Training of Trainers (TOT) Handbook

Supporting Parents and Caregivers of Children Living with HIV

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Foreword

Over two million children are living with HIV. Approximately 90% of them live in sub-Saharan Africa, where the majority do not have access to adequate care and treatment. Without access to care and treatment, it is estimated that half of all HIV-positive infants will die before their second birthday (MSF, 2007). Globally, approximately 780,000 HIV-positive children are in need of antiretroviral (ARV) drugs but only 15% have access to them. The slow progress in rolling out treatment for children has frustrated health care professionals and advocates throughout the world. Even more so, because it has been well documented that when children with HIV receive care and treatment, they respond very well and can go on to experience full active lives. There is an urgent need for families, communities and children to call on their leaders and policy makers to enhance access to antiretroviral therapy (ART) for children. Parents and primary caregivers need high quality information about HIV and its impact on children and opportunities to build their knowledge and skills to effectively care for and support children living with HIV.

SAfAIDS, in collaboration with the American Jewish World Services (AJWS) and Firelight Foundation have developed a Regional *Children's HIV Treatment Literacy Toolkit*. The primary aim of the toolkit is to support children living positively or on ART, and to support their parents and caregivers, and others in their “Circle of Care”. The toolkit contains a variety of materials for children, parents as well as primary caregivers and service providers. This Handbook is one of the components of the toolkit and can be used together with the Service Providers’ Manual and pieces of the Children’s Toolkit.

Outline of the Handbook

To a child, parents and primary caregivers are the centre of their life. Their care and dedication to the child is essential to promote a healthy development and a full, active life. For all children, including those living with HIV, a parent or guardian's ability to care for and nurture their children is enhanced by the development of a deep loving bond.

The HIV epidemic has presented a unique challenge to families and communities throughout southern Africa. Rising to this challenge will mean parents and caregivers need to develop the confidence and skills needed to care for their child, whether they are HIV positive or not.

This handbook is intended for trainers or facilitators working with parents and primary caregivers of children living with HIV. It gives guidance, information and activities to build the capacity of trainers and facilitators who work with parents and primary caregivers of children living with HIV, and specifically children who are on antiretroviral therapy (ART). Trainers and facilitators will then be able to transfer skills and knowledge to parents, guardians and primary caregivers, who can in turn take on a more informed and active role in caring for children living with HIV.

The goal of the handbook is to provide trainers and community facilitators with skills and information to support parents, guardians and primary caregivers to:

- Be better informed about the basics of HIV and antiretroviral therapy (ART) for children.
- Know the needs of children living with HIV and those receiving ART.
- Implement or participate in activities to increase the support for children on ART in their communities.

The handbook has six modules, each containing background information and activities to reinforce key concepts. The entire handbook is designed to be covered in five days. This can be shortened depending on the knowledge and skill levels of the participants, as judged by the lead trainer. The modules are as follows:

1. **Introduction to Training**
2. **Children and HIV**
3. **Antiretroviral Therapy for Children**
4. **Caring for a Child on ART**
5. **Caring for the Caregiver**
6. **Taking Action**

The handbook also includes handouts with additional reference material to be used in the training, a proposed training schedule and evaluation tools. Further, it contains guidance for effective facilitation of training sessions. It will be important to go through this information (Annex 1) and to be confident in your skills as a facilitator before you begin your training of trainers.

Terms to Remember

Adherence

Means sticking to, or being devoted to, something. In antiretroviral therapy (ART), adherence involves taking medications in the correct amount, at the correct time and in the way they are prescribed.

AIDS

AIDS stands for '*Acquired Immunodeficiency Syndrome'*. AIDS is the name given to a group of serious illnesses in HIV positive people. AIDS develops when People Living with HIV (PLHIV) are no longer able to fight off infections because of lowered immunity.

Antibodies

These are proteins that are produced by the body in response to an infection. HIV antibodies are specific proteins produced to show that the body has reacted to HIV infection.

Antiretroviral (ARV) medicines

These are medicines that interfere with, or disturb the life cycle of HIV by slowing down the processes that HIV uses to make copies of itself.

