number
 - possible side effects that can happen with the treatment
 - things to avoid when taking treatment
 - existing illnesses or health problems
 - name and address of organisations that could provide support
 - daily living requirements, including recommended nutrition.
- People on ARV treatment must choose who they will give this information to according to the role these people play in their treatment support and monitoring

- In terms of medical follow-up, people on ARV treatment have the right to clear, easy-to-understand and accurate information on their treatment and the impact of this treatment on their health. This relates to:
 - the effectiveness of treatment (particularly how CD4 levels change)
 - the side effects of treatment and how to deal with them
 - issues of sexuality and prevention during treatment
 - the possibility of having a child while on treatment.
- It is best for the person on ARV treatment to prepare any questions relating to treatment before an appointment, because doctors usually have only a short time to spend with each patient
- People who are well informed usually adhere better to their ARV treatment
- It is important to be aware that there are many sources of information but that information may differ according to where it comes from.

ARV treatment follow-up

The role of the person on ARV treatment in follow-up

Example from training workshop in Côte d'Ivoire

Participants were asked:

- What information should a person on ARV treatment have about their condition and treatment?
- What information should a person with HIV not on ARV treatment have about their condition and treatment?
- Where can a person with HIV get information about their condition and treatment?

A person with HIV who is <i>not yet</i> on ARV treatment needs information about	A person with HIV who is on ARV treatment needs information about
<ul style="list-style-type: none"> • Risk of re-infection (SW, CC, doctor, info) • Medical background • Weight (patient) • Names of authorised information centres, clinics, pharmacy and laboratories (CC, media, VCT, freephone, Min) • Availability of treatment (doctor, local clinic, CC, VCT) • Information on ARVs 	<ul style="list-style-type: none"> • Names of medication (doctor, AC, CC, media) • Presentation of medication (doctor, AC, CC, media) • Risks of re-infection • Side effects of ARVs (doctor, CC, AC, media) • CD4 and significance of CD4 levels (doctor, media, CC) • Weight (patient, doctor, family) • Current illnesses (doctor, patient) • Other medicines which affect ARVs (doctor, patient, medication instructions)
<p>Sources of information</p> <p>Number of medical file (doctor, SW, CC)</p> <p>NGOs/CBOs (CC, SW, doctor, media, VCT, freephone)</p> <p>Information on nutrition (CC, doctor, dietitian trained in HIV, info)</p> <p>Information on opportunistic illnesses (doctor, CC, SW)</p> <p>Daily hygiene rules (CC, doctor)</p> <p>Long-term toxicity of ARVs (doctor, info)</p> <p>Last doctor seen (patient)</p> <p>Information on positive living (CC, freephone)</p>	
<p>Key: sources of information</p> <p>SW: Social workers</p> <p>AC: Authorised information centres</p> <p>CC: Community/ NGO/CBO counsellors</p> <p>VCT: Voluntary counselling and testing centres</p> <p>Info: Information documents</p> <p>Min: Ministries</p>	

The role of the person on ARV treatment in follow-up

What information should a person on ARV treatment provide to a confidante (relative, friend etc.), a community counsellor or a doctor?

Close friend or family member	Counsellor	Doctor
Risk of re-infection		
		Medical background
		Weight
Treatment centre address		
Availability of ARVs		Availability of ARVs
Information on ARVs	Information on their ARV treatment	
Names of drugs	Names of drugs	
What the medicines look like	What the medicines look like	
Side effects	Side effects	Side effects
CD4 count	CD4 count	
Current illnesses		Current illnesses
Contraindications		Contraindications
Number of medical file	Number of medical file	
NGOs/CBOs		
Nutrition		
Possible illnesses		
Daily hygiene		
Toxicity		
		Last doctor seen

Changing ARV treatment

Why change ARV treatment?



Aim of the session

At the end of the session participants will be able to:

- explain the reasons why it is sometimes necessary to change treatment.



Methodology

- Q&A session led by the trainers
- Summary presentation of essential points to remember.



Time

- 30 minutes



Materials needed

- Poster 'Essential things to remember about changing ARV treatments' (see page 73)



Preparation

- Prepare a poster 'Essential things to remember about changing ARV treatments' (see page 73)



Activity

1. With the whole group, ask the participants to make a list of reasons why a person might need to change their ARV treatment based on what they have learned so far. Note the answers on a flip chart and comment on them, stating if each is a realistic reason or not, and offering accurate explanations for each reason.
2. Ask the participants how long someone can stay on the same treatment.
3. Present the poster 'Essential things to remember about changing ARV treatments' (see page 73) and give any additional information.



Essential information

The main reasons for changing treatment

- Treatment is not working (**treatment failure**) for either or both of two reasons:
 - laboratory criteria – fall in CD4 count, increase in viral load
 - clinical criteria – loss of weight, illnesses appear or re-appear.
- The treatment works, but a substitute treatment must be found for a particular reason:
 - the patient is pregnant – some ARVs cannot be used during pregnancy
 - there are significant side effects (the patient cannot tolerate a drug)
 - interaction with other medication must be avoided (for example, if the patient has TB)
 - taking the drugs is too difficult (number of tablets, difficulty swallowing)
 - the treatment is too expensive and/or the patient cannot pay all the costs involved
 - there is an interruption in the supply of drugs.

It must be clearly understood that if the prescribed ARVs do not have the desired effect on the immune system and do not improve or maintain the person's health, a change in medication is necessary to ensure effective treatment.

If treatment works but the change has to be made for specific reasons, the ARV drugs have not failed and it may be possible to start taking the treatment again at a later date; for example, after pregnancy or if a regular supply of the drugs is resumed.

For how long can the same treatment be taken?

- There is no need to change treatment unless there is treatment failure, or some other reason such as avoiding interactions with TB treatment, pregnancy, drug supply problems
- First-line treatment can continue for some years if adherence is good and side effects are not a problem. It may be effective for ten years or more, but it often has to be changed after three to four years; for example, because of side effects. Then, you can change the treatment to other drugs that will still be effective against the virus
- First-line treatment can usually continue for longer than second-line or further treatments, but a person can survive for many years with ARV treatment, especially if they have good nutrition and look after their physical and psychosocial well-being. Also, research continues to develop new drugs for treating HIV.



Additional information

Treatment holidays

The idea of taking a **holiday** from treatment, also called structured treatment interruption, is based on the experience that effective treatment results in the patient's immunity recovering to higher levels than when treatment started. Some people thought it might therefore be possible to interrupt treatment when the immune system is sufficiently strong; for example, when the CD4 count rises to over 350. However, research so far has shown no benefits from doing this. People who take treatment holidays seem to have less success with treatment than people who take treatment continuously without a break. Further research still needs to be done to confirm this. Nobody should stop treatment without discussing it with a specialist HIV doctor.

When ending treatment, efavirenz or nevirapine should be stopped at least one week **before** stopping the other drugs. This is because these two drugs remain in the body for longer, so if they are stopped at the same time as the others, small amounts of efavirenz or nevirapine will remain in the body after the other drugs have been stopped. This increases the chances of the virus becoming resistant to efavirenz or nevirapine.

Resistance

- Resistance occurs when the virus adapts itself and becomes able to survive the effect of the ARV drugs.
- What causes resistance?
 - Non-adherence to treatment
 - Some NNRTI ARVs are not effective on the HIV-2 virus strain.

Essential things to remember about changing ARV treatments

Why does treatment have to be changed?

Treatment is not working (treatment failure) for either or both of two reasons:

- Laboratory criteria – fall in CD4 count, increase in viral load
- Clinical criteria – loss of weight, illnesses appear or re-appear

The treatment works, but a substitute treatment must be used for a particular reason:

- The patient is pregnant – some ARVs cannot be used during pregnancy
- There are significant side effects (the patient cannot tolerate a drug)
- Interaction with other medication must be avoided (for example, if the patient has TB)
- Taking the drugs is too difficult (number of tablets, difficulty swallowing)
- The treatment is too expensive and/or the patient cannot pay all the costs involved
- There is an interruption in the supply of drugs

Changing ARV treatment

Effects on adherence



Aim of the session

At the end of the session, participants will be able to:

- explain how treatment can be changed in practical terms
- give several examples of the negative and positive effects of changing treatment on a person with HIV
- explain why this is important for adherence support.



Methodology

- Presentation
- Q&A session led by the trainers



Time

- 15 minutes



Materials needed

Poster 'Essential points to remember – changing treatment' (see page 75)



Preparation

Prepare the poster 'Essential points to remember – changing treatment' (see page 75)



Activity

1. Explain in practical terms how treatment is changed.
2. Discussion in the form of a Q&A session on the consequences of changing treatment for a person with HIV. ('In your opinion, what are the positive and negative effects of changing treatment for a person on ARVs?')
3. Presentation of the poster 'Essential points to remember – changing treatment' (see page 75).



Essential information

Remember that a change in treatment may be decided by the doctor because:

- the treatment is too difficult to adhere to
- the treatment is not effective
 - the patient's immune system is not improving
 - the virus is not reducing sufficiently in the blood
 - resistance tests (not available in some countries) are showing resistance
- the patient cannot tolerate the treatment
 - side effects
 - drug toxicity
- the patient's state of health has changed
 - they must take other medication (for example, against TB) that would run the risk of interacting with their current treatment
 - the patient is pregnant.

It is important that the doctor clearly explains the reasons for changing. Treatment must be changed in line with the doctor's advice, who will specify when to change from one treatment to the other. This is done without interruption between the two treatments.

There must be close monitoring following a change in treatment, just as for a new treatment.

A change in treatment always has significant consequences for the person. These consequences may be positive or negative. The information given to the patient when treatment is about to be changed is therefore particularly important.

Positive consequences

- The person has a new sense of hope
- When the previous treatment involved a large number of side effects, there is an improvement in the quality of the person's life/state of health
- Renewed confidence in the drugs
- Possibility of having children with a reduced risk of transmission.

Negative consequences

- The person has a sense of failure; the feeling that their efforts have been in vain
- They fear that the new treatment will not work either
- They have to get used to a new routine, which might lead to possible non-adherence.

It is important to consider these factors during counselling sessions in order to help support adherence. When a treatment is changed, try to boost the client's confidence and help them define new strategies to face up to the limitations of the new treatment.

Essential points to remember – changing treatment

Why does treatment have to be changed?

Negative consequences:

- The person has a sense of failure; the feeling that their efforts have been in vain
- They fear that the new treatment will not work either
- They have to get used to a new routine, meaning possible non adherence

Positive consequences:

- The person has a new sense of hope
- Possibility of having children with a reduced risk of transmission
- Renewed confidence in the drugs
- When the previous treatment involved a large number of side effects, there is an improvement in the quality of the person's life/state of health

ARV treatment – differences between men and women



Aim of the session

At the end of the session, participants will be able to:

- explain some differences and similarities of ARV treatment for men and women
 - at the social level
 - at the economic level
 - at the medical level
- describe other differences between men and women in terms of barriers to and support for adherence to ARV treatment.



Methodology

- Work in small groups
- Plenary presentations



Time

- 1 hour 30 minutes



Materials needed

- Poster with instructions for working in small groups
- Poster 'Essential points to remember – side effects that are specific to women' (see page 77)
- Flip charts
- Markers



Preparation

Prepare the posters:

- 'Instructions for working in groups – differences between men and women with regard to ARV treatment' (see below)
- With three columns – health level, social level, financial level (see page 75)
- 'Essential points to remember – side effects that are specific to women' (see page 77)



Activity

1. Divide the participants into male and female groups.
2. Ask the male group(s) to discuss:
 - For men, what are the specific risks and benefits of taking ARV treatment
 - in terms of health?
 - at a social level?
 - at a financial level?
 - What barriers to adherence are specific to men? The participants can draw on previous discussions during the training.
3. Ask the female group(s) to discuss:
 - For women, what are the specific risks and benefits of taking ARV treatment
 - in terms of health?
 - at a social level?
 - at a financial level?
 - What barriers to adherence are specific to women? The participants can draw on previous discussions during the training course.
4. Give each group flip charts previously divided into three columns: health level, social level, financial level.
5. Ask each group to make a presentation to the plenary group and encourage discussion on the differences and similarities.
6. Present the poster on the side effects of ARV treatment for women.



Essential information

- The benefits and risks of taking ARV treatment can vary. Some risks and benefits are more specific to men or women. In terms of risk, some drug side effects affect women more than men (see poster 'Essential points to remember – side effects that are specific to women' on page 77).
- However, many benefits and risks are equally common for both men and women.
- Obstacles to adherence can also vary according to gender. A woman who is also a mother may have significant difficulties in taking ARV treatment:
 - she may have numerous domestic responsibilities
 - pregnancy may interfere with treatment if the woman is not helped to plan correctly and is not monitored
 - she may be financially dependent on her husband and/or family and be unable to continue treatment if it is not provided for free.
- Factors encouraging adherence for women can include
 - a feeling of responsibility towards her children; wanting to become healthy in order to support and look after them
 - if the woman wants to have children, taking ARVs is a way of ensuring good health so that she can consider one or more pregnancies.

Instructions for working in groups – differences between men and women with regard to ARV treatment

- Risks and benefits of taking ARV treatment at a:
 - social level
 - financial level
 - medical level
- Obstacles and factors that promote adherence for:
 - women
 - men

Essential points to remember – changing treatment

- At each stage of HIV infection, women have higher viral loads and higher CD4 counts compared to men.
- However, there is no difference in the way men and women progress through the stages of HIV.

Side effects: women are more likely than men to:

- have hepatitis (liver inflammation) when using nevirapine
- stop didanosine (DDI) because of side effects
- get body fat changes (lipodystrophy)
- have osteoporosis (bone disease)
- develop lactic acidosis
- develop allergies with nevirapine
- develop anaemia (in women who menstruate).

Women can also experience side effects that cause:

- changes to the menstrual cycle, especially if they have opportunistic infections and/or are taking protease inhibitors
- reduction in effectiveness of oral contraceptive pills; this is one reason why condoms are recommended for contraception, and not oral contraceptives.

Why?

- Differences in weight and fat distribution in the body
- Differences in the way that the liver metabolises the drugs
- Differences in the reproductive system

Example from training workshop in Côte d'Ivoire

Negative effects of ARV treatment for women

Social level	Financial level	Health level
<ul style="list-style-type: none"> • Embarrassment and fear if the husband does not know • Pressure from family • Overwork and stress caused by an accumulation of side effects and domestic work 	<ul style="list-style-type: none"> • Financial dependence (no financial resources to buy ARVs) • Family responsibilities 	<ul style="list-style-type: none"> • Disruption to the menstrual cycle • Illness in cases of poor adherence, but this is not directly linked to taking the treatment • Side effects

Positive effects of ARV treatment for women

Social level	Financial level	Health level
<ul style="list-style-type: none"> • Happiness and a sense of freedom • Family support • Refound dignity • Living positively • Marriage plans 	<ul style="list-style-type: none"> • Financial prosperity • Financial support of the family 	<ul style="list-style-type: none"> • Less ill • Fewer visits to the health centre • Possibility of having children • Beautiful, seductive

continued over...

ARV treatment – differences between men and women

Example from training workshop in Côte d'Ivoire

Negative effects of ARV treatment for women (continued)

Negative effects of ARV treatment for men

Social level	Financial level	Health level
<ul style="list-style-type: none"> Working life disrupted Stigmatisation Survivor syndrome Problems at home (divorce) Loss of job Difficulties in taking treatment at work Fall in productivity 	<ul style="list-style-type: none"> Fall in income Financial dependence Increased expenditure 	<ul style="list-style-type: none"> Reduced libido Toxicity

Positive effects of ARV treatment for men

Social level	Financial level	Health level
<ul style="list-style-type: none"> Social reintegration Improved social life 	<ul style="list-style-type: none"> Stability and improvement in income Guarantee of work 	<ul style="list-style-type: none"> Improved health Increased life expectancy

Factors that obstruct or encourage women's adherence to ARV treatment

Specific obstacles	Factors encouraging adherence
<ul style="list-style-type: none"> Feeding (of babies) Pregnancy Domestic responsibilities Family pressure Financial dependence Side effects 	<ul style="list-style-type: none"> Concern for their children Organisational life Desire to have children, to live Support from the family (if they know) Financial independence Support of husband Desire to be beautiful

Factors that obstruct or encourage men's adherence to ARV treatment

Specific obstacles	Factors encouraging adherence
<ul style="list-style-type: none"> How they spend their working time How they spend their free time Lack of family involvement 	<ul style="list-style-type: none"> Good health Resumption of activities Acceptance from the family and community

Notes

Living with ARV treatment – new horizons

Living with ARV treatment – sexuality and wanting to have children



Aim of the session

At the end of the session participants will be able to identify:

- key issues linked to the success of ARV treatment around sexuality and wanting to have children
- key messages for the community on sexuality and wanting to have children.

The aim of the session is also to enable the participants to talk about subjects such as sexuality and wanting to have children, which are often overlooked when talking about HIV and treatment. The objective is especially aimed at better communication on issues of sexuality.



Methodology

- Q&A
- Work in small groups
- Presentations in plenary



Time

- 1 hour 40 minutes



Materials needed

Three flip charts on which to list the output of question and answer sessions



Notes for the facilitator

Small groups should include no more than six participants.

It is very important to have groups separated by gender wherever possible in order to facilitate discussions on sexuality. Some participants will feel uncomfortable discussing such issues in the presence of the opposite sex.



Activity

1. Q&A to identify the issues in successful treatment: 'When treatment is successful, what are the new issues for a person on treatment?' Note the participants' answers by grouping them into three themes: sexuality, desire for children and plans for healthy living.
2. When you have noted and grouped the answers, explain that you are now going to consider issues of sexuality and wanting to have children.
3. Break the group up into a number of smaller groups depending on the number of participants:
 - one or more single-sex groups to discuss the issue of sexuality
 - one or more mixed groups to discuss the issue of wanting to have children.
4. Ask each group to identify the questions a person with HIV on ARV treatment might ask in relation to the group's theme (sexuality or the desire for children) and how one might talk about these in the community.
5. In the plenary, each group should report back on their discussion. Emphasise the possible differences between the male group(s) and the female group(s) in order to strengthen the messages of the previous module on gender differences in ARV treatment.
6. Conclude with the essential messages.