CD4 cells

A CD4 cell is a type of cell called a lymphocyte that helps the immune system to stay strong and fight diseases. CD4 cells are also called 'Helper T lymphocytes' and are killed by HIV at a very fast rate.

CD4 cell count

This involves a blood test to tell how well the immune system is doing by finding out the number of CD4 cells in your body.

Complementary treatments

These are forms of treatment that may help repair the immune system or treat opportunistic infections.

Counselling

This is a special form of confidential communication between a patient (such as People living with HIV (PLHIV)) and a service provider in which thoughts, feelings and attitudes are explored to make a person feel good about himself/herself or help him/her to make decisions.

Voluntary disclosure

This refers to when a person shares information about his or her HIV status with other people. A counsellor should help the client to recognise the possible impacts of their decision to disclose.

Full disclosure

This is when PLHIV publicly reveal their HIV status, for example to a family member, friend, support group or to the media. Before clients disclose their HIV status, a counsellor can assist them in thinking about who to tell, and how and when to tell them so they remain in control of what to say and how to say it.

Partial disclosure

This means that PLHIV will only tell certain people about their HIV status, for example, a spouse, a relative, a counsellor or a friend. Counsellors need to help PLHIV to think carefully and prepare themselves for the range of possible outcomes before disclosing their status as they may not be able to control what happens once they have disclosed.

Non-disclosure

This means that PLHIV do not reveal their HIV status to anyone.

Involuntary disclosure

This happens when someone reveals the status of PLHIV without their approval or even without their knowledge. Involuntary disclosure can also occur when PLHIV are forced to reveal their HIV status in the workplace, or for international travel requirements. Most cases of involuntary disclosure happen when PLHIV decide to partially disclose their status and the information is made public by an individual or organisation.

Discrimination

A term used to describe treating other people differently or unfairly because they are HIV positive.

First-line treatment

A term used to describe the first set of ARV drugs given as part of ART. Usually, the set is a combination of three antiretroviral medicines aimed at increasing CD4 counts and decreasing viral load.

HIV

HIV stands for Human Immunodeficiency Virus. This means HIV is a virus that weakens the human immune system.

Immune system

The immune system is a combination of the different parts of our body – the chemicals, cells, tissues and organs that protect the body. The immune system can tell the difference between what belongs to the body and what does not belong. When your immune system is strong, you can fight foreign bodies that enter your body and avoid getting sick. HIV makes the immune system weak and that is why if you are infected with HIV, over time you begin to get sick more often.

Informed consent

The basis of Voluntary Counselling and Testing (VCT), where the decision to take an HIV test is made entirely by the individual being tested.

Non-adherence

The failure or inability of PLHIV to stick to their ARV treatment.

Opportunistic infections (OIs)

These are diseases caused by bacteria, fungi or viruses that take advantage of the weakened immune system in PLHIV.

Parent-to-Child Transmission (PTCT)

This is when HIV positive parents pass HIV to their baby either during pregnancy, at birth or during breastfeeding. Because the virus directly comes from the mother, this is also referred to as mother-to-child transmission (MTCT) or vertical transmission. It is now called PTCT because a baby's HIV status is the responsibility of both parents.

Positive living

A term used to describe steps taken by people living with HIV that enhance their lives and increase their health.

Post-exposure Prophylaxis (PEP)

PEP is treatment with medicines to prevent HIV from developing within the body. This requires taking ARV medicines for a short period after being exposed to HIV. PEP is usually given after an accident, or forced sexual intercourse.

Prevention of Parent-to-Child Transmission (PPTCT)

Methods that help prevent a mother passing HIV on to her baby during pregnancy, child birth or breastfeeding.

Resistance

A term used to describe the ability of HIV to change its structure so that ARV medicines become less effective. The fewer antiretroviral medicines a person is taking, the greater the chance HIV will be able to change. Resistance is the reason why ARVs are usually prescribed as a combination of three medicines.

Safer sex

These are sexual practices that prevent possible contact with infected sex fluids. These include sexual intercourse using a female or male condom, oral sex, non-penetrative sex and mutual masturbation.

Second-line treatment regimen

This is the second group of ARV medications given to people who have developed resistance to first-line ARV treatment, or who experienced treatment failure.