Essential information

- Issues of sexuality and wanting to have children are raised by successful treatment. In fact, treatment may have positive effects on sexuality, such as a return of desire. People who were concentrating on their illness or fears about infecting others find themselves with renewed energy and hope, and start to think about sex and having a family as part of their future
- Someone who is HIV positive has the right to a sexual life, since it is part of the right to a healthy life. They also have rights about choosing whether, and when, to have a child
- However, it is important to stress that prevention is still needed, even when ARV treatment is working well, and condoms must be used consistently
- It is possible to have sex without a condom if you want to have a child, but this should first be discussed with a doctor because you must ensure that the woman's treatment is adapted to pregnancy. You must also be sure that the pregnancy represents no significant risk to the health of the mother or child (See Module 3: ARV treatment and prevention)
- It is important to diagnose and treat any sexually transmitted infections, since these increase the risks of HIV transmission and can reduce a person's fertility.

Examples from a training workshop in Côte d'Ivoire

Questions from participants around sexuality for people on ARV treatment

Men's group	Women's group
<ul style="list-style-type: none">• Does having many sexual partners wear you out?• How do you tell your partner(s) your status?• How do you negotiate wearing a condom?• How do you avoid reinfection?• How do you 'control' your sexuality?• How can you find a partner?	<ul style="list-style-type: none">• Can I have sex?• Can I have regular sex?• Why have sex?• Will I remain beautiful and sensual?• Must I have protected sex – even with another person with HIV?• Can I have sex only with another HIV-positive person?• Could I have sex with an unprotected person who is HIV positive?• Can I have sex if I have a sexually transmitted infection?

Questions and answers on wanting to have children

Questions	Answers
<ul style="list-style-type: none">• Can I become pregnant?• What is the impact of ARV treatment on pregnancy?• What will the mother's health be like after childbirth?• Will the child be infected?• What medical care will the child get?• How should I feed the child?• Will the child survive?	<ul style="list-style-type: none">• Yes, an HIV-positive woman on treatment can have a child, depending on her CD4 count• The child may not be infected• The child will have the same medical care as other children, plus Bactrim.

Living with ARV treatment – new horizons

Living with ARV treatment – making a plan for healthy living



Aim of the session

At the end of the session participants will be able to explain:

- the main stages in making a life plan for a person on ARV treatment
- the role of CBOs/NGOs in helping people on ARV treatment to make healthy living plans.



Methodology

- Presentation
- Q&A



Time

- 1 hour 15 minutes



Materials needed

- Poster 'Elements of a healthy lifestyle' (see page 84)
- Poster 'Stages in the formulation of a healthy living plan' (see page 84)
- Photocopies of grid for a healthy living plan (see page 85).



Notes for the facilitator

- When the participants work on the healthy living plan grid, tell them that what they discuss in pairs will not be disclosed in the whole group, so as to protect confidentiality and make them more at ease.
- Many people are not used to thinking in a structured way about the future – some people may need assistance to define realistic goals and activities and to define the individual steps they need to take to achieve them.

You should emphasise that this tool is not about creating a new service. Instead, it makes a support method already used by CBOs/NGOs more formal and helps to ensure the individual's commitment to their life with ARV treatment.



Preparation

- Prepare the posters 'Elements of a healthy lifestyle' (see page 84) and 'Stages in the formulation of a healthy living plan' (see page 84).
- Make photocopies of the healthy living plan grid (see page 85).



Activity

1. Introduce the session.
2. Ask the participants: 'How can CBOs/NGOs help people on ARVs to change their lives when treatment offers them new prospects?' Note the participants' suggestions on a flip chart; for example, 'We must help them find work', 'We must implement income-generating activities' etc.
3. Then present the approach to formulating a healthy living plan, explaining that this process has been developed by a number of CBOs/NGOs. Several aspects of life must be taken into account to develop this plan. Show the poster 'Elements of a healthy lifestyle' (see page 84) and comment on it. For each element, a healthy living plan depends on analysing and identifying:
 - what you would like to improve
 - what is realistically achievable.
 Depending on the answers, a person can set realistic and achievable objectives by following a number of stages in a process. Show and comment on the poster 'Stages in the formulation of a healthy living plan' (see page 84).
4. Distribute a healthy living plan grid to each participant. Each person must consider what they would like to change/improve in their life, relating to the lifestyle factors shown on the grid. They must choose a maximum of two or three and express the changes/improvements in terms of achievable short-term objectives.
5. Break the participants up into pairs. Each member of the pair must in turn ask themselves:
 - What activities can I implement in the coming six months to achieve my objectives?
 - Who can I ask for support in achieving these results?
6. Discuss the possible role of CBOs/NGOs in helping people to develop their healthy living plans.



Essential information

By focusing on the practical details of ARV treatment and adherence, we risk overlooking the fact that these drugs, when they are correctly taken, enable people to live a long and healthy life with HIV.

When people are first diagnosed with HIV, some give up their activities, become withdrawn, lose all hope and live only from one day to the next. When they start ARV treatment, they must start to think about changing/rebuilding their life.

Treatment enables people to think about new horizons, but there are also new challenges. Recognising these challenges, both in terms of the stress they represent and the future they promise, enables the ultimate objective of treatment to be achieved – healthy living.

The support provided to people with HIV by CBOs/NGOs must take into account the way that successful treatment changes people's lives.

The process of formulating a healthy living plan for people with HIV on treatment⁵

A person with HIV must:

1. Analyse their lifestyle – decide what they want to change/improve and what is realistic, taking into account:
 - diet/nutrition
 - physical condition
 - physical appearance (clothes, make-up, hair etc.)
 - housing
 - transport
 - family life
 - interpersonal relations – friends, partners, colleagues
 - communication with others
 - life within their organisation
 - education and/or work
 - leisure.
2. Based on this analysis, define achievable objectives in terms of changes and improvements to their lifestyle (for each factor).
3. According to their achievable objectives, plan activities that will enable them to achieve their identified objectives, focusing on short-term and longer-term goals (for example, what will I do this week, this month, within six months, within a year?).
4. Seek support for their healthy living plan from close family and friends, community organisations and health professionals.
5. Evaluate progress against the plan after six months.

The role of the CBOs/NGOs in formulating a healthy living plan for people with HIV on treatment

- Making a healthy living plan can be part of the counselling and self-help activities that CBOs/NGOs are already doing
- The objective of a healthy living plan is for the person on treatment to be 'pro-active', which means taking the initiative in their life without always waiting to be told what they should do or having someone else do things for them
- CBOs/NGOs should not become caught in a dynamic of 'assistance', which could lead people on treatment to believe, for example, that the role of the organisation is to provide for all their needs or find them a job.

5. This model has been adapted from the Maison d'Observance Project, Association African Solidarité, Ouagadougou.

Living with ARV treatment – new horizons

Living with ARV treatment – making a plan for healthy living

Elements of a healthy lifestyle

- Diet/nutrition
 - Physical condition
 - Physical appearance (clothes, make-up, hair etc.)
 - Housing
 - Transport
 - Family life
 - Interpersonal relationships – friends, partners, colleagues
 - Communication with others
 - Life in organisations
 - Education and work
 - Leisure
-

Stages in the formulation of a healthy living plan

1. Analyse your lifestyle – what do you want to change/improve and what is realistic?
2. Define achievable objectives.
3. Plan activities enabling the identified objectives to be achieved.
4. Seek support from close family and friends, community organisations and health professionals.
5. Evaluate progress against the plan after six months.
6. If good progress has been made, the person can develop a longer-term healthy living plan.

Living with ARV treatment – making a plan for healthy living

Living with ARV treatment: grid for developing a healthy living plan

Aspect of daily living	What do I want to change or improve?	Realistic objectives to make this happen	What do I need to do in the next six months to achieve my objectives?	Who can support me in achieving these objectives?
Food/nutrition				
Physical health				
Physical appearance				
Housing				
Transport				
Family life				
Relationships with others – friendship, love, work colleagues				
Communication				
Social life				
Education/work				
Leisure/recreation				

ARVs and the prevention of mother-to-child transmission (PMTCT)



Aim of the session

At the end of the session participants will be able to explain:

- three ways in which mother-to-child transmission of HIV can happen (through the placenta, during labour, breastfeeding)
- what ARV medicines are used for PMTCT and how
- why ARVs are only given at the end of pregnancy
- options for breastfeeding or bottle-feeding.



Methodology

- Q&A session led by the trainers
- Summary presentation



Time

- 1 hour 50 minutes



Materials needed

- Poster outlining the country's PMTCT protocols
- Poster 'Essential points to remember on PMTCT' (see page 89)



Notes for the facilitator

- Ensure that people understand how PMTCT and ARV treatment for the mother make a difference for the child. When people realise how the risk of HIV transmission can be dramatically reduced, they will be much more enthusiastic about using the necessary treatment at the right times
- Remember that with PMTCT, as with all ARV treatment, science is always developing and treatment recommendations are regularly revised. It is important to keep up to date with new recommendations and regulations in the country where the training is taking place
- You must ensure that participants clearly understand the difference between ARVs used in treatment and ARVs used as prevention in the context of PMTCT
- The aim of the small poster activity is to show that it is not easy to take decisions related to pregnancy and feeding when you are HIV positive (or the partner of an HIV-positive woman)
- If there are HIV-positive women who are open about their status in the group, the trainer could invite them to share their experiences, if they are happy to do so.



Activity

1. Begin by asking participants how and when an HIV-positive mother can infect her child (during pregnancy, during labour, when breastfeeding) and note the participants' responses on a flip chart.
2. Then discuss each of the three situations by asking questions about the reasons for infection, the use of ARVs and their limitations. Ask the participants to explain, or explain yourself, by adding to and correcting the information given. Use the posters on PMTCT protocols (see page 87) and 'Essential points to remember on PMTCT' (see page 89) to recap the main messages of the session.
3. Ask the participants if they know what are the chances of a baby being born with HIV infection if the mother is positive. Mark out a line on the floor or on a flip chart, with 0 per cent at one end and 100 per cent at the other. Ask participants to go and stand at a place along the line on the floor (or mark the line on the flip chart) where they think the risk is. Correct any wrong answers, then ask what happens to the risk if PMTCT is provided, and finally what happens to the risk if PMTCT and ART for the mother are provided. Make sure that all have understood before moving on.
4. In three separate places in the training room, place three small posters on which you have written 'Yes', 'No' and 'Not sure'. Ask the participants to get up. Explain to them that they will be asked a number of questions. If their answer to the question is 'yes' they must move to stand by the 'Yes' poster, if their answer is 'no', they must move to the 'No' poster and if they are not sure they must move to the 'Not sure' poster. Ask the participants to answer sincerely and honestly.
 - For the women, imagine that you are HIV positive and on ARV treatment. Would you choose to have a child?
 - For the men, imagine that you are married to a woman who is HIV positive and on ARV treatment. Would you choose to have a child with her?
5. When the groups have formed around each poster, encourage the participants in each group to explain why they chose that response.
6. Repeat the activity with the following questions:
 - For the women, imagine that you are HIV positive and on ARV treatment. You have just given birth to a child. Would you choose to breastfeed your child?
 - For the men, imagine that you are married to a woman who is HIV positive and on ARV treatment. Your wife has just given birth to a child. Do you think that she should breastfeed the child?



Essential information

Definitions: preventing mother-to-child transmission

Mother-to-child transmission is the main way in which children under 15 years of age are infected with HIV. Infection happens near the end of pregnancy, during childbirth (70 per cent) and through breastmilk.

Originally, PMTCT referred only to the use of ARVs to prevent the child from becoming HIV infected, and not to treat the mother's HIV infection. Based on greater experience, PMTCT is now an essential part of comprehensive prevention, testing and ARV treatment programmes. It includes a set of important activities which give the best results for the baby and the mother when used together. These include:

- preventing women from becoming HIV infected – including prevention by both men and women
- ensuring access to ARV treatment as well as prevention – this makes people more confident to have an HIV test and to learn how to protect themselves and their baby
- enabling pregnant women who need ARV treatment to start it as soon as possible



Preparation

- Prepare the poster 'Essential points to remember on PMTCT' (see page 89)
- Prepare the sheets to stick on the wall with 'Yes', 'No', and 'Not sure'.

- using standard treatment protocols to enable as many women as possible to use ARV treatment and PMTCT with the necessary support
- good maternity care to reduce the child's risk of exposure to HIV during labour
- safe infant feeding, using infant milk substitutes or exclusive breastfeeding.

Treatment protocols for preventing mother-to-child transmission

National PMTCT guidelines have been developed for many countries, usually based on the WHO Guidelines for PMTCT, which are regularly updated as knowledge and experience improves. The approach varies according to whether a pregnant HIV-positive woman is already on ARV treatment, is not on ARV treatment and does not yet need it, or is not on ARV treatment but needs to start it as soon as possible during pregnancy.

- In some low-resource settings, only one drug is used (usually nevirapine) around the time of birth. This is effective only for protecting the baby from HIV infection. It does not help the mother and can cause drug resistance problems when she needs to start triple ARV treatment to protect her own health
- Therefore, in many countries, two drugs are used now around the time of birth, usually zidovudine and nevirapine
- If the mother is already on ARV treatment, the baby is also given treatment for some days after birth
- If the mother is not on ARV treatment and does not yet need it, she should start a short course of treatment some weeks before the birth and the baby will also be given a short course of treatment around the time of birth
- If a mother is only found to be HIV positive when she is about to deliver the baby, the short course of treatment is started then, using three drugs such as zidovudine, nevirapine and lamivudine
- In all cases, the mother needs to be counselled about infant feeding choices and helped to make appropriate decisions on formula or breastfeeding, depending on her financial and social circumstances.

What is the risk to the baby, and how does PMTCT change it?

PMTCT does not guarantee 100 per cent prevention of HIV transmission, but it does minimise the risk. *Without* any PMTCT, and if the baby is breastfed, the risks of mother-to-child HIV transmission are about one in three (on average, one out of every three babies would be HIV positive, the other two would not). If the mother does not breastfeed, the risk is reduced to about one in four. Using ARV treatment only to protect the baby will halve the risks. If both the mother and the baby receive the appropriate ARV treatment, the risk will be less than 1 in 50. Comprehensive PMTCT, including ARV treatment for mothers, can therefore make a dramatic difference to the numbers of children born with HIV.

Care of the mother and child during labour

The risk of transmission is high during labour because the HIV virus is present in many of the body's fluids, including: blood lost by the mother, the fluid in the womb and secretions in the vagina. Caesarean section is used when there are sufficient resources in an attempt to prevent contact between the baby and these fluids. However, this is not recommended in low-resource settings, where there might be inadequate facilities and therefore additional risks of infection to the mother.

Preventing HIV transmission during infant feeding

HIV is present in the mother's milk and so there is a risk of transmission. Feeding with infant formula (milk substitute) is therefore the safest option to protect the baby. If feeding using a milk substitute is not possible or safe, and/or if the woman prefers to breastfeed, the risks are less if the baby is exclusively breastfed and is not given 'mixed' feeding with formula, water or other fluids. The baby should be weaned early, after four to six months.

ARVs and the prevention of mother-to-child transmission (PMTCT)

Bottle-feeding is recommended, but it should not be imposed upon mothers who experience cultural and social pressures to breastfeed. The feeding method should therefore be discussed with the mother and support given to help her reduce the risks to the baby. There are some important risks linked to bottle-feeding, especially if the water used is not sterilised correctly, leading to increased risk of diarrhoea, illness and early death of the baby from infections.

Mixed feeding is strongly discouraged as research has shown that this feeding method weakens the newborn baby and increases the risk of HIV transmission. After four months of exclusive breastfeeding, good local foods should be used that carry fewer risks for the child. Bottle-feeding can continue at the same time as the introduction of locally used weaning foods.



Additional information

Why is treatment not started in the early stages of pregnancy of an HIV-positive woman?

At the start of pregnancy, even though the mother is providing her unborn child with nutrients through the placenta, it has been proved that the risk of HIV transmission is very low. The risk is much greater at the end of pregnancy. This is why treatment for PMTCT is given in the last few weeks. Giving treatment for the whole nine months of pregnancy is unnecessary and could be toxic for the child.

The role of CBOs/NGOs in PMTCT

- If the baby is to be born at home, there may be problems with regard to close family and friends. So the role of CBOs is to ensure the well-being of the child to make sure that the mother and child can take the necessary treatment during pregnancy and after delivery, or when recommended by the doctor
- CBO/NGO support workers can help the mother learn how to feed and make sure that she correctly follows the doctor's instructions about breastfeeding or using formula milk for the child, checking the quantity that has been given to the child (for example, by counting the number of drums of milk consumed)
- CBO/NGO support workers can promote bottle-feeding of children born to HIV-positive mothers. If the mother chooses to breastfeed, this should be the only method of feeding; early weaning should be promoted to minimise the risks of HIV transmission
- CBO/NGO support workers can promote voluntary HIV testing and counselling before pregnancy or as soon as possible during pregnancy to facilitate treatment and prevent HIV transmission to the child.

Serodiscordant couples If the mother is HIV negative and the father is HIV positive, the father cannot infect the child, because HIV is not hereditary. The child is only at risk if the mother is HIV positive. If the child of an HIV-negative mother is HIV positive, other possible methods of infection must be considered, including sexual abuse or use of unsterile injection or cutting equipment.

Essential points to remember on the prevention of mother-to-child transmission

Using ARV treatment for the prevention of mother-to-child transmission:

- Using ARV treatment to prevent the transmission of the HIV virus from the HIV-positive mother to her unborn child does not work in all cases
- However, using the simplest treatment for PMTCT can double the baby's chances of being born without HIV infection. The risks of transmission are reduced far more (down to less than 1 in 50) if the mother also receives the correct ARV treatment for herself when she needs it
- The child is born with its mother's antibodies. It is impossible to know if the child is HIV positive using current HIV screening tests. A different technique has to be used which detects HIV fragments (PCR) until the child produces its own antibodies (between 12 and 18 months after birth)
- Pregnancy presents risks for the HIV-positive mother. If she is already ill, the infection may progress more rapidly and transmission to the child can happen more easily
- HIV can also be transmitted from an HIV-positive mother to her child when breastfeeding. If the mother agrees, it is preferable to use formula milk instead of breastmilk. If bottle-feeding is not possible, she must breastfeed exclusively. Mixed feeding (mixing breastfeeding with bottle-feeding) is more likely to result in HIV transmission than exclusively breastfeeding
- If an HIV-positive woman is already on treatment, her drugs must be reviewed by the doctor and changed if there is a risk that they may be toxic to the child.

ARV treatment for children

ARV treatment for children



Aim of the session

At the end of the session participants will be able to:

- explain which children need to be treated with ARV drugs and why
- give some examples of ARV treatment issues specific to children
- give some examples of issues to consider when providing treatment counselling to children on ARV treatment (for example, disclosure, adherence).



Methodology

Q&A led by the trainers plus brief presentations by the trainers



Time

- 40 minutes



Materials needed

- Poster 'ARV treatment protocols for children' (see page 93)
- Poster 'Essential points to remember – ARV treatment for children' (see page 93)



Preparation

Prepare the posters:

- 'ARV treatment protocols for children' (see page 93)
- 'Essential points to remember – ARV treatment for children' (see page 93)



Activity

1. Begin with the question: 'Which children need ARV treatment and why?' to check that the participants have fully understood the importance of PMTCT and of ensuring that adults are on treatment if they need it.
2. Explain the criteria for starting treatment with the help of the corresponding poster.
3. Ask the question: 'What are the specific limitations of prescribing ARVs for children' (see below). Note the participants' suggestions on a flip chart and correct/complete them or get them to do this themselves.
4. Ask the participants 'What are the main issues you would raise with regard to ARV treatment and children?'
5. End by recapping with the help of the poster 'Essential points to remember – ARV treatment for children' (see page 93).



Essential information

How do you know if a child is HIV positive or not?

Most infected children have no symptoms at birth. You cannot use the usual HIV antibody tests to find out if a child is HIV positive because the child is born with the mother's antibodies and has not yet developed any of its own. An HIV antibody test would therefore only detect the mother's antibodies. The child starts to produce its own antibodies at around 12 to 18 months. A different testing technique therefore has to be used for young infants, which can detect HIV fragments (PCR, AgP24) soon after birth. However, this test is currently less widely available, and in some low-resource settings it is still not possible to confirm until 18 months after birth if the child is HIV positive or not.

The treatment criteria for children

For children under 18 months As it is impossible to carry out a routine HIV antibody test (see above), techniques can be used enabling HIV fragments to be detected (PCR, AgP24). These techniques are costly and require well-trained laboratory staff. When these techniques cannot be used, clinical criteria have to be used in order to make a diagnosis and decide whether to put the child on treatment. Where a CD4 count is available, children with a CD4 count of less than 25 per cent are treated (this means the percentage of CD4 cells compared with the total number of white blood cells).

For children over 18 months Symptomatic children who present with WHO clinical stage II or III symptoms should be treated irrespective of the CD4 count. Treatment is recommended to asymptomatic children if CD4 is less than 5 per cent.

Treatment should not usually start unless there is some certainty that the child will be able to continue to take the treatment right through to adulthood.

Treatment protocols for children (being updated by WHO in 2006 – when finalised, new versions will be available on the WHO website at www.who.int/hiv/pub/guidelines/en/). As with adults, children must be treated with triple ARV therapy. First-line regimes combine the following ARVs:

- 2 reverse transcriptase nucleoside inhibitors (NRTI) plus 1 reverse transcriptase non-nucleoside inhibitor (NNRTI) = **2 NRTI + 1 NNRTI**
- The NNRTI choice depends on age or weight: if the child's age is less than 3, or weight is less than 10 kg, use NVP and if age is more than 3 or weight more than 10 kg, use NVP or EFV.

Second-line regimes include a protease inhibitor:

- 2 reverse transcriptase nucleoside inhibitors (NRTI) plus a protease inhibitor
= 2 NRTI + 1 PI
- Recommended option is: ABC plus ddl, plus LPV/r or NFV, or SQV/r if weight is more than 25kg.

Limitations of ARVs with children

- Many ARVs have not yet been adapted for use by children. For example, many tablets are too large or are difficult to divide into smaller doses, some syrups have an unpleasant taste, etc. Other ARVs have not been tested on children and it is not known if they have any harmful effects on a child's development or health
- Some ARVs designed for adults can be adapted for children to take, especially tablets, but others cannot be used unless a paediatric form is developed (especially soft gel capsules, which cannot be divided into smaller doses)
- Adherence depends both on the child and on the family. If the family (or usual carer) is not involved, treatment is likely to fail
- It is best to tell children on treatment as soon as possible why they are taking the ARV medicines because this can improve adherence
- Support for children on treatment must also address the child's psychological, physical and social development. Children who do not receive support on these issues are less likely to thrive or to benefit from treatment
- A mother who is on ARV treatment herself will have better adherence if she is confident that her child will also receive ARV treatment if and when there is a need.



Additional information

Obstacles to adherence for children

- Parents or regular carers are not always there to help the child take their medication
- Parents do not understand the importance of adherence and/or are not sufficiently involved in supporting the child
- Tablets are too big or difficult to divide into accurate smaller doses
- Treatment is too complicated to fit into the child's daily routine.
- Family situation is unstable.

Factors encouraging adherence for children

- The child's family, or at least some of them, are involved to ensure the child's adherence to treatment
- How to take the treatment is clearly explained both to the close family and the child (depending on age and ability to understand sufficiently)
- The child feels they can trust the carers
- The child gradually becomes responsible for their own treatment, depending on their level of maturity
- The presentation of drugs must be adapted to children (syrup, easily swallowed tablets, etc.)
- The number of drugs taken every day and/or the number of times per day are as few as possible
- The parents must be very attentive to symptoms that could appear in the child while on treatment and talk to the doctor about them, even if they are not ARV side effects.

ARV treatment for children

ARV treatment for children

Should children be told they are HIV positive and/or that their mother or both parents are HIV positive?

This is always a sensitive subject but it is best not to hide the truth from children. At some stage children need to understand why they are on medication. Understanding the reasons for treatment will help the child with adherence.

It is best that a child learns directly from their mother or both parents if they are HIV positive rather than anyone else. If not, the child may feel betrayed and lose trust in the people responsible for their care. The parent's HIV status can be revealed to a child with the support of a family counsellor.

Should information on the HIV status of a child be shared with third parties?

For children attending school, it may be necessary to tell the teacher that the child is on treatment and what the treatment is for in order to avoid problems if the child has to leave the class at regular times to take their medication. It is therefore important that the CBOs/NGOs work in the education environment in order to raise awareness, involve teachers and prevent stigmatisation of positive children.

ARV treatment protocols for children

Being updated by WHO in 2006 – when finalised, new versions will be available on the WHO website at www.who.int/hiv/pub/guidelines/en/.

As with adults, children must be treated with triple therapy. First-line regimes combine the following ARVs:

- 2 reverse transcriptase nucleoside inhibitors (NRTI) + 1 reverse transcriptase non-nucleoside inhibitor (NNRTI)
= 2 NRTI + 1 NNRTI
- The NNRTI choice depends on age or weight. If age < 3 or weight < 10 kg, use NVP and if age > 3 or weight > 10 kg, use NVP or EFV.

Second-line regimes include a protease inhibitor:

- 2 reverse transcriptase nucleoside inhibitors (NRTI) + a protease inhibitor **= 2 NRTI + 1 PI**
- Recommended option is: ABC plus ddI plus LPV/r or NFV, or SQV/r if weight > 25kg.

Essential points to remember – ARV treatment for children

- Many ARVs have not yet been adapted for use by children. For example, many tablets are too large or are difficult to divide into smaller doses, some syrups have an unpleasant taste, etc. Other ARVs have not been tested on children and it is not known if they have any harmful effects on a child's development or health
- Some ARVs designed for adults can be adapted for children to take, especially tablets, but others cannot be used unless a paediatric form is developed (especially soft gel capsules, which cannot be divided into smaller doses)
- Adherence depends both on the child and on the family. If the family (or usual carer) is not involved, treatment is likely to fail
- It is best to tell children on treatment as soon as possible why they are taking the ARV medicines because this can improve adherence
- Support for children on treatment must also address the child's psychological, physical and social development. Children who do not receive support on these issues are less likely to thrive or to benefit from treatment
- A mother who is on ARV treatment herself will have better adherence if she is confident that her child will also receive ARV treatment if and when there is a need.

The role of CBOs/NGOs in supporting people on ARV treatment

The role of CBOs/NGOs in supporting people on ARV treatment



Aim of the session

Participants will be able to identify the potential ways that CBOs/NGOs can:

- support people who are on ARVs, and their families
- inform the general public about ARV treatment in the context of HIV prevention and the promotion of HIV testing and counselling
- advocate for increased access to ARV treatment and quality care for people with HIV.



Methodology

- Work in three small groups
- Presentation of results of work to whole group



Time

- 1 hour 10 minutes



Materials needed

Flip charts with questions for each small group to work on



Notes for the facilitator

If training on ARV treatment is part of a technical and policy support programme for local organisations, you can use this session to identify more clearly the technical and policy support needs of these organisations. This will enable increased and better-focused involvement in ARV treatment. If this is the case, the trainers can add another question to the small group discussions: 'What technical and policy support do you need to achieve these goals?'

The small group discussions are essential for this module. The 'Essential information' section should only be used by the trainers as a supplement to the discussion.



Preparation

- Prepared posters with the instructions for work in small groups, with the themes and questions on each theme (one or two posters for each group).



Activity

Prepare participants for work in three small groups: 'Based on all the information you have learned about ARVs during this training, we now need to understand what roles your organisations can play in different areas.'

1. The groups will discuss the following areas:
 - support for people on ARV treatment and for their families (counselling to encourage adherence) and for people with HIV who are not on ARV treatment but are likely to need it in the future (information and awareness)
 - information on ARVs for the general public, integrated with promoting prevention and VCT (including ARV treatment issues in IEC campaigns and outreach prevention work)
 - advocacy for increased access to ARV treatment and quality care for people with HIV (choice and quality of drugs and services, quality of follow-up treatment, etc.).
2. Questions for each individual group:

Group A – Support Now that you have done this training course, what activities should CBOs/NGOs (including your own) put in place to support ARV treatment? If activities are already in place, what could be improved and how?

Group B – Prevention Now that you have done this training course, what new messages do you think should be included in promotion of HIV prevention and HIV testing and counselling?

Group C – Advocacy Now that you have done this training course, what advocacy work is a priority for ARV treatment-related issues?
3. Allow about 40 minutes for discussion, then bring the whole group together and ask each small group in turn to feed back on their discussions.



Essential information

ARV treatment is expanding rapidly in many countries, putting serious pressure on human resources. Many more trained people are needed to prepare increasing numbers of people with HIV for ARV treatment, to prescribe and follow up treatment and to provide support for adherence and psychosocial needs. However, health service staff – doctors, nurses, pharmacists, social workers, psychologists – are too few in number and challenged by rapidly increasing workloads.

The role of civil society organisations in supporting people on ARV treatment

The staff and volunteers of organisations already involved in the care and support of people with HIV can play an important role, especially if they collaborate with health staff in the public and private sector. The organisations can act on a number of levels to support people on ARV treatment.

With people who are not yet on treatment (and their families, where appropriate)

They can provide information on the different aspects of ARV treatment as part of their ongoing activities through:

- individual and family counselling
- home and hospital visits
- support and self-help groups
- information meetings.

This role can be particularly important when a person is just about to start ARV treatment. Before the treatment starts, the organisation can provide pre-treatment counselling to help the person to assess their ability to take the treatment and to prepare for the lifetime commitment that it will require.

With people taking ARV treatment (and their families, where appropriate)

Organisations can include treatment education in the same activities mentioned above, particularly to help people with ARV treatment adherence.

Organisations can support the setting up of self-help groups for, with or by people on ARV treatment, so that they can meet regularly to discuss issues that arise while taking treatment. These groups (sometimes called adherence groups or clubs) can also be included in the follow-up monitoring of ARV treatment, in co-ordination with the medical teams.

Individuals who are not willing or are unable to join treatment support groups can also be identified by the organisation, which can, depending on resources, ensure support and follow-up outside a group setting.

The role of civil society organisations in informing the general public about ARV treatment in the context of HIV prevention and the promotion of HIV testing and counselling

The role of civil society organisations in scaling up access to ARV treatment should extend beyond providing care and support. Availability of, and increasing access to, ARVs has important consequences for HIV prevention, especially VCT.

Organisations that are working on HIV/AIDS prevention and promotion of testing and counselling must ensure that they include messages about ARV treatment in their information and awareness-raising campaigns. These messages include, for example:

- If you have an HIV test, you will know your HIV status. If you are HIV positive you can get ARV treatment and you will live longer and have a healthier life
- ARVs are not necessary for all people who are HIV positive. If you are HIV positive and still have good health, you will not need to take ARVs until or unless there is damage to your immune system
- ARVs are not a cure for HIV/AIDS. They stop the virus from damaging the immune system but do not completely remove it from the body
- Once you start ARV treatment, you will have to take it for your whole life
- You can still infect another person with HIV, even when you are taking ARVs, so you must still practice prevention and continue to use condoms for sex.

Organisations can also provide information on where ARV treatment can be obtained and the procedure for accessing treatment. For example, they can develop a local or national directory with details of various services for prevention, treatment and care, or develop information materials and other ways of ensuring that people get the right information (for example, through radio, telephone hotlines, printed materials, etc.). If resources are insufficient, they can advocate for other organisations to provide these resources.

The role of CBOs/NGOs in supporting people on ARV treatment

The role of CBOs/NGOs in supporting people on ARV treatment

The role of civil society organisations in advocacy for improved access to ARV treatment

Even though more and more people are able to access ARV treatment, there are still many challenges. Civil society should ensure that access to ARV treatment remains an advocacy priority.

Topics for civil society advocacy on treatment and care include the following examples:

- Increasing access to ARV treatment
 - mechanisms for providing free treatment and laboratory examinations for those with no resources, no social insurance and/or no private medical insurance
 - medical insurance schemes, where they exist, should cover all medical costs linked to ARV treatment, including treatment for opportunistic infections
 - access to lower-cost drugs (generic drugs in particular)
 - no breakdowns in the supply chain
 - decentralisation of treatment services, so that people do not have to travel far for diagnosis and treatment.
- Quality care
 - a wider choice of drugs so that patients can change treatment if necessary
 - good quality drugs from reliable sources
 - good quality care from multidisciplinary teams correctly trained in diagnosis, prescribing and monitoring
 - no stigma or discrimination from health providers or within facilities
 - rights to accurate and appropriate information on all aspects of treatment, prevention and care
 - meaningful involvement of people with HIV and communities in support for those on treatment.

The role of civil society organisations must not be limited just to implementing ARV treatment programmes developed and managed by others. On the contrary, they should be stakeholders and participate in development and management processes, and in monitoring and evaluation of the different ARV treatment, prevention and care initiatives.

Example: small group feedback from a training workshop in Côte d'Ivoire

How can our organisations integrate information on ARV treatment into promotion of HIV prevention and VCT?

Question to participants Now that you have done this training course, what new messages do you think should be included in promotion of HIV prevention and HIV testing and counselling?

Key messages about ARV treatment, suggested by participants:

- The important of adherence to ART
- The need to always have protected sexual relationships
- The need to consult a doctor before deciding to have a child
- The need to remain in contact with counsellors
- The importance of positive living
- The fact that ARVs must be taken for life and perseverance is therefore necessary
- The need to adhere to advice on infant feeding and prevention of mother-to-child HIV transmission
- Awareness about drug interactions
- Importance of an adequate and balanced diet
- The need for good personal hygiene to prevent infections

The role of CBOs/NGOs in supporting people on ARV treatment

Example: small group feedback from a training workshop in Senegal

Potential advocacy roles linked to ARV treatment		
Advocacy goals	Aiming to influence	Comments
Expansion of the range of ARVs available in Senegal	<ul style="list-style-type: none"> Partners in development Sponsors States 	<ul style="list-style-type: none"> Meetings with those concerned Take advantage of national programmes and campaigns
Effective decentralisation of the National ARV Treatment Initiative	<ul style="list-style-type: none"> State Ministry of Health AIDS Division Managers from the National ARV Treatment Initiative 	<ul style="list-style-type: none"> Meetings
Involvement of local groups in providing care	<ul style="list-style-type: none"> Regional councils District councils Rural communities 	<ul style="list-style-type: none"> Meetings Correspondence Training of local representatives
Recruitment and capacity building on reproductive health within the National ARV Treatment Initiative	<ul style="list-style-type: none"> Education 	<ul style="list-style-type: none"> Expansion of personnel
Effective involvement of NGOs/CBOs in the National ARV Treatment Initiative	<ul style="list-style-type: none"> National and regional select technical committees 	<ul style="list-style-type: none"> Signing of a convention Giving communities roles and responsibility within treatment programmes
Effective collaboration between health care professionals and communities	<ul style="list-style-type: none"> Medical authorities Regional committees against AIDS 	<ul style="list-style-type: none"> Implementation of a forum for dialogue Developing a community referral system
Better care for HIV patients in the regions	<ul style="list-style-type: none"> State National AIDS Committee Partners involved with development 	<ul style="list-style-type: none"> Introduction of testing centres in all regions Implementation of PMTCT in all regions
Free prescriptions for people on ARV treatment	<ul style="list-style-type: none"> State Partners in development National AIDS Committee 	<ul style="list-style-type: none"> Meetings Correspondence
Improvement of the quality of life for people with HIV on ARV treatment	<ul style="list-style-type: none"> State Partners in development Local councils 	<ul style="list-style-type: none"> Implementation of fund for income-generating activities Creation of health insurance companies

The role of CBOs/NGOs in supporting people on ARV treatment

The treatment journey – developing community action on ARV treatment



Aim of the session

At the end of the session participants will be able to explain:

- the usefulness of the treatment journey for understanding the experiences of people with HIV when seeking help for their health problems
- how the treatment journey can be used in developing an effective community referral system.