Shared confidentiality

This means sharing certain information with people chosen by the patient.

Stress

A term used to describe feelings of being emotionally, physically or mentally overwhelmed when faced with a certain situation, event or person.

Stigma

This means negative attitudes toward people who are HIV positive.

Support network

A term used to describe people in your life that you can talk openly and honestly with about things that trouble you, and who can offer you suggestions on overcoming your challenges.

Syndrome

This is a collection of signs and symptoms that together give a picture of a particular disease or health condition.

Treatment failure

A term used to describe the failure of ARV medicines to continue preventing opportunistic infections and/or to improve CD4 levels.

MODULE ONE

Introduction to Training

Duration:
3 hours

Required materials:

Flipchart, Name tags,
Sticky stuff, Ball,
A small booklet for
each participant,
Markers.

Session 1: Introductions – Getting to know each other

Purpose:

This session sets the tone and foundation of the training and gives opportunities for participants and facilitators to learn about each other.

Objectives

By the end of this session, participants should:

1. Know something about the backgrounds of other participants, and
2. Share and agree on their expectations from the workshop.

1.1 Introducing participants (15 minutes)

Welcome the participants and introduce yourself, giving some information on your background and experience.

Ball Game

Ask all participants to stand in a circle. Starting with the facilitator, each participant should give their name, their organisation and a brief description of their work. Next, the facilitator starts the ball game by calling out a person's name and throwing the ball to them. The person receiving the ball calls out another name and throws the ball, continuing around the circle until everyone has caught the ball.

1.2 Setting ground rules (15 minutes)

Ground rules will help the participants and facilitator to work well together to achieve the objectives of the training. Some important ground rules include how to raise points in a discussion (by a show of hands) and how to deal with issues which are raised, but not directly related to the topic (to keep sessions focused introduce the 'parking lot' concept).

Ask participants to identify positive behaviours that will help the learning process (e.g. punctuality, attentiveness, working together, respecting others' opinions, confidentiality, sensitivity, listening skills). Record these points on a flip chart and display this at the front of the training room for the duration of the training.

1.3 Expectations (15 minutes)

Each participant will begin the training with a certain set of expectations. It is important for the facilitator to understand the specific expectations of participants and outline what can and can't be achieved in this training. It is also important to align the workshop objectives with those shared by participants.

Ask the participants to work in groups of four to identify their expectations for the workshop (at least three expectations). A representative from each group will be asked to write these on a flip chart and share them with the whole group. These flip charts can then be displayed where they can be viewed throughout the workshop, and reviewed during the wrap-up session on the last day.

Session 2: Introducing the Objectives, Content and Evaluation Methods of the Training

Purpose:

This session gives an overview of important information and concepts for the training to be successful. It gives participants direction on how content and activities will be presented throughout the training.

Objectives

By the end of this session, participants should be able to:

1. Demonstrate an understanding of the goal and objectives of the training;
2. Demonstrate an understanding of the module topics they will be trained on;
3. Describe the various ways the training will be evaluated.

2.1 Objectives of the workshop (15 minutes)

The overall goal of this training is to provide participants with the knowledge and skills to support parents and primary caregivers in improving their care of children on ART.

Introduce participants to the objectives of the training as follows:

The objectives of the training are to:

1. Increase **knowledge** around the basics of HIV, and the support needed by children living with HIV and receiving ART;
2. Address **attitudes** of participants at the personal level and community level, around the support required by children on ART;
3. Equip participants with **problem solving skills** to create a supportive community environment for children living with HIV;
4. Promote the **transfer of skills** from participants to parents and caregivers to support children on ART.

2.2 Training modules (10 minutes)

Each module of this handbook has been developed to address the specific objectives of the training. Using the information at the beginning of the handbook, go through each Module topic with participants, and also draw their attention to the 'terms to remember' listed at the beginning of the handbook. Explain that throughout the training, these terms will be used so participants are encouraged to review the definitions to ensure they get the most out of the training sessions.