Methodology

- Introduction to the treatment journey
- Present case studies on flip charts and discuss, working in small groups
- Report back in plenary
- Role plays



Time

- 1 hour 30 minutes

Materials needed

- Flip chart paper
- Coloured pens
- Cards with descriptions of fictitious community members
- Cards with different moments/points on the treatment journey



Notes for the facilitator

The descriptions of community members should be adapted to the local situation, including names, types of activity etc. Examples from Zambia are given on page 100.



Preparation

- Prepare cards with descriptions of 'typical' (fictional) community members
- Prepare cards with different moments or points on the treatment journey
- Have flip charts ready to record themes and issues, good and bad experiences.



Activity

1. Introduce the idea of a treatment journey to participants. For example, in a workshop in Zambia, the facilitator related a personal journey while walking around the room and halting by different individual participants as stopping points on the way (an NGO worker, a nurse, a counsellor, a traditional healer):
 - You have a health condition that starts to concern you. What do you do? Who do you speak to? Where do you go?
 - You might start by talking to a family member, a friend or a neighbour. They might suggest that you see the traditional healer or that you go to the local clinic. Then you might go to the market to buy herbs, or the clinic sends you to the VCT centre. Your journey might then take you to a laboratory to have some more tests done and onward to the local hospital. Depending on the results of these, you may be sent to the local hospital. At the same time, you might also visit an NGO working in your neighbourhood for further advice or counselling.
 - The journey can be long and winding, and you might deal with many different people on the way
 - The ease of this journey depends on a number of factors – the attitude of the people you have to deal with, the distances you have to travel, the availability of the services that you require (as well as their opening times), the clarity and accuracy of the information that you receive and so on.
2. Divide participants into small groups (five to six people) and give each group one of the cards or papers with the description of a 'typical' community member, some flip chart paper and some coloured marker pens. Ask each group to think about the treatment journey that their assigned community member may follow and draw this on a flip chart, showing where the person goes to, the people they will encounter and significant events and experiences along the way. You can show participants examples of pictures produced in previous trainings (see photographs pages 101-102).
3. After about 20-30 minutes, ask the first group to present the drawing of their assigned individual's treatment journey to the rest of the participants and describe what happens.
4. Ask for questions and observations from the large group and note any important points regarding helpful and unhelpful aspects of the journey on a flip chart.
5. Ask the rest of the groups to present their illustrated journeys, each time followed by questions and observations.
6. To summarise, look at the points noted during the presentations of the group work and ask how the treatment journey could be made better, quicker and easier.
7. Use the results as the basis for discussion on how to make an effective referral system for the community concerned. Elements to include, for example, would be knowing where people can be referred to and for what, a referral directory, providing information for the client, a referral form, appointment systems, arrangements for follow-up in the community and so on.



Essential information

What is a treatment journey?

- When a person finds that something is going wrong with their body, a personal journey usually starts – **the treatment journey**.
- Questions arise and decisions have to be made about what to do. For example: 'Should I treat myself?', 'Who should I turn to for help?', 'Where should I go?', 'Who can give me the right information?', 'What helps and what gets in the way?'
- Such journeys often do not follow straight lines and are not just one-way, especially for a person with a chronic condition such as HIV. What happens after treatment or care has been accessed? How does the journey continue?

- The ‘journey’ concept can help us consider many aspects of living with HIV and dealing with the problems it raises. It is very useful for looking at the factors involved in accessing and using ARV treatment. The strength of this tool is that the person with HIV is at the centre of the picture, making them a constant reference point for understanding and planning how to tackle a variety of challenges.

Why is the treatment journey important for VCT and ARV treatment?

- Planning for health services and treatment programmes usually depends on the expertise of people within health systems
- Even when the importance of community involvement is acknowledged, the community perspective is often not properly included. Consequently there is a risk of a lack of community support for service users and poor uptake of services
- Having a user-centred approach and starting with the experience of an individual will allow development of referral systems or other services that are better targeted on real needs and experience, and help to build dialogue and co-operation between users and providers of services and support – both in the community and within the health system
- An important role for community involvement in ARV treatment is in ensuring that people who have, or suspect they have, HIV or might need ARV treatment are referred to the right places to get services, know what to expect and are followed up when they return to the community. A simple community referral system can greatly assist with this process. An example of a referral form used in the ACER project in Zambia is given on page 00.



Additional information

Asking an individual, a group of people with HIV or a mixed group of community members and service providers to illustrate an individual's journey using flip chart and pens is a simple tool that provides useful detail and highlights connections between key people, facilities, challenges and factors. Especially if the group is a mixed one, experience shows that doing a treatment journey activity together will contribute to an important sharing of knowledge and experience about how people with HIV try to do something about their health problems.

It works best if local people, who know their own situation best, are involved in developing the fictional scenarios about individuals whose journeys are to be described. Sometimes a real person's journey can be described, but informed consent and confidentiality are highly important and must be respected.

This activity has been adapted and used for planning services, designing referral networks, developing linkages between people with HIV and service providers, and for understanding important factors such as the effects of stigma on treatment and prevention.

The role of CBOs/NGOs in supporting people on ARV treatment

The treatment journey – developing community action on ARV treatment

Examples of cards/paper with descriptions of individual community members

Treatment journey: Samuel Zulu (Zambia)

- 35 years old, married and living with his wife, has a girlfriend
- Has five children and one dependant
- Is a Zambeef branch manager with a management diploma
- Likes going out for drinks and playing pool, is a soccer fan and goes to church sometimes
- Is frequently sick, coughing a lot and has repeated malaria

Treatment journey: Chanda Mulenga (Zambia)

- 45 years old, husband died two years ago after a long illness, six children, one has died
- Marketeer buying and selling tomatoes, vegetables and dried fish, travels to buy food stuffs
- Strong member of church group
- Has lost 10 kilos and fears she may be HIV positive

Treatment journey: Natasha (Zambia)

- Six years old, mother died, living with aunt and uncle who do not neglect her but shout at her a lot
- Small for her age, doesn't play with other children, seems sad
- Is frequently ill

Treatment journey: Marcia (Caribbean)

- 14-year-old girl who lives with her mother at home
- Was involved with a 19-year-old boyfriend who was also having sex with another girl in the same area
- The boy became sick, went to the doctor, was asked to take an HIV test and found out he was HIV positive
- He has told Marcia of his status and has advised her that the nurse wants her to visit the clinic also

Treatment journey: Tike (Caribbean)

- 24 year-old 'boy on the block'
- Has had sex with and without condoms for three or four years
- Just found out that one of his frequent partners died
- People are gossiping that the death might be due to AIDS

The treatment journey – developing community action on ARV treatment

Examples of treatment journeys from workshops in Zambia and the Caribbean



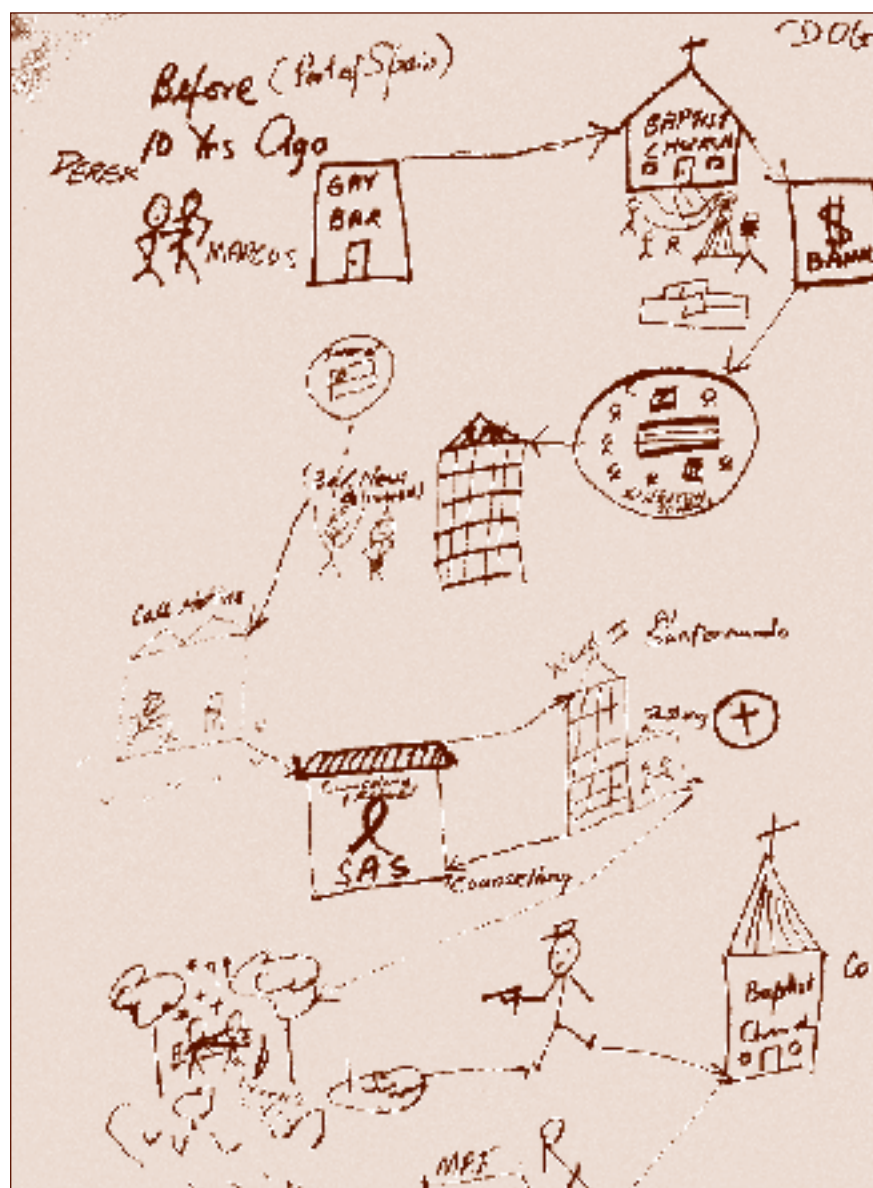
The treatment journey of Sibeso in Zambia

She is 19 years old and is pregnant with an older married man's child. She found out that she is HIV positive at the antenatal clinic. She also has a one-year-old child who is being looked after by her grandmother and has a boyfriend who is the same age as her but does not know about her being pregnant. She did not finish school, leaving after Grade 5.

What was her treatment journey like? Who did she go to? Who helped her?
How did she get information? Where did she go for services and support?
What obstacles did she meet with? How could the journey have been better?

The role of CBOs/NGOs in supporting people on ARV treatment

The treatment journey – developing community action on ARV treatment



Derek's journey, Trinidad

Derek is 30 years old, married to Sandra and works at a bank. He has one child, aged ten. He found out from a nurse at the clinic that a previous sexual partner, Marcus, has tested positive for HIV. Derek has never had an HIV test and is scared to go for a test because some of the nurses know him.

Barriers he met with:

- Fear that HIV means death
- How to disclose to his wife
- "Forbidden" sexual practice – having sex with men
- Fear of violence
- Popular person, known in the community

Support he found:

- Anonymous telephone hotline
- Referred to support group
- Counselling and testing away from home
- Treatment from ARV clinic

Two-part community referral form used by the ACER Project, Zambia



Plot 3020, Mosi-na-Tunya Road,
PO Box 33798, 10101 Lusaka
Woodlands Shopping Complex
Tulu Fax: +260 1 250818, 284792, 263088
Cell: 097-771123
info@alliancezambia.org.zm

Supporting Community Action on AIDS in Developing Countries

REFERRAL FORM

To: _____

No: **1301**

From: _____

Date: / /

Age/Sex: /

Name: _____

Residential Address: _____

Reason for Referral: _____

Name: _____

Designation: _____

Signature: _____

FEEDBACK

No: **1301**

Age/Sex: /

Name: _____

Date: / /

Comments: _____

Name: _____

Designation: _____

Signature: _____

Tables of ARV medicines available in 2006

Table 1	NRTIs – nucleoside reverse transcriptase inhibitors	Page 105
Table 2	NNRTIs – non-nucleoside reverse transcriptase inhibitors	Page 106
Table 3	PIs – protease inhibitors (anti-proteases)	Page 106
Table 4	Fusion (entry) inhibitors	Page 107
Table 5	Triple combinations of more than one category of ARV	Page 107

Table 1: Nucleoside reverse transcriptase inhibitors (nucleosides/'nukes'/NRTI)

International non-proprietary name (INN) (generic name)	Abbreviation	Trade (brand/proprietary) name	Producer
ABACAVIR	ABC	ZIAGEN®	GlaxoSmithKline
DIDANOSINE	ddl	VIDEX®	Bristol-Myers Squibb
EMTRICITABINE	FTC	EMTRIVA®	Gilead
LAMIVUDINE	3TC	EPIVIR®	GlaxoSmithKline
		AVOLAM®, ANOLAM®, VIROLAM® – generics	Ranbaxy
		LAMIVIR® – generic	Cipla
		HEPTAVIR® – generic	Hetero Drugs
		No brand name – generic	Strides Arcolab
STAVUDINE	d4T	ZERIT®	Bristol-Myers Squibb
		STAG® – generic	Hetero Drugs
		STAVIR® – generic	Cipla
		VIROSTAV®, AVOSTAV® - generic	Ranbaxy
TENOFOVIR	TDF	No brand name – generic	Strides Arcolab
ZALCITABINE	ddC	VIREAD®	Gilead Sciences
		HIVID®	Roche
ZIDOVUDINE	AZT or ZDV	RETROVIR®	GlaxoSmithKline
		ZIDO-H® – generic	Hetero Drugs
		ZIDOVIR® - generic	Cipla
		VIRO-Z® – generic	Ranbaxy
		ZIDOVUDINA® – generic	Combino Pharm
Fixed dose combinations (NRTIs only) (see Table 5 for others)			
LAMIVUDINE + STAVUDINE	3TC + d4T	COVIR-LS®, VIROLIS®, LAMIVIR-S® – generics	Ranbaxy
		No brand name – generic	Strides Arcolab
		No brand name – generic	Aurobindo
LAMIVUDINE + ZIDOVUDINE	3TC + AZT	COMBIVIR®	GlaxoSmithKline
		AVOCOMB® – generic	Ranbaxy
		ZIDOLAM® – generic	Hetero Drugs
		DUOVIR® – generic	Cipla
LAMIVUDINE + ZIDOVUDINE + ABACAVIR	3TC + AZT + ABC	TRIZIVIR®	GlaxoSmithKline

Tables of ARV medicines available in 2006

Table 2: Non-nucleoside reverse transcriptase inhibitors (non nucleosides)'non-nukes'/NNRTI

International non-proprietary name (INN) (generic name)	Abbreviation	Trade (brand/proprietary) name	Producer
DELAVIDINE	DLV	RESCRIPTOR®	Pfizer
EFAVIREN	EFV	SUSTIVA®	Bristol-Myers Squibb
		STOCRIN®	Merck Sharp & Dohme (MSD)
		EFAVIR® – generic	Cipla
NEVIRAPINE	NVP	VIRAMUNE®	Boehringer-Ingelheim
		NEVIR® – generic	Hetero Drugs Ltd
		NEVIPAN® – generic	Ranbaxy
		NEVIMUNE® – generic	Cipla
		No brand name – generic	Strides Arcolab

Table 3: Protease inhibitors (PI)

International non-proprietary name (INN) (generic name)	Abbreviation	Trade (brand/proprietary) name	Producer
AMPRENAVIR	APV	AGENERASE®	GSK/VERTEX
FOS-AMPRENAVIR		TELZIR®, LEXIVA®	GSK/VERTEX
ATAZANAVIR	ATV	REYATAZ®	Bristol-Myers Squibb
INDINAVIR	IDV	CRIXIVAN®	Merck Sharp & Dohme (MSD)
		AVIRODIN® – generic	Ranbaxy
		INDIVIR® – generic	Hetero Drugs
		INDIVAN® – generic	Cipla
LOPINAVIR + RITONAVIR	LPV + RTV or LPV/r	KALETRA® ALUVIA®	Abbott
NELFINAVIR	NFV	VIRACEPT®	Roche/Agouron
RITONAVIR	RTV	NORVIR®	Abbott
SAQUINAVIR – soft gel capsules 200mg	SQV-SG or FTV	FORTOVASE®	Roche
SAQUINAVIR – hard gel capsules 200mg	SQV-HG or INV	INVIRASE®	Roche
TIPRANAVIR	TPV	APTIVUS®	Boehringer-Ingelheim

Table 4: Fusion (entry) inhibitors

International non-proprietary name (INN) (generic name)	Abbreviation	Trade (brand/proprietary) name	Producer
ENFUVIRTIDE	T20	FUZEON®	Roche/Triméris

Table 5: Triple combinations of more than one type of ARV (2 NRTI + 1 NNRTI) in the same tablet

International non-proprietary name (INN) (generic name)	Abbreviation	Trade (brand/proprietary) name	Producer
STAVUDINE + LAMIVUDINE + NEVIRAPINE	d4T + 3TC + NVP	TRIVIRO® or TRIVIRO-LNS or VIROLANS® – generics	Ranbaxy
		TRIOMUNE® – generic	Cipla
		NEBULAM-SN® – generic	Nebumed Pharma
ZIDOVUDINE + LAMIVUDINE + NEVIRAPINE	ZDV + 3TC + NVP	DUOVIR-N® – generic	Cipla

Fact sheets on ARVs available in 2006

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Abacavir/ABC ZIAGEN®

Category	NRTI – Nucleoside reverse transcriptase inhibitor
Presentation	<ul style="list-style-type: none"> Tablets, 300mg Syrup, 20mg/ml
Dose	<p>Adult:</p> <ul style="list-style-type: none"> 1 tablet twice a day (a total of 2 tablets each day) <p>Child:</p> <ul style="list-style-type: none"> 8mg/kg twice a day
Food	Can be taken with or without food
Main side effects	<p>At the start of treatment:</p> <ul style="list-style-type: none"> Tiredness Digestive problems Stiffness, pain in muscles <p>Abacavir can cause serious allergic reactions (hypersensitivity) in some people. These allergies happen especially between 1 and 6 months after starting treatment, but they can also happen later. The symptoms are:</p> <ul style="list-style-type: none"> the skin becomes hot and red/dark, indicating fever nausea and/or vomiting and/or diarrhoea and/or mouth ulcers tiredness and/or muscular stiffness and/or generally feeling ill sore throat and/or cough and/or difficulty with breathing. <p>If fever develops, it is essential to consult a doctor immediately</p> <p>NEVER USE ABACAVIR AGAIN IF TREATMENT HAD TO BE STOPPED BECAUSE OF A SEVERE ALLERGIC REACTION</p> <p>During treatment:</p> <ul style="list-style-type: none"> Tiredness Joint pains Lactic acidosis
Interactions with other drugs	No interactions known
Interactions with other ARVs	No interactions known
Storage	Room temperature, not more than 30°C

Adapted from information provided by: AIDES, AIDSMEDS.COM and JSI-DELIVER

Tables of ARV medicines available in 2006

Didanosine/ddI VIDEX®	
Category	NRTI – Nucleoside reverse transcriptase inhibitor
Presentation	<ul style="list-style-type: none"> • Capsules (delayed release), 400, 250, 200, 125mg • Tablets, chewable or dispersible (mixed with water to drink), 200, 100, 25mg • Powder to make oral solution, in sachets of 2g or 4g
Dose	<p>Adult over 60kg:</p> <ul style="list-style-type: none"> • 1 capsule 400mg daily in 1 dose, or 2 tablets 200mg daily in 1 dose <p>Adult less than 60kg:</p> <ul style="list-style-type: none"> • 1 capsule 250mg once daily <p>Children over 6 years:</p> <ul style="list-style-type: none"> • Capsules, 240mg/sq.m. once daily, or paediatric suspension 5mg/kg per dose in 2 doses per day
Food	Videx capsules must be taken on an empty stomach, which means at least 2 hours before or 2 hours after a meal. Some doctors suggest taking Videx with a large glass of water on getting up from bed, about 30-45 minutes before breakfast
Main side effects	<p>At the start of treatment: sometimes, nausea, vomiting, diarrhoea</p> <p>During treatment:</p> <ul style="list-style-type: none"> • Tingling or loss of feeling in the feet or hands (peripheral neuropathy). Consult the doctor • Bloating of the abdomen (gas) • Mouth ulcers • Rarely, pancreatitis, with symptoms such as abdominal pain, nausea, vomiting, confirmed by blood tests • Sometimes serious fatigue, muscle spasm and frequent cramps, abdominal pain, nausea, vomiting, difficulty in breathing – these symptoms indicate possible lactic acidosis; consult a doctor immediately
Interactions with other drugs	<ul style="list-style-type: none"> • Didanosine/ddI should not be used at the same time as treatment for hepatitis C with ribavirin. • Didanosine/ddI increases the concentration in the blood of ganciclovir (used in treatment of cytomegalovirus CMV)
Interactions with other ARVs	<ul style="list-style-type: none"> • Didanosine/ddI tablets must not be taken with indinavir • It is not recommended to use didanosine/ddI and stavudine/d4T together • Didanosine/ddI must be taken 2 hours before atazanavir if these two ARVs are to be used together
Storage	Room temperature

Adapted from information provided by: AIDES, AIDSMEDS.COM and JSI-DELIVER

Emtricitabine/FTC EMTRIVA®

Category	NRTI – Nucleoside reverse transcriptase inhibitor
Presentation	<ul style="list-style-type: none"> • Capsules, 200mg • Oral solution, 10mg/ml
Dose	<p>Adults:</p> <ul style="list-style-type: none"> • 1 capsule 200mg once daily <p>Children:</p> <ul style="list-style-type: none"> • 4mg/kg once daily (if capsules are used, not more than 200mg per day; if oral solution is used, not more than 240mg per day)
Food	No special requirements
Main side effects	<ul style="list-style-type: none"> • Vertigo • Insomnia • Diarrhoea, nausea, vomiting, abdominal pain • Pruritus (severe skin itching), urticaria (red, itchy areas of skin) • Anaemia (low red blood cell count)
Interactions with other ARVs	Do not use along with lamivudine/3TC or zalcitabine/ddC
Storage	Room temperature

Adapted from information provided by: AIDES, AIDSMEDS.COM and JSI-DELIVER

Fact sheets on ARVs available in 2006

Lamivudine/3TC EPIVIR®; LAMIVIR®; HEPTAVIR®; AVOLAM®; ANOLAM®; VIROLAM®	
Category	NRTI – Nucleoside reverse transcriptase inhibitor
Presentation	<ul style="list-style-type: none"> Tablets, 150mg or 300mg Oral solution 10mg/ml
Dose	<p>Adults:</p> <ul style="list-style-type: none"> 1 tablet 150mg per dose, 2 doses per day OR 1 tablet 300mg, 1 dose per day <p>Children:</p> <ul style="list-style-type: none"> Oral solution 4mg/kg per dose, 2 doses per day
Food	No special requirements
Main side effects	<ul style="list-style-type: none"> Sometimes, serious fatigue, muscle spasm and frequent cramps, abdominal pain, nausea, vomiting, difficulty in breathing – these symptoms indicate possible lactic acidosis; consult a doctor immediately
Interactions with other drugs	No major interactions known
Interactions with other ARVs	Not usually used with zalcitabine/ddC
Storage	<ul style="list-style-type: none"> Tablets below 30°C Oral solution below 25°C. After opening, a bottle of oral solution may be kept for up to one month only

Adapted from information provided by: AIDES, AIDSMEDS.COM and JSI-DELIVER

Stavudine/d4T ZERIT®; ZERIT XR®; STAG®; STAVIR®; VIROSTAV®; AVOSTAV®

Category	NRTI – Nucleoside reverse transcriptase inhibitor
Presentation	<ul style="list-style-type: none"> • Capsules, 40, 30, 20, 15mg • Capsules (slow-release), 100, 75, 50, 37.5mg • Powder to make oral solution, 1mg/ml
Dose	<p>Adults over 60kg:</p> <ul style="list-style-type: none"> • 1 capsule 40mg per dose, 2 doses per day OR • 1 slow-release capsule 100mg per dose, 1 dose per day <p>Adults less than 60kg:</p> <ul style="list-style-type: none"> • 1 capsule 30mg per dose, 2 doses per day OR • 1 slow-release capsule 75mg per dose, 1 dose per day <p>Children less than 30kg:</p> <ul style="list-style-type: none"> • Oral solution 1mg/kg per dose, 2 doses per day <p>Children more than 30kg:</p> <ul style="list-style-type: none"> • Same dose as adults less than 60kg
Food	No special requirements
Main side effects	<ul style="list-style-type: none"> • Tingling or loss of feeling in the feet or hands (peripheral neuropathy) Consult the doctor • Rarely, pancreatitis, with symptoms such as abdominal pain, nausea, vomiting, confirmed by blood tests • Loss of fat from the face, buttocks or thighs, arms, legs • Sometimes, serious fatigue, muscle spasm and frequent cramps, abdominal pain, nausea, vomiting, difficulty in breathing – these symptoms indicate possible lactic acidosis; consult a doctor immediately
Interactions with other drugs	<ul style="list-style-type: none"> • Stavudine/d4T should not be taken with drugs that are toxic to the nervous system; for example some anti-TB drugs • Use of stavudine/d4T is not recommended at the same time as ribavirin for treatment of hepatitis C
Interactions with other ARVs	<ul style="list-style-type: none"> • Use of stavudine/d4T along with didanosine/ddI is not recommended because this increases the risk of side effects • Stavudine/d4T must not be used along with zidovudine/ZDV (COMBIVIR, RETROVIR, TRIZIVIR etc. – see page 105 to check the full list of trade names)
Storage	Room temperature

Adapted from information provided by: AIDES, AIDSMEDS.COM and JSI-DELIVER

Fact sheets on ARVs available in 2006

Tenofovir/TDF VIREAD®	
Category	NRTI – Nucleoside reverse transcriptase inhibitor
Presentation	Tablets, 300mg
Dose	1 tablet in 1 dose per day
Food	Tenofovir/TDF can be taken with or without food
Main side effects	<ul style="list-style-type: none"> • Fatigue, vertigo • Nausea, vomiting, diarrhoea, flatulence (gas) • Kidney problems (rare)
Interactions with other drugs	Tenofovir/TDF should not be used along with other drugs that are toxic to the kidneys
Interactions with other ARVs	Tenofovir/TDF increases the blood concentration of didanosine/ddI when ddI is taken as capsules
Storage	Room temperature

Adapted from information provided by: AIDES, AIDSMEDS.COM and JSI-DELIVER

Zalcitabine/ddC HIVID®

Category	<p>NRTI – Nucleoside reverse transcriptase inhibitor</p> <p>ATTENTION: the use of zalcitabine/ddC is no longer recommended because it causes a high rate of side effects</p>
Presentation	<ul style="list-style-type: none"> • Tablets, 0.750 and 0.375mg • Syrup for children, 0.1mg/ml
Dose	<p>Adults:</p> <ul style="list-style-type: none"> • 1 tablet 0.750mg per dose, 3 doses per day. Sometimes prescribed as 1.125mg per dose in 2 doses per day <p>Children:</p> <ul style="list-style-type: none"> • 0.01mg/kg per dose, 3 doses per day
Food	No special requirements
Main side effects	<p>At the start of treatment:</p> <ul style="list-style-type: none"> • Zalcitabine/ddC sometimes causes digestive problems: nausea, vomiting, diarrhoea. These usually disappear during the few weeks after starting treatment <p>During treatment:</p> <ul style="list-style-type: none"> • Tingling or loss of sensation in the feet or hands (peripheral neuropathy). Consult the doctor • Mouth ulcers • Rarely, pancreatitis, with symptoms such as abdominal pain, nausea, vomiting, confirmed by blood tests • Causes a decrease in levels of red blood cells, white blood cells and platelets • Sometimes serious fatigue, muscle spasm and frequent cramps, abdominal pain, nausea, vomiting, difficulty in breathing – these symptoms indicate possible lactic acidosis; consult a doctor immediately
Interactions with other drugs	No major interactions
Interactions with other ARVs	Do not use zalcitabine/ddC with lamivudine/3TC (EPIVIR, COMBIVIR, TRIZIVIR etc. – see page 105 to check the full list of trade names)
Storage	Room temperature

Adapted from information provided by: AIDES, AIDSMEDS.COM and JSI-DELIVER

Fact sheets on ARVs available in 2006

Zidovudine/ZDV/AZT RETROVIR®; ZIDO-H®; ZIDOVIR®; VIRO-Z®; ZIDOVUDINA®	
Category	NRTI – Nucleoside reverse transcriptase inhibitor
Presentation	<ul style="list-style-type: none"> • Tablets, 300mg • Capsules, 100mg, 250mg • Oral solution, 10mg/ml • Injection for intravenous infusion, 200mg/ml
Dose	<p>Adults:</p> <ul style="list-style-type: none"> • 1 capsule 250mg per dose, or 1 tablet 300mg per dose, in 2 doses per day <p>Children:</p> <ul style="list-style-type: none"> • 4mg/kg, 2 doses per day
Food	No special requirements
Main side effects	<p>At the start of treatment:</p> <ul style="list-style-type: none"> • Nausea, sometimes severe, which usually becomes less over time. Anti-nausea drug can be prescribed by the doctor <p>During treatment:</p> <ul style="list-style-type: none"> • Decreased levels of red blood cells, and sometimes white blood cells. If severe, the doctor might decide to change treatment • Muscle pains. This can be related to muscle damage. Consult a doctor immediately • Headache, mild fatigue, dark coloration of nails and (less often) the skin • Sometimes serious fatigue, muscle spasm and frequent cramps, abdominal pain, nausea, vomiting, difficulty in breathing – these symptoms indicate possible lactic acidosis; consult a doctor immediately
Interactions with other drugs	No major interactions known with other drugs
Interactions with other ARVs	Do not use zidovudine/ZDV with stavudine/d4T
Storage	Room temperature

Adapted from information provided by: AIDES, AIDSMEDS.COM and JSI-DELIVER

Lamivudine + Stavudine (3TC + d4T) COVIR-LS®; VIROLIS®, LAMIVIR-S®

Category	NRTI – Nucleoside reverse transcriptase inhibitors, a combination of 2 antiretrovirals from the same category
Presentation	Tablets, each containing: <ul style="list-style-type: none"> stavudine/d4T 40mg + lamivudine/3TC 150mg OR stavudine/d4T 30mg + lamivudine/3TC 150mg
Dose	1 tablet per dose, 2 doses per day
Food	No special requirements
Main side effects	See information sheets on stavudine/d4T and lamivudine/3TC
Interactions with other drugs	See information sheets on stavudine/d4T and lamivudine/3TC
Interactions with other ARVs	See information sheets on stavudine/d4T and lamivudine/3TC
Storage	Room temperature

Adapted from information provided by: AIDES, AIDSMEDS.COM and JSI-DELIVER

Fact sheets on ARVs available in 2006

Lamivudine + Zidovudine (3TC + ZDV/AZT) COMBIVIR®; DUOVIR®; AVOCOMB®; ZIDOLAM®	
Category	NRTI – Nucleoside reverse transcriptase inhibitors a combination of 2 antiretrovirals from the same category
Presentation	Tablets, each containing 150mg lamivudine/(3TC) + 300mg zidovudine/ZDV/AZT
Dose	1 tablet per dose, 2 doses per day
Food	No special requirements
Main side effects	<p>At the start of treatment:</p> <ul style="list-style-type: none"> Nausea, sometimes severe, which usually becomes less over time. Anti-nausea drugs can be prescribed by the doctor <p>During treatment:</p> <ul style="list-style-type: none"> Decreased levels of red blood cells and sometimes white blood cells. If severe, the doctor might decide to change treatment Muscle pains. This can be related to muscle damage. Consult a doctor immediately Headache, mild fatigue, dark coloration of nails and (less often) the skin Sometimes, serious fatigue, muscle spasm and frequent cramps, abdominal pain, nausea, vomiting, difficulty in breathing – these symptoms indicate possible lactic acidosis; consult a doctor immediately
Interactions with other drugs	No major interactions known with other drugs
Interactions with other ARVs	Do not use lamivudine/(3TC) + zidovudine/ZDV/AZT along with stavudine
Storage	Room temperature

Adapted from information provided by: AIDES, AIDSMEDS.COM and JSI-DELIVER

Abacavir + Lamivudine + Zidovudine (ABC + 3TC + ZDV) TRIZIVIR®

Category	NRTI – Nucleoside reverse transcriptase inhibitors, a combination of 3 antiretrovirals from the same category
Presentation	Tablets 300mg zidovudine/ZDV + 150mg lamivudine/3TC + 300mg abacavir/ABC
Dose	1 tablet per dose, 2 doses per day
Food	No special requirements
Main side effects	<p>At the start of treatment:</p> <p>This combination contains Abacavir, which causes allergies in some patients, especially in the first 6 weeks of treatment. Symptoms of these allergies can include:</p> <ul style="list-style-type: none"> • Red/dark areas on the skin, itching, fever • Nausea and/or vomiting and/or diarrhoea • Tiredness and/or muscular stiffness and/or general feelings of illness • Sore throat and/or cough and/or difficulty breathing <p>See the information sheet on Abacavir</p> <p>During treatment:</p> <ul style="list-style-type: none"> • Nausea • Decreased levels of red blood cells and sometimes white blood cells • Muscle pains • Headache, tiredness, brown colouring of the nails and skin • Joint pains • Lactic acidosis
Interactions with other drugs	No interactions with other drugs known
Interactions with other ARVs	Do not use Trizivir with stavudine/d4T or zalcitabine/ddC
Storage	Room temperature, below 30°C

Adapted from information provided by: AIDES, AIDSMEDS.COM and JSI-DELIVER

Fact sheets on ARVs available in 2006

Delavirdine/DLV RESCRIPTOR®	
Category	NNRTI – Non-nucleoside reverse transcriptase inhibitor
Presentation	Tablets, 100mg
Dose	Adults: <ul style="list-style-type: none"> 4 tablets per dose, 3 doses per day Children: <ul style="list-style-type: none"> Not normally used for children
Food	No special requirements, but it is better to avoid taking delavirdine/DLV with very oily or fatty food
Main side effects	At the start of treatment: <ul style="list-style-type: none"> Risk of allergies: if red/dark patches appear on the skin, consult a doctor Digestive problems: nausea, diarrhoea which gradually gets less and stops
Interactions with other drugs	Many interactions with other drugs
Interactions with other ARVs	Delavirdine increases the concentration in the blood of indinavir, nelfinavir and saquinavir, and of anti-TB drugs
Storage	Room temperature