2.3 Schedule of training (15 minutes)

Distribute a copy of the proposed training schedule (Annex 2) for participants to review, and explain that they will spend four days covering the content of the manual, while the fifth day will be used for action planning, preparing for training in communities and for practising facilitating in training sessions. Also remember that you as facilitator can adapt this schedule according to the knowledge and skill levels of your participants.

2.4 Introduction to SAfAIDS' Children's Treatment Literacy Toolkit for Communities (30 minutes)

This handbook and training manual for parents and caregivers is designed to work together with a set of materials developed by SAfAIDS that include the *Children's Treatment Literacy Toolkit for Communities*. This toolkit aims to provide knowledge and skills for supporting children as well as parents, caregivers and service providers. Provide each participant with a Toolkit. Also, let participants know that they will each receive a copy of this handbook at the end of training.

Introduce participants to the materials in the CTLT:

- ART Board Game.
- Pack of 20 Kids ART and HIV Quiz Cards.
- Kids' Adherence Calendar and watch.
- Series of 8 Booklets covering the following topics:
    - Bk 1: *Introduction to the children's ART literacy series*;
    - Bk 2: *HIV & AIDS and my treatment*;
    - Bk 3: *My family and my treatment*;
    - Bk 4: *My body and my treatment*;
    - Bk 5: *People who support me with my treatment*;
    - Bk 6: *My daily life and my treatment;*
    - Bk 7: *My future and my treatment*; and
    - Bk 8: *Learning about my treatment can be fun*.
- 3 ART advocacy stickers.
- Interactive poster.
- *Training of Trainers Handbook for Service Providers of Children on ART*.

The participants will probably be very interested in all the materials – so let them know that they will spend time looking at the different materials throughout the training.

Activity 1

To get participants thinking about ART and children at the outset of the training, do a quick run-through of how the ART and HIV Quiz cards could be used. You could set this up as a 'game show' – divide the group into two teams by splitting them down the middle of the room.

Then stand at the front and shout out questions from the quiz cards. Participants on each team should raise their hands when they have the answer and they will get a point for each correct answer. Record the points on a flip chart, but emphasise to participants that this is just meant to be a fun exercise, not to form judgement on their knowledge levels. At the end of this activity encourage participants to read and reflect, throughout the training, on how the materials in the toolkit can be distributed and used within their community.

2.5 Evaluation Tools (15 minutes)

To ensure that the training is meeting the needs of participants as well as its intended objectives, evaluation tools have been developed. Participants will be given an opportunity to evaluate the training they receive by saying how the training helped them, areas of training in the module they found too difficult or too easy, what parts of training they found most enjoyable and how they feel training could be improved. Share and review with participants the evaluation tool and explain that time will be set aside at the end of the training to allow participants to fill in this tool.

Session 3: Understanding the Role of Parents and Caregivers (45 minutes)

Purpose:

The purpose of this session is to get participants to begin thinking about the roles of parents and caregivers of children living with HIV, who they will be going out to support in their communities.

Objectives

By the end of this session, participants should be able to:

1. Define the roles of parents and primary caregivers in the care and treatment of children living with HIV;
2. Identify ways parents and caregivers can ensure their child has optimal support.

Who is a parent or caregiver?

A parent is a father or mother; one who gives birth to and/or nurtures and raises a child. The role of parents varies throughout the life of the child.

A caregiver is someone that takes care of a child. This person may or may not be a relative. They may or may not be the legal guardian of the child. It can be someone who lives with the child or as in the case of many child-headed households, someone who lives near the child, but helps with their daily livelihoods and upbringing.

Parents and caregivers are the centre of a child's life. Their care and dedication is essential to promote a healthy, happy life. For all children, including those living with HIV, a parent or guardian's ability to care for and nurture them is enhanced by the development of a deep loving bond.

This training has been designed to provide participants with the knowledge and skills to support and assist parents with children on ART in their communities. It is important that participants reflect on the role, responsibilities and challenges that parents and caregivers may face in caring for a child on ART. By so doing, participants will be better able to understand how they will be able to help parents and caregivers within their communities.