Adapted from information provided by: AIDES, AIDSMEDS.COM and JSI-DELIVER

Efavirenz/EFV SUSTIVA®; STOCRIN®; EFAVIR®

Category	NNRTI – Non-nucleoside reverse transcriptase inhibitor
Presentation	<ul style="list-style-type: none"> Tablets, 600mg Capsules, 50, 100, 200mg Syrup, 30mg/ml
Dose	<p>Adults:</p> <p>1 tablet 600mg or 3 capsules 200mg per dose, 1 dose per day (preferably in the evening, after a meal and before going to bed).</p> <p>If the person is also receiving TB treatment, up to 800mg per dose, 1 dose per day (preferably in the evening, after a meal and before going to bed) because the anti-TB drug rifampicin reduces the concentration of efavirenz in the blood</p> <p>Children:</p> <p>According to weight, based on a fixed-dose schedule provided by the producer</p>
Food	Avoid very oily or fatty food before taking efavirenz/EFV because such food can increase side effects from the drug
Main side effects	<p>At the start of treatment:</p> <ul style="list-style-type: none"> Frequently: vertigo, insomnia, problems with concentration, sleepiness, nightmares Rarely: hallucinations Risk of allergy, appearing as red/dark or purplish areas on the skin (more frequent in children). Consult a doctor Children: agitation <p>During treatment:</p> <ul style="list-style-type: none"> Problems such as vertigo, insomnia, nightmares might continue After several weeks, possibility of depression, aggressiveness, suicidal ideas and psychiatric problems Increase in the amount of fat in the blood (cholesterol) Hepatitis (inflammation of the liver), confirmed by blood tests
Interactions with other drugs	Many interactions with other drugs
Interactions with other ARVs	Efavirenz/EFV reduces the concentration in the blood of some protease inhibitors such as amprenavir, atazanavir, indinavir and saquinavir. It increases the blood concentration of other protease inhibitors – nelfinavir and ritonavir
Storage	Room temperature

Adapted from information provided by: AIDES, AIDSMEDS.COM and JSI-DELIVER

Fact sheets on ARVs available in 2006

Nevirapine/NVP VIRAMUNE®; NEVIPAN®; NEVIVIR®; NEVIMUNE®	
Category	NNRTI – Non-nucleoside reverse transcriptase inhibitor
Presentation	<ul style="list-style-type: none"> Tablets, 200mg Oral solution, 50mg/5ml
Dose	<p>It is recommended to start treatment with a half dose for the first 14 days of treatment to reduce the risk of side effects</p> <p>Adults:</p> <ul style="list-style-type: none"> During the first 14 days of treatment, 1 tablet 200mg, 1 dose per day, always at the same time each day After the first 14 days, increase the dose to 1 tablet per dose, 2 doses per day <p>Children:</p> <ul style="list-style-type: none"> During the first 14 days of treatment, 4mg/kg, 1 dose per day, always at the same time each day <p>After the first 14 days:</p> <ul style="list-style-type: none"> 7mg/kg, 2 doses per day for children less than 8 years old 4mg/kg, 2 doses per day for children more than 8 years old (but no more than a total of 400mg per day) <p>Newborn infants (PMTCT):</p> <ul style="list-style-type: none"> 2mg/kg in 1 dose
Food	No special requirements
Main side effects	<p>At the start of treatment:</p> <p>Risk of allergy, appearing as red/dark or purplish areas on the skin, rashes or other skin problems and/or fever. This can affect women more than men. Consult a doctor. Also, possible nausea</p> <p>During treatment:</p> <p>Liver function can be affected, shown by symptoms such as jaundice, nausea, vomiting, fever, serious fatigue</p>
Interactions with other drugs	Many interactions with other drugs
Interactions with other ARVs	Nevirapine/NVP reduces the concentration in the blood of the following ARVs: amprenavir, fosamprenavir, indinavir, lopinavir, nelfinavir and saquinavir
Storage	Room temperature

Adapted from information provided by: AIDES, AIDSMEDS.COM and JSI-DELIVER

Amprenavir/APV AGENERASE®

Category	PI – Protease inhibitor (anti-protease)
Presentation	<ul style="list-style-type: none"> • Capsules 150mg, 50mg • Syrup 15mg/ml
Dose	<p>Adults:</p> <ul style="list-style-type: none"> • 8 capsules per dose, 2 doses per day (total 16 capsules per day) • Combined with low-dose ritonavir: amprenavir 4 capsules per dose + ritonavir 1 capsule 100mg per dose, 2 doses of each drug per day (total 10 capsules per day) <p>Children:</p> <ul style="list-style-type: none"> • 20mg/kg per dose, 2 doses per day if taken as capsules • 17mg/kg per dose, 3 doses per day if taken as syrup <p>Not to be given to children less than 4 years old</p>
Food	No special requirements. Never take amprenavir/APV with very fatty or oily foods
Main side effects	<p>At the start of treatment: Possibility of skin problems. Consult a doctor</p> <p>During treatment:</p> <ul style="list-style-type: none"> • Digestive problems, especially nausea • Tiredness, headache • Increase in the amount of fat and sugar in the blood
Interactions with other drugs	<ul style="list-style-type: none"> • Many interactions with other drugs • Vitamin E supplements, or products containing vitamin E, must not be taken along with amprenavir
Interactions with other ARVs	<ul style="list-style-type: none"> • Ritonavir increases the concentration of amprenavir in the blood • Efavirenz reduces the concentration of amprenavir in the blood
Storage	Room temperature

Adapted from information provided by: AIDES, AIDSMEDS.COM and JSI-DELIVER

Fact sheets on ARVs available in 2006

Fosamprenavir TELZIR®, LEXIVA®	
Category	PI – Protease inhibitor (anti-protease)
Presentation	<ul style="list-style-type: none"> Tablets, 700mg Oral solution, 50mg/ml
Dose	<p>Adults:</p> <ul style="list-style-type: none"> 1 tablet 700mg fosamprenavir and 1 capsule 100mg ritonavir per dose, 2 doses per day <p>OR</p> <ul style="list-style-type: none"> 2 tablets 700mg fosamprenavir and 2 capsules 100mg ritonavir per dose, 1 dose per day
Food	No special requirements
Main side effects	<p>At the start of treatment: Possibility of skin problems. Consult a doctor</p> <p>During treatment:</p> <ul style="list-style-type: none"> Digestive problems, especially nausea Increase in the amount of fat and sugar in the blood
Interactions with other drugs	<ul style="list-style-type: none"> Many interactions with other drugs Vitamin E supplements, or products containing vitamin E, must not be taken along with fosamprenavir
Interactions with other ARVs	<ul style="list-style-type: none"> Ritonavir increases the concentration of fosamprenavir in the blood Efavirenz reduces the concentration of fosamprenavir in the blood
Storage	Room temperature

Adapted from information provided by: AIDES, AIDSMEDS.COM and JSI-DELIVER

Atazanavir/ATV REYATAZ®

Category	PI – Protease inhibitor (anti-protease)
Presentation	Capsules 150mg, 200mg
Dose	<p>Adults:</p> <p>1 dose per day of one of the following possible combinations:</p> <ul style="list-style-type: none"> • ATV + RTV: 2 capsules 150mg atazanavir + 1 capsule 100mg ritonavir • ATV + RTV + EFV: 2 capsules 150mg atazanavir + 1 capsule 100mg ritonavir + 3 capsules 200mg or 1 capsule 600mg efavirenz • ATV + FTV: 2 capsules 200mg atazanavir + 6 capsules 200mg FTV (saquinavir soft-gel) • ATV + RTV + TDF: 2 capsules 150mg atazanavir + 1 capsule 100mg ritonavir + 1 tablet 300mg tenofovir
Food	To be taken during a meal. Do not take grapefruit juice at the same time as atazanavir
Main side effects	<p>At the start of treatment:</p> <p>Possibility of skin problems at the start of treatment</p> <p>Atazanavir can cause jaundice (yellow colouring of the skin or eye, caused by an increase in levels of bilirubin in the blood); this is not harmful</p> <p>During treatment:</p> <ul style="list-style-type: none"> • Diarrhoea, nausea, abdominal pain • Headache, fatigue
Interactions with other drugs	Many interactions with other drugs
Interactions with other ARVs	<ul style="list-style-type: none"> • Atazanavir increases the concentration of saquinavir in the blood • Ritonavir increases the concentration of atazanavir in the blood (atazanavir and ritonavir are often used together) • Efavirenz, nevirapine and tenofovir reduce the concentration of atazanavir in the blood
Storage	Room temperature

Adapted from information provided by: AIDES, AIDSMEDS.COM and JSI-DELIVER

Fact sheets on ARVs available in 2006

Indinavir/IDV AVIRODIN®; CRIXIVAN®; INDIVIR®; INDIVAN®	
Category	PI – Protease inhibitor (anti-protease)
Presentation	Capsules 400mg, 333mg, 200mg
Dose	<p>Adults:</p> <ul style="list-style-type: none"> 2 capsules 400mg per dose, 1 dose every 8 hours (3 doses per day), take when the stomach is empty, at least 1 hour before or 2 hours after eating <p>There are several other possible doses that can be prescribed, sometimes with ritonavir</p> <p>Children:</p> <ul style="list-style-type: none"> 500mg/sq.m. per dose, 1 dose every 8 hours <p>When used with ritonavir, 600mg/sq.m. indinavir + 100mg/m² ritonavir</p>
Food	<ul style="list-style-type: none"> Indinavir must be taken on an empty stomach Indinavir must be taken with plenty of water (3 to 4 glasses of water during the half hour after taking a dose) in order to prevent kidney stones or 'gravel' in the urine For general health, drink 2 to 3 litres of water per day
Main side effects	<p>At the start of treatment:</p> <ul style="list-style-type: none"> Tiredness Nausea, serious vomiting, diarrhoea <p>These side effects are common at the start of treatment, but they usually happen less often as treatment continues</p> <p>During treatment:</p> <ul style="list-style-type: none"> Dryness of skin, sore lips 'Gravel' in the urine, or kidney stones. Kidney stones can cause pain in the middle of the back or in the bladder (lower abdomen), or sometimes in the testicles (men), and sometimes blood in the urine. Consult the doctor Ingrowing toe nails Loss of beard or body hair, sometimes loss of hair on the head Increased fat and sugar in the blood (triglycerides, cholesterol, glucose) Accumulation of fat on the abdomen, breasts, neck Loss of fat on the limbs, cheeks, hips or thighs
Interactions with other drugs	Many interactions with other drugs
Interactions with other ARVs	<ul style="list-style-type: none"> Nelfinavir and other ARVs increase the concentration of indinavir in the blood Nevirapine and efavirenz reduce the concentration of indinavir in the blood
Storage	Protect from moisture

Adapted from information provided by: AIDES, AIDSMEDS.COM and JSI-DELIVER

Nelfinavir/NFV VIRACEPT®

Category	PI – Protease inhibitor (anti-protease)
Presentation	<ul style="list-style-type: none"> Tablets, 625mg, 250mg Powder to mix with oral liquid (such as juice), 50mg/1g
Dose	<p>Adults:</p> <ul style="list-style-type: none"> 2 tablets 625mg per dose, 2 doses per day OR 3 tablets 250mg per dose, 3 doses per day OR 5 tablets 250mg per dose, 2 doses per day <p>Children:</p> <ul style="list-style-type: none"> 50 to 55mg/kg per dose, 2 doses per day OR 25 to 30mg/kg per dose, 3 doses per day
Food	Nelfinavir must be taken in the middle of a meal, which improves absorption of the drug into the body. For the morning dose it is therefore important to have an adequate breakfast
Main side effects	<p>At the start of treatment:</p> <ul style="list-style-type: none"> Tiredness Nausea, vomiting, diarrhoea Skin rashes <p>These side effects are common at the start of treatment, but usually become less frequent as treatment continues</p> <p>During treatment:</p> <ul style="list-style-type: none"> Diarrhoea (frequent, sometimes serious) Bloating of the abdomen, nausea, flatulence Increased fat and sugar in the blood (triglycerides, cholesterol and glucose) Build-up of fat on the abdomen, breasts, neck Loss of fat on the limbs, cheeks, hips or thighs
Interactions with other drugs	Many interactions with other drugs
Interactions with other ARVs	Indinavir, efavirenz and some other ARVs increase the concentration of nelfinavir in the blood
Storage	Room temperature

Adapted from information provided by: AIDES, AIDSMEDS.COM and JSI-DELIVER

Fact sheets on ARVs available in 2006

Ritonavir/RTV NORVIR®	
Category	PI – Protease inhibitor (anti-protease)
Presentation	<ul style="list-style-type: none"> • Capsules, 100mg • Oral solution, 80mg/ml
Dose	<p>Adults:</p> <ul style="list-style-type: none"> • 6 capsules 100mg per dose, 2 doses per day (this dose is rarely used, because full doses of ritonavir are difficult to tolerate) • Ritonavir is more often used to improve the effects of other protease inhibitors, using 1 to 4 capsules ritonavir per dose, 2 doses per day <p>Children:</p> <ul style="list-style-type: none"> • 350 to 400mg/sq.m., 2 doses per day (do not exceed 600mg twice per day)
Food	Ritonavir should be taken during a meal
Main side effects	<p>At the start of treatment:</p> <p>Ritonavir is better tolerated if a low starting dose is given, which is gradually increased to full dose over 14 days</p> <p>Adaptation to this drug takes place over 4 to 6 weeks. During this time, side effects are common, including: tiredness, nausea, vomiting, diarrhoea</p> <p>During treatment:</p> <ul style="list-style-type: none"> • Digestive problems (nausea, vomiting, diarrhoea) • Increased fat and sugar in the blood (triglycerides, cholesterol and glucose) • Tingling sensations around the mouth, loss of ability to taste • Tingling ('pins and needles') in the feet and hands (peripheral neuropathy)
Interactions with other drugs	Many interactions. Do not use with anti-TB drugs
Interactions with other ARVs	Ritonavir increases the concentration of other protease inhibitors in the blood. It also increases the blood concentration of efavirenz
Storage	Store capsules in a refrigerator if room temperature exceeds 25°C. However, do <i>not</i> store the oral solution in a refrigerator

Adapted from information provided by: AIDES, AIDSMEDS.COM and JSI-DELIVER

Saquinavir/SQV-SG or FTV FORTOVASE®

Category	PI – Protease inhibitor (anti-protease)
Presentation	<p>Capsules (soft gel), 200mg</p> <p>Note Fortovase and Invirase (see below) contain the same drug but they act differently in the body – so do not substitute one for the other except when planned with the doctor</p>
Dose	<p>Adults:</p> <ul style="list-style-type: none"> • 6 capsules 200mg per dose, 3 doses per day, OR • 8 capsules 200mg per dose, 2 doses per day <p>Other doses are used, depending which other ARVs are included in the regimen</p> <p>If 3 doses per day are taken, the time between the evening and morning doses should be 8 hours; this means having a late evening meal and an early breakfast</p> <p>Children:</p> <p>Usually used along with another protease inhibitor; for example nelfinavir: 50mg/kg saquinavir + 55mg/kg nelfinavir</p>
Food	Saquinavir must be taken during a meal or just after
Main side effects	<p>At the start of treatment:</p> <p>Tiredness, digestive problems</p> <p>During treatment:</p> <ul style="list-style-type: none"> • Digestive problems • Increased fat and sugar in the blood (triglycerides, cholesterol and glucose)
Interactions with other drugs	Many interactions with other drugs
Interactions with other ARVs	<ul style="list-style-type: none"> • Ritonavir, Kaletra and nelfinavir increase the concentration of saquinavir in the blood • Nevirapine and efavirenz decrease the concentration of saquinavir in the blood
Storage	Store capsules in a refrigerator if room temperature exceeds 25°C

Adapted from information provided by: AIDES, AIDSMEDS.COM and JSI-DELIVER

Fact sheets on ARVs available in 2006

Saquinavir/SQV INVIRASE®	
Category	PI – Protease inhibitor (anti-protease)
Presentation	<ul style="list-style-type: none"> Tablets, 500mg Capsules (hard gel), 200mg <p>Note Invirase and Fortovase (see above) contain the same drug but act differently in the body. Do not interchange them</p>
Dose	<p>Adults:</p> <p>Invirase is usually used along with low-dose ritonavir</p> <ul style="list-style-type: none"> 2 tablets 500mg + 1 capsule 100mg ritonavir per dose, 2 doses per day (total per day: 6 tabs/caps) 5 capsules 200mg + 1 capsule 100mg ritonavir per dose, 2 doses per day (total per day: 12 capsules) 2 capsules 200mg + 4 capsules 100mg ritonavir per dose, 2 doses per day (total per day: 12 capsules) 8 capsules 200mg + 1 capsule 100mg ritonavir, 1 dose per day (total per day: 9 capsules)
Food	Saquinavir must be taken during a meal or just after
Main side effects	<p>At the start of treatment:</p> <p>Tiredness, digestive problems</p> <p>During treatment:</p> <ul style="list-style-type: none"> Digestive problems Increased fat and sugar in the blood (triglycerides, cholesterol and glucose)
Interactions with other drugs	Many interactions with other drugs
Interactions with other ARVs	Ritonavir, Kaletra and nelfinavir increase the concentration of saquinavir in the blood
Storage	Room temperature

Adapted from information provided by: AIDES, AIDSMEDS.COM and JSI-DELIVER

Tipranavir/TPV Aptivus®

Category	PI – Protease inhibitor (anti-protease)
Presentation	Capsules, 250mg
Dose	Adults: Used along with ritonavir: 2 capsules 250mg tipranavir + 2 capsules 100mg ritonavir per dose, 2 doses per day
Food	Tipranavir must be taken during a meal or just after
Main side effects	<p>At the start of treatment:</p> <ul style="list-style-type: none"> • Tiredness • Nausea, vomiting, diarrhoea <p>These side effects are common at the start of treatment, but usually become less frequent as treatment continues</p> <p>During treatment:</p> <ul style="list-style-type: none"> • Increased levels of fat and sugar in the blood (triglycerides, cholesterol and glucose) • Digestive problems • Possible liver problems
Interactions with other drugs	Tipranavir is used along with ritonavir, which interacts with many other drugs that are removed from the body by the liver
Interactions with other ARVs	Tipranavir is used along with ritonavir, which interacts with many other ARVs
Storage	Room temperature

Adapted from information provided by: AIDES, AIDSMEDS.COM and JSI-DELIVER

Fact sheets on ARVs available in 2006

Lopinavir + ritonavir/LPV+RTV KALETRA® ALUVIA®	
Category	PI – Protease inhibitor (anti-protease)
Presentation	<ul style="list-style-type: none"> • Capsules, 133.3mg lopinavir + 33.3mg ritonavir • Oral solution, 80mg/ml lopinavir + 20mg/ml ritonavir
Dose	<p>Adults:</p> <ul style="list-style-type: none"> • 2 tablets per dose, 2 doses per day (do not break, chew or crush the tablets) • 3 capsules per dose, 2 doses per day • 4 capsules per dose, 2 doses per day, if taken with efavirenz <p>If a person has not received any ARV treatment before:</p> <ul style="list-style-type: none"> • 4 tablets per dose, 1 dose per day <p>Children: use oral solution only; do not break or crush adult tablets to provide doses for children.</p> <p>According to body weight:</p> <ul style="list-style-type: none"> • 7 to 15kg: 12mg lopinavir + 3mg ritonavir per kg, twice per day • 15 to 40kg: 10mg lopinavir + 2.5mg ritonavir per kg, twice per day <p>According to surface area:</p> <ul style="list-style-type: none"> • Under 40kg: 230mg lopinavir + 57.5mg ritonavir per sq.m.
Food	<p>Tablets can be taken with or without food</p> <p>Capsules or oral liquid – take with food</p>
Main side effects	<p>At the start of treatment:</p> <p>In the early stages of treatment, some side effects are common: tiredness, nausea, vomiting, diarrhoea</p> <p>During treatment:</p> <ul style="list-style-type: none"> • Digestive problems (nausea, vomiting, diarrhoea) • Increased levels of fat and sugar in the blood (triglycerides, cholesterol and glucose) • Tingling sensations around the mouth, loss of ability to taste • Tingling ('pins and needles') in the feet and hands (peripheral neuropathy)
Interactions with other drugs	Many interactions. Do not use with anti-TB drugs
Interactions with other ARVs	<ul style="list-style-type: none"> • Ritonavir increases the concentration of other protease inhibitors in the blood • Efavirenz decreases the concentration of lopinavir in the blood
Storage	<p>Tablets: not sensitive to heat, keep container closed against humidity</p> <p>Oral liquid or capsules: store in refrigerator; if stored at room temperature use within two months</p>

Adapted from information provided by: AIDES, AIDSMEDS.COM and JSI-DELIVER

Enfuvirtide/T20 FUZEON®

Category	Fusion/entry inhibitor
Presentation	Powder for injection, single-use vial 108mg + 1.1ml vial, water for injection
Dose	<p>Adults:</p> <ul style="list-style-type: none"> 90mg (1ml) injection, subcutaneous (under the skin), into the upper arm, abdomen or upper thigh, 2 doses per day <p>Children:</p> <ul style="list-style-type: none"> 2mg/kg injection, subcutaneous (under the skin), do not exceed 90mg per injection in 2 injections per day
Food	No special requirements
Main side effects	<p>Fuzeon can cause skin reactions at the site of injection, such as reddening, pain, small swellings, hardening of skin. Also, avoid injecting in sites where there is risk of irritation. Avoid areas 2 to 3cm around the navel</p> <p>General side effects:</p> <ul style="list-style-type: none"> Headache Pain and numbness in the feet and legs Insomnia Loss of appetite Muscle pains Constipation
Interactions with other drugs	No interactions known
Interactions with other ARVs	No interactions known
Storage	At room temperature in the original packaging. While the solution for injection is being prepared, it must be stored in a refrigerator, up to a maximum of 24 hours (some time is needed for the powder to dissolve properly in the water)

Adapted from information provided by: AIDES, AIDSMEDS.COM and JSI-DELIVER

Fact sheets on ARVs available in 2006

Stavudine + Lamivudine + Nevirapine (3TC + NVP + d4T) TRIOMUNE®; NEBULAM-SN®; TRIVIRO®; TRIVIRO-LS®; TRIVIRO-LNS®; VIROLANS®

Category	Triple combination containing 3 different ARVs from 2 categories (2 NRTIs + 1 NNRTI)
Presentation	Tablets, each containing: <ul style="list-style-type: none"> stavudine 40mg + lamivudine 150mg + nevirapine 200mg OR stavudine 30mg + lamivudine 150mg + nevirapine 200mg
Dose	Adults: 1 tablet per dose, 2 doses per day
Food	No special requirements
Main side effects	See information sheets on stavudine, lamivudine and nevirapine
Interactions with other drugs	See information sheets on stavudine, lamivudine and nevirapine
Interactions with other ARVs	Do not take with zidovudine/ZDV/AZT
Storage	Room temperature

Adapted from information provided by: AIDES, AIDSMEDS.COM and JSI-DELIVER

Lamivudine + Zidovudine + Nevirapine (d4T + ZDV/AZT + NVP) DUOVIR-N®

Category	Triple combination containing 3 different ARVs from 2 categories (2 NRTIs + 1 NNRTI)
Presentation	Tablets, each containing: <ul style="list-style-type: none"> lamivudine 150mg + zidovudine 300mg + nevirapine 200mg
Dose	Adults: 1 tablet per dose, 2 doses per day
Food	No special requirements
Main side effects	See information sheets on zidovudine, lamivudine and nevirapine
Interactions with other drugs	See information sheets on zidovudine, lamivudine and nevirapine
Interactions with other ARVs	Do not take with stavudine/d4T
Storage	Room temperature

Adapted from information provided by: AIDES, AIDSMEDS.COM and JSI-DELIVER

Notes

Examples of prescriptions for ARV triple combinations, with doses relating to weight of patient (for use as “samples” in modules 3 and 4)

Note: Real patients need ARV combinations chosen with the help of their doctor – these examples are only for training activities

Weight of patient	ARV 1	Dosage instructions	ARV 2	Dosage instructions	ARV 3	Dosage instructions
70 kg	3TC 150mg +d4T 40mg +NVP 200mg (triple combination)	1 tablet in the morning 1 tablet in the evening				
37 kg	3TC 150mg +d4T 30mg +NVP 200mg (triple combination)	1 tablet in the morning 1 tablet in the evening				
64 kg	ddl 200mg	1 tablet in the evening Take doses 1hr before or 2hrs after a meal	Abacavir 300mg	1 tablet in the morning 1 tablet in the evening	Indinavir 400	2 capsules in the morning 2 capsules at midday 2 capsules in the evening Take doses 1hr before or 2hrs after a meal. Drink plenty of water
63 kg	ddl 200mg	1 tablet in the morning 1 tablet in the evening Take doses 1hr before or 2hrs after a meal	3TC 150mg	1 tablet in the morning 1 tablet in the evening	Nevirapine 200	1 tablet in the morning 1 tablet in the evening
60 kg	AZT 300mg +3TC 150mg (double combination)	1 tablet in the morning 1 tablet in the evening	Nelfinavir 250mg	3 tablets in the morning 3 tablets at midday 3 tablets in the evening		

Weight of patient	ARV 1	Dosage instructions	ARV 2	Dosage instructions	ARV 3	Dosage instructions
62 kg	AZT 300mg	1 tablet in the morning 1 tablet in the evening	3TC 150mg	1 tablet in the morning 1 tablet in the evening	Indinavir 400	2 capsules in the morning 2 capsules at midday 2 capsules in the evening Take doses 1hr before or 2hrs after a meal. Drink plenty of water
62 kg	3TC 150mg	2 tablets in the evening	d4T 40mg	1 tablet in the morning 1 tablet in the evening	Efavirenz 600	1 capsule in the evening at bedtime
54 kg	3TC 150mg	2 tablets in the evening	ddl 200mg	1 tablet in the evening Take doses 1hr before or 2hrs after a meal	Efavirenz 600	1 capsule in the evening at bedtime
54 kg	3TC 150mg	2 tablets in the evening	d4T 30mg	1 tablet in the morning 1 tablet in the evening	Efavirenz 200	3 capsules in the evening at bedtime
54 kg	3TC 150mg	2 tablets in the evening	ddl 200mg	1 tablet in the evening Take doses 1hr before or 2hrs after a meal	Efavirenz 200	3 capsules in the evening at bedtime
54 kg	3TC 150mg	1 tablet in the morning 1 tablet in the evening	ddl 200mg	1 tablet in the evening Take doses 1hr before or 2hrs after a meal	Efavirenz 600	1 capsule in the evening at bedtime
54 kg	3TC 150mg	1 tablet in the morning 1 tablet in the evening	ddl 200mg	1 tablet in the evening Take doses 1hr before or 2hrs after a meal	Efavirenz 200	3 capsules in the evening at bedtime

Examples of prescriptions for ARV triple combinations, with doses relating to weight of patient (for use as “samples” in modules 3 and 4)

Weight of patient	ARV 1	Dosage instructions	ARV 2	Dosage instructions	ARV 3	Dosage instructions
60 kg	AZT 300mg +3TC 150mg (double combination)	1 tablet in the morning 1 tablet in the evening	Indinavir 400mg	2 capsules in the morning 2 capsules at midday 2 capsules in the evening Take doses 1hr before or 2hrs after a meal. Drink plenty of water		
37 kg	AZT 250	1 tablet in the morning 1 tablet in the evening	ddl 200mg	1 tablet in the evening Take doses 1hr before or 2hrs after a meal	Indinavir 400	2 capsules in the morning 2 capsules at midday 2 capsules in the evening Take doses 1hr before or 2hrs after a meal. Drink plenty of water
60 kg	AZT 300mg +3TC 150mg (double combination)	1 tablet in the morning 1 tablet in the evening	Nevirapine 200mg	1 tablet in the morning 1 tablet in the evening		
62 kg	AZT 300mg +3TC 150mg +NVP 200mg (triple combination)	1 tablet in the morning 1 tablet in the evening				
70 kg	AZT 300mg +3TC 150mg (double combination)	1 tablet in the morning 1 tablet in the evening	Efavirenz 200mg	3 capsules in the evening at bedtime		
70 kg	AZT 300mg +3TC 150mg (double combination)	1 tablet in the morning 1 tablet in the evening	Efavirenz 600mg	1 capsule in the evening at bedtime		
76 kg	Abacavir 300mg	1 tablet in the morning 1 tablet in the evening	ddl 200mg	1 tablet in the evening Take doses 1hr before or 2hrs after a meal	Lopinavir 133mg + ritonavir 33.3mg ('boosted' combination)	3 capsules in the morning 3 capsules in the evening Take doses with a meal
62 kg	ddl 400mg	1 tablet per day	Atazanavir 200mg	Two tablets	3TC 150mg	1 tablet per day
55 kg	Tenofovir 300mg	1 tablet per day	Atazanavir 150 mg + Ritonavir 100mg (boosted combination)	2 tablets atazanavir and 1 tablet ritonavir per day	FTV 200mg	1 capsule per day

Notes

Fact sheets on the main side effects of ARVs

(for photocopying, to use in module 3)

Digestive

Bloating, wind or stomach pains	page 141
Diarrhoea	page 142
Dry mouth or changes in taste	page 142
Loss of appetite	page 143
Nausea, vomiting	page 143

Internal

Hepatic (liver) problems	page 144
Kidney stones	page 144
Lactic acidosis	page 145
Pancreatitis	page 145
Lipodystrophy or lipoatrophy	page 146
Muscle pains and weakness	page 146

Nervous system

Peripheral neuropathy	page 147
Fatigue	page 147
Sexual problems	page 148
Sleeplessness	page 148

Skin and nails

Dark blotches, purple marks, spots, allergic rashes on the skin	page 149
Other skin, hair or nail problems	page 150

Side effects of antiretrovirals

Bloating, wind or stomach pains

What is it?	<p>Due to difficulties in digestion, gas (wind) develops in the gut. This causes:</p> <ul style="list-style-type: none"> • bloating, which is swelling of the abdomen and/or stomach • sharp 'gripping' pains in the abdomen
Which ARVs can cause it?	<p>Bloating and wind protease inhibitors, especially Indinavir or Nelfinavir</p> <p>Stomach pains Zidovudine, protease inhibitors at the start of treatment</p>
What should a person do about these effects?	<p>For bloating and wind</p> <ul style="list-style-type: none"> • ask the doctor for advice • drugs that alleviate bloating and gas can reduce absorption of other drugs in the intestine and reduce their effectiveness <p>For stomach pains</p> <ul style="list-style-type: none"> • take antispasmodic drugs in early stages of ARV treatment, especially if using protease inhibitors <p>If strong pains suddenly occur during a treatment that is well tolerated, inform their doctor immediately</p>
How can a person prevent or reduce these effects?	<p>For bloating and wind</p> <ul style="list-style-type: none"> • identify and avoid foods and drinks that make bloating worse (for example, cabbage, onions, peppers, chillies, carbonated drinks, coffee, alcohol, very spicy food and sometimes milk) • eat while sitting down • chew food well • if possible, take physical activity, especially walking

Fact sheets on the main side effects of ARVs

(for photocopying, to use in module 3)

Side effects of antiretrovirals

Loss of appetite	
What is it?	A person on ARVs should eat properly in order to recover quickly and make treatment work well
Which ARVs can cause it?	Loss of appetite can be caused by several ARVs, especially when starting or changing treatment It can also happen if a person is depressed or has pains in the mouth which make it hard to eat
What should a person do about these effects?	<ul style="list-style-type: none"> • Check with the doctor to find out if the loss of appetite might be due to the drugs that the person is taking • Talk to a counsellor if depressed • Do not stop taking ARVs
How can a person prevent or reduce these effects?	<ul style="list-style-type: none"> • Choose tasty food for a balanced diet • Avoid sweets and coffee • Eat smaller, more frequent meals

Side effects of antiretrovirals

Nausea, vomiting	
What is it?	Nausea and vomiting are common signs of illness or disturbance in the body. They can be caused by food, anxiety or some drugs
Which ARVs can cause it?	Zidovudine, Combivir, Didanosine (caplets in particular), Indinavir, Nelfinavir
What should a person do about these effects?	<ul style="list-style-type: none"> • Ask the doctor for advice • The doctor might prescribe anti-nausea medication such as metoclopramide. It is important not to take such drugs without advice and not to take more than prescribed • Do not take anti-acid medicines with protease inhibitors (indinavir, nelfinavir)
How can a person prevent or reduce these effects?	<ul style="list-style-type: none"> • Drink several mouthfuls of cold carbonated drink or lemon water in the morning when waking and before meals • Drink mint tea or boiling water containing a small piece of peeled ginger • Eat small but more frequent meals • Eat more cold than hot meals • Avoid spicy or fatty foods • Limit consumption of coffee, cigarettes and alcohol • Do not go to bed immediately after eating • Keep a few dry biscuits next to the bed and eat one or two before getting up in the morning <p>Note If vomiting occurs some hours after taking a dose, do not repeat that dose again, just take the next dose at the correct time</p>

Side effects of antiretrovirals

Hepatic (liver) problems

What is it?	Inflammation and other disorders in the liver. Symptoms can include: <ul style="list-style-type: none"> • increase in transaminase enzymes in the blood • in severe cases, jaundice
Which ARVs can cause it?	Many drugs can affect the function of the liver. These include ARVs, especially Nevirapine and Efavirenz The function of the liver is also affected by some natural or traditional drugs, excessive alcohol and the hepatitis viruses (A, B, C etc)
What should a person do about these effects?	<ul style="list-style-type: none"> • Ensure that the doctor checks the liver regularly, usually at the start of treatment and at the same time as checking the CD4 count • The patient must always inform the doctor if they are taking any other medication, including traditional remedies, as these can also affect the liver • If the person has a hepatitis virus, regular blood tests must be done to monitor the liver • If the level of transaminase enzymes increases too much, the doctor may decide to halt a treatment and prescribe another
How can a person prevent or reduce these effects?	Healthy eating and drinking is essential for having a healthy liver: <ul style="list-style-type: none"> • avoid too much alcohol, smoking or fatty foods • do not take other medications when taking ARVs unless the doctor has said it is alright

Side effects of antiretrovirals

Kidney stones

What is it?	Small stones formed from crystals, which develop inside the kidneys Symptoms can include: <ul style="list-style-type: none"> • intense pain in the base of the spine that radiates to the bladder • blood in the urine
Which ARVs can cause it?	Indinavir is removed from the body through the kidneys, where it sometimes forms stones
What should a person do about these effects?	<ul style="list-style-type: none"> • Consult the doctor • The doctor might prescribe an antispasmodic drug such as Buscopan and a pain-killer, usually an anti-inflammatory
How can a person prevent or reduce these effects?	<ul style="list-style-type: none"> • Drink two to three litres of water or other liquids per day, starting with three to four glasses during the half-hour following each dose of Indinavir. This can be any liquid except alcohol, coffee, tea and milk, which can cause other problems • Avoid drinking more than the recommended amount, because this might cause loss of nutrients from the body through the urine

Fact sheets on the main side effects of ARVs

(for photocopying, to use in module 3)

Side effects of antiretrovirals

Diarrhoea

What is it?	Some ARVs can stimulate the gut to move too quickly, resulting in diarrhoea
Which ARVs can cause it?	Didanosine (tablets in particular), Nelfinavir, Indinavir Diarrhoea is common at the start of ARV treatment, but it disappears after some weeks. It might continue when taking a drug such as Nelfinavir. Some opportunistic infections or HIV itself can also cause diarrhoea. If diarrhoea persists, consult a doctor
What should a person do about these effects?	<ul style="list-style-type: none"> • Treat diarrhoea quickly, because it can cause dehydration. It can also cause loss of weight and loss of important nutrients from the body • If the diarrhoea happens when starting ARV treatment, use an anti-diarrhoea drug to stop it, such as loperamide. Such drugs should not be used for more than three days without consulting a doctor • If the diarrhoea continues even when taking an anti-diarrhoea drug, it might be caused by an infection, so a doctor might prescribe antibiotics • If an ARV causes persistent diarrhoea that cannot be controlled, a doctor might decide to change the ARV treatment
How can a person prevent or reduce these effects?	<ul style="list-style-type: none"> • Drink two to three litres of liquids during the day. Have soups and unchilled sugared carbonated drinks (sodas) because these will help to replace the minerals lost through diarrhoea (open soda some minutes before drinking to allow gas to escape) • Avoid large amounts of tea, coffee, alcohol and milk, which make food pass more quickly through the gut • Avoid fats and sugary foods • Eat helpful foods such as oats, yoghurt, bananas, rice, rice water, cooked carrots

Side effects of antiretrovirals

Dry mouth or changes in taste

What is it?	Producing saliva is important for making it easier to chew food and to protect teeth from decay. A bad taste in the mouth can discourage eating
Which ARVs can cause it?	Dry mouth: several drugs, including ARVs, can cause a decrease in the production of saliva. This increases the risk of tooth decay Change in taste: ARVs, especially protease inhibitors, can sometimes change a person's ability to taste and give the impression of having a bad taste in the mouth
What should a person do about these effects?	<ul style="list-style-type: none"> • For a dry mouth, consult the doctor, who might be able to prescribe a drug to increase secretion of saliva • Zinc supplements sometimes help to improve the sense of taste
How can a person prevent or reduce these effects?	<p>For a dry mouth</p> <ul style="list-style-type: none"> • Chew chewing gum to stimulate the production of saliva • Drink water frequently <p>For change in taste</p> <ul style="list-style-type: none"> • Eat menthol sweets or chew gum to change the taste in the mouth

Side effects of antiretrovirals

Lactic acidosis

What is it?	<p>A serious disorder of the blood. Effects can include:</p> <ul style="list-style-type: none"> • immense tiredness without any particular reason • sudden loss of weight • digestive problems – nausea, vomiting, loss of appetite • muscular weakness or repeated cramps • stomach pains • breathlessness
Which ARVs can cause it?	<p>Stavudine, Didanosine, Combivir, Zidovudine, Lamivudine.</p> <p>It can occur several months or years after first taking ARV treatment</p>
What should a person do about these effects?	<ul style="list-style-type: none"> • Consult the doctor as soon as possible, especially if treatment has been tolerated well so far • The doctor will order a blood test to measure the level of lactate in the blood. If it is abnormally high, it can mean lactic acidosis • If this is the case, the person must be admitted to hospital and ARV treatment must stop immediately. Treatment can be started with different drugs later after the person recovers
How can a person prevent or reduce these effects?	<p>This is an unexpected and rare side effect. There are no known methods of preventing or foreseeing it</p>

Side effects of antiretrovirals

Pancreatitis

What is it?	<p>An inflammation of the pancreas, which is important for digesting fats and proteins. It can cause a serious infection. Symptoms can include:</p> <ul style="list-style-type: none"> • strong pains in the stomach or back, which start suddenly • diarrhoea • nausea • vomiting
Which ARVs can cause it?	<p>Didanosine</p>
What should a person do about these effects?	<ul style="list-style-type: none"> • Inform the doctor immediately • The doctor will usually take a blood test to measure amylase and lipase. These are enzymes that increase when the pancreas is infected. If there is risk of infection, antibiotics will be prescribed. If an ARV causes persistent diarrhoea that cannot be controlled, a doctor might decide to change the ARV treatment
How can a person prevent or reduce these effects?	<p>When recovering from pancreatitis:</p> <ul style="list-style-type: none"> • avoid fatty foods • avoid alcohol

Fact sheets on the main side effects of ARVs

(for photocopying, to use in module 3)

Side effects of antiretrovirals

Lipodystrophy or lipoatrophy

What is it?	Lipodystrophy is excess fat, which can occur in different places on the body: chest (with women in particular), stomach and neck Lipoatrophy is loss of fat. This can affect the limbs, buttocks and face
Which ARVs can cause it?	Excess fat is mainly caused by protease inhibitors: Indinavir, Nelfinavir etc. Loss of fat is mainly caused by nucleosides (Combivir, Lamivudine, Zidovudine, Didanosine, Stavudine) These problems can appear after several months or several years of treatment
What should a person do about these effects?	<ul style="list-style-type: none"> • Talk to the HIV doctor. Changing treatment can sometimes reverse the changes
How can a person prevent or reduce these effects?	<ul style="list-style-type: none"> • Be active whenever possible • Maintain a balanced diet and avoid becoming overweight • Avoid smoking and alcohol

Side effects of antiretrovirals

Muscle pains and weakness

What is it?	Cramps or weakness in leg muscles
Which ARVs can cause it?	Zidovudine (AZT) and Combivir, which decrease the amount of fat in the blood and can damage muscle cells
What should a person do about these effects?	<ul style="list-style-type: none"> • Take magnesium to limit the effects of cramps • If muscle weakness progresses rapidly or cramps happen very often, along with tiredness, breathlessness or stomach pains, consult the doctor urgently as there is a risk of lactic acidosis
How can a person prevent or reduce these effects?	<ul style="list-style-type: none"> • Take regular, gentle activity • If cramps happen, massage the muscle to relax it

Side effects of antiretrovirals

Peripheral neuropathy

What is it?	These are problems of the nervous system. Symptoms can include abnormal sensations or pain in the feet, tingling, sensations of burning or strange feelings in the legs or feet
Which ARVs can cause it?	Didanosine, Stavudine and, on rare occasions, Lamivudine. Anti-tuberculosis drugs, the HIV virus itself or dietary deficiencies can cause neuropathies. Neuropathies can appear several weeks, months or even years after first taking ARV treatment
What should a person do about these effects?	<ul style="list-style-type: none"> • Consult the doctor immediately • For moderate pain, the doctor might prescribe anti-inflammatory drugs such as ibuprofen or indometacin • For serious nerve pain, the doctor might prescribe an anti-depressant or anticonvulsant which can also control pain • Use complementary treatments, such as B vitamins, magnesium, calcium, massage
How can a person prevent or reduce these effects?	<ul style="list-style-type: none"> • Soak the affected foot in very cold water • Ensure shoes are not too tight • Do not stand or walk for long periods; take regular rests

Side effects of antiretrovirals

Fatigue

What is it?	This is a general feeling of lack of energy or tiredness that occurs even after a long rest. The symptoms often include feeling 'drained' during the day. It can last several days or even longer
Which ARVs can cause it?	ARVs can cause fatigue, particularly at the start of treatment. It takes about one month for the body to get used to the drugs. If fatigue occurs or increases during a treatment that is well tolerated, it is necessary to consult a doctor
What should a person do about these effects?	<ul style="list-style-type: none"> • Inform the doctor • In some cases, the doctor might prescribe vitamins A, B, C and E, as well as magnesium, calcium and selenium • These must never be taken in very large quantities or they will cause problems
How can a person prevent or reduce these effects?	<ul style="list-style-type: none"> • Rest, but do not sleep more than normally needed • Try to maintain a balanced diet, with enough vitamins (for example, from fresh fruit and vegetables) • Avoid coffee and tea in large quantities, as well as alcohol • Be active whenever possible

Fact sheets on the main side effects of ARVs

(for photocopying, to use in module 3)

Side effects of antiretrovirals

Sexual problems

What is it?	<p>Loss of sexual desire</p> <p>Failure to achieve or maintain an erection for men</p> <p>Difficulty in reaching orgasm for women</p>
Which ARVs can cause it?	<p>Many people on triple therapy have experienced such problems, although it is not known exactly why it happens</p> <p>There might also be other causes. These include tiredness, stress, depression, alcohol, smoking and drug use</p>
What should a person do about these effects?	<ul style="list-style-type: none"> • A man with impotence might choose to take Viagra
How can a person prevent or reduce these effects?	<ul style="list-style-type: none"> • Speak to a specialist in sexual issues, such as a psychologist or urologist • Eat well and get enough rest • Reduce alcohol, tobacco or drug use

Side effects of antiretrovirals

Sleeplessness

What is it?	<p>Difficulty falling asleep, or waking in the night and failing to go back to sleep</p>
Which ARVs can cause it?	<p>Efavirenz, especially at the start of treatment</p> <p>Sleeplessness might also be due to many other causes:</p> <ul style="list-style-type: none"> • stress or depression • stimulants such as caffeine, tobacco or alcohol • anxiety about living with HIV or starting or changing treatment • other problems not linked to HIV
What should a person do about these effects?	<ul style="list-style-type: none"> • Inform the doctor • The doctor might decide to prescribe sleeping tablets (to help with sleep) or tranquillisers (drugs to combat anxiety). The choice must take into account possible interactions with ARVs
How can a person prevent or reduce these effects?	<ul style="list-style-type: none"> • Do not sleep longer than needed • Go to bed and get up at set times, because an irregular life can make insomnia worse • Activity every day, preferably soon after getting up from bed • Have smaller meals in the evening so that the stomach is not full when going to bed • Reduce or cut out stimulants such as tea, coffee, alcohol and cigarettes. For example, drink herbal tea in the evening • Try to sit and relax before going to bed • If possible, create an area of calm in the home

Side effects of antiretrovirals

Dark blotches, purple marks, spots, allergic rashes on the skin

What is it?	Marks which appear on the skin after starting ARV treatment
Which ARVs can cause it?	<ul style="list-style-type: none"> Red blotches, purplish marks and spots: Efavirenz, Nevirapine and Delavirdine. These generally appear about two weeks after the start of treatment Allergic reaction on the skin: Nevirapine. This usually appears two to three weeks after starting treatment
What should a person do about these effects?	<p>For red blotches, purplish marks and spots:</p> <ul style="list-style-type: none"> inform the doctor – this type of skin problem can be the result of many other causes as well as HIV or ARV drugs <p>For allergic rashes on the skin:</p> <ul style="list-style-type: none"> inform the doctor this usually disappears and ARV treatment does not need to be stopped in some cases, the doctor might decide to stop Nevirapine and start a different ARV instead for the first two weeks of using Nevirapine, it is vital to take just one 200mg dose. Then, if there are no negative reactions, the doctor will increase the dose to two tablets per day
How can a person prevent or reduce these effects?	<p>For dark blotches, purplish marks and spots:</p> <ul style="list-style-type: none"> it is not usually necessary to use any medication if the doctor thinks there is infection, an antibiotic might be prescribed <p>For allergic reaction on the skin:</p> <ul style="list-style-type: none"> itching can be relieved by using calamine, aloe vera or some other calming lotion on the skin

Fact sheets on the main side effects of ARVs

(for photocopying, to use in module 3)

Side effects of antiretrovirals

Other skin, hair or nail problems

What is it?	Changes in the texture and colour of the skin, hair and finger or toe nails, which can appear some time after starting ARV treatment
Which ARVs can cause it?	<p>Indinavir can cause several problems, such as:</p> <ul style="list-style-type: none"> • dry skin • chapped (sore) lips • change in the texture of head and body hair • loss of body hair • inflammation around the nails • in-growing nails (whitlow)
What should a person do about these effects?	<ul style="list-style-type: none"> • Inform the doctor. The changes might also be caused by the HIV virus itself or other factors • If the problems are very significant and continue for a long time, the doctor might decide to stop prescribing Indinavir
How can a person prevent or reduce these effects?	<p>For dry skin and cracked or sore lips:</p> <ul style="list-style-type: none"> • keep the skin hydrated and keep the lips lubricated • use shea butter or aloe vera cream on the skin

Information adapted from a French publication *Mieux Vivre avec son Traitement Anti-VIH* (AIDES, 2003), available at: www.aides.org/sites/vih-infos/

Notes

Example of an agenda for a training workshop

ARV treatment Community Education & Referral (ACER) project, Zambia: Four-day skills-building workshop, August 2004		
	Day 1	Day 2
9:00 – 10:30	Introduction-workshop Welcome Housekeeping Objectives Introductions Content and methodology Ground rules Expectations	Living with ARV treatment Food and healthy living Living with a chronic condition Treatment for other diseases and relationship to ARVs Changing treatment – why, when, how
10:30 – 10:45	Break	
10:45 – 12:30	ARV basics 1 Action of HIV on immune system Basic information on ARVs – different classes of drugs Names and types of ARVs	Prevention and ARV treatment Why and what needs prevention Prevention for people on ART Talking about sex
12:30 – 13:30	Lunch	
13:30 – 14:45	ARV basics 2 Who should have ARVs and when? Providing information on ARV treatment	Special issues in ARV treatment Differences between men and women PMTCT Children and treatment PEP
14:45 – 15:00	Break	
15:00 – 16:30	ARV basics 3 Providing information on side effects and how to manage them	Adherence 1 What is adherence and why does it matter? Medication beliefs Challenges to adherence
16:30 – 17:00	Materials review groups review existing materials available in country	Materials review groups review existing materials available in country

**ARV treatment Community Education & Referral (ACER) project,
Zambia: Four-day skills-building workshop, August 2004**

	Day 3	Day 4
9:00 – 10:30	Adherence 2 What is non-adherence and why does it matter? How do we know treatment is working? What if treatment seems not to work? Steps to help adherence How can we help in our communities?	Referral and using available services What does referral mean? What kinds of referrals are there? What makes a helpful referral? Referrals – how will we make a two-way system that works for our community and clinic?
10:30 – 10:45	Break	
10:45 – 12:30	Adherence 3 Personal, cultural, social and medical challenges to adherence Dealing with stigma	Technical support needs Community partners Community mobilisers Treatment support workers
12:30 – 13:30	Lunch	
13:30 – 14:45	A treatment-friendly community 1 The ‘treatment journey’ – what is it like to be a person needing treatment (who do they talk to, where do they go, what helps, what gets in the way?)	Materials development What materials do we need for community IEC? What materials do we need for people on ARVs?
14:45 – 15:00	Break	
15:00 – 16:30	A treatment-friendly community 2 How can we make our communities more treatment-friendly?	Next steps Technical support needs Evaluation of training
16:30 – 17:00	Materials review groups develop suggestions on how to create materials around ARV treatment	

Wall chart headings

(for photocopying onto coloured card or paper for activities in modules 1 and 2)

NNRTI

Non-nucleoside reverse transcriptase inhibitors

NRTI

**Nucleoside reverse
transcriptase inhibitors**

P

Protease inhibitors

Fusion or entry inhibitors

Fixed (double or triple) combinations

INN

=

Generic name

Chemical name or abbreviation

Trade or proprietary name

Useful resources

1. **AIDS InfoNet** – US website with a wide range of fact sheets and resources relating to HIV and ARV treatment, in plain language, downloadable, regularly updated, in English and Spanish at www.aidsinfonet.org/factsheets.php
2. **Change Project and ICRW (2003)**. *Understanding and challenging HIV stigma: toolkit for action*. Available at www.changeproject.org/technical/hivaids/stigma.html
3. **International HIV/AIDS Alliance (2005)**. *ARV fact sheets*. Available at www.aidsalliance.org/sw19588.asp
4. **International HIV/AIDS Alliance (2005)**. *What is community engagement for ARV treatment?* Available at www.aidsalliance.org/sw7427.asp
5. **International HIV/AIDS Alliance (April 2005)**. *Community education and referral: supporting adherence to ARV treatment and prevention for people with HIV in Zambia*. Available at www.aidsalliance.org/sw23263.asp
6. **International HIV/AIDS Alliance (October 2004)**. *Voices from Zambian communities – experiences of HIV/AIDS-related treatment in urban and rural settings*. Available at www.aidsalliance.org/sw7434.asp
7. **International HIV/AIDS Alliance and WHO (July 2004)**. *A public health approach for scaling up ARV treatment – A toolkit for programme managers*. Available at www.who.int/hiv/pub/prev_care/en/ARVToolkitE.pdf
8. **International HIV/AIDS Alliance (March 2004)**. *Antiretroviral treatment in Zambia – A study of the experiences of treatment users and health care workers*. Available at www.aidsalliance.org/sw7422.asp
9. **International HIV/AIDS Alliance, WHO, UNAIDS (May 2003)**. *Handbook on access to HIV/AIDS-related treatment: a collection of information, tools and resources for NGOs, CBOs and PLWHA groups*. Available at www.aidsalliance.org/sw7421.asp
10. **International HIV/AIDS Alliance (May 2003)**. *The care and support cellule: an integrated and decentralised approach to care and support for people with HIV in Senegal*. Available at www.aidsalliance.org/sw8152.asp
11. **International HIV/AIDS Alliance (June 2002)**. *Improving access to HIV/AIDS-related treatment – A report sharing experiences and lessons learned on improving access to HIV/AIDS-related treatment*. Available at www.aidsalliance.org/sw7423.asp
12. **World Health Organization (March 2006)**. *Antiretroviral therapy*. Provides access to wide range of web pages and documents, at www.who.int/hiv/treatment/en/index.html
13. **World Health Organization (March 2006)**. *Progress on global access to HIV antiretroviral therapy: a Report on 3 by 5 and beyond*. Available at www.who.int/hiv/progreport2006_en.pdf
14. **World Health Organization (2004)**. *Scaling up antiretroviral therapy in resource-limited settings: treatment guidelines for a public health approach*. Available at www.who.int/hiv/pub/prev_care/en/arvrevision2003en.pdf

Other Alliance resources on HIV care and treatment are available at www.aidsalliance.org/sw7418.asp

To order Alliance publications, please email
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