As a group, ask participants to define what it means to be a parent or caregiver, and record these answers on a flipchart. Next, ask participants for explanations of the role of parents and caregivers with respect to a child who is HIV positive. Some of the responses may include the following:

Role of a parent or caregiver

1. Talk to the child about his/her HIV status and take him/her for testing.
2. Find a programme that will provide treatment.
3. Discuss with the child their readiness to begin ART.

4. Take the child for follow-up visits to the doctor and clinic for health checks and new supplies of pills.
5. Check everyday that the child has taken his/her medication.
6. Make sure the child is eating properly.
7. Motivate the child to take responsibility for his/her illness and treatment.
8. Encourage him/her when (s)he wants to give up ART.
9. Talk about what HIV and ART means for the child.
10. Talk to others in the child's life about their treatment. (e.g. teachers or community workers).
11. Talk about stigma that the child might face and help protect them from stigma and bullying.
12. Talk about the family's beliefs. This helps them see where they belong in the world and to accept their positive status.

If these points are not mentioned, add them to the discussion. Now ask participants to identify which of the tasks, roles and responsibilities may present a challenge to most parents and caregivers.

Activity 2

To help participants understand the difficulties that parents and caregivers face, it is useful to draw on the real-life experiences of people in their communities. Divide participants into four groups. Each group is tasked with discussing for 15 minutes some of the challenges that they have seen parents and care givers in their communities face. Remind participants that they don't need to mention names or to share personal experience that they are not comfortable with, but rather they should just have a general discussion of some of the challenges they have seen in their communities. After 15 minutes, lead a discussion on the challenges, giving participants from each group a chance to give their ideas. Some of the main challenges that parents and caregivers in communities might face include:

- Stigma and discrimination against themselves and their children.
- Difficulties with schools and teachers.
- Difficulties in providing the nutrition and other support their children need.
- Difficulties in helping their young children to understand their illness.

Module Wrap Up

(15 minutes)

To conclude the Module, ask participants to discuss any questions or concerns they have about the training. Is there any additional information they feel they need before training begins? Respond to queries and introduce the following activity:

Homework: Active reflection

A key aspect of the training is the active participation and reflection of participants on how they can go back and transfer the skills and knowledge they gain to parents and caregivers in their communities. To encourage reflection, each participant is asked to keep a diary during the training week.

Provide all participants with a small booklet with a blank cover. Ask participants to decorate the cover and to record an introductory entry on something from the introductory session that has impacted on them personally. Emphasise to participants that:

- Their diaries are confidential;
- Grammar and spelling do not matter;
- They can be creative and record in any format they choose;
- They will be given time at the end of each training day to fill in their diaries;
- As they write things down in their diary, they need to be thinking of a creative way they will share the information and skills they gained with people in their community.

MODULE TWO

Children and HIV

Duration:

6 hours

Required materials:

This module can also be used with:

- The ART board game
- The pack of 20 HIV and ART quiz cards
- Booklet 2: HIV and AIDS and My Treatment in the Children's Treament Literacy Toolkit

Session 1: Basics on HIV and AIDS (1 hour)

Purpose:

The purpose of this session is to review basic facts about HIV and AIDS, its progression as well as methods of transmission and prevention strategies.

Objectives

By the end of this session, participants should be able to:

1. Understand and define HIV and AIDS.
2. Explain, in an easily understood language, how HIV and AIDS affect the body.
3. Correct myths and misconceptions about HIV and AIDS.

Materials required: Copies of Handout 1

This session aims to get participants to a stage where they can easily and simply explain correct basic information about HIV and AIDS. Participants will have different levels of HIV knowledge and experience. The facilitator should anticipate that some will know more than others. This presents an opportunity to learn from each other. Explain to participants that you will give them a brief presentation about some HIV and AIDS basics, which are also included in Handout 1. They will then be tasked with an activity in which they will need to present back this information in a role play scenario. Therefore, even if they think they know the basics, they should pay special attention to this section.

Take several minutes to present to participants the information below, which is also included in Handout 1.

1.1 Definitions: HIV and AIDS

HIV is the Human Immunodeficiency Virus that causes AIDS. It attacks the immune system — the body's defence against disease. HIV is found in blood, breast milk, semen and vaginal fluids. Once a person is infected with HIV, the virus remains in the body of the child or adult for life.

The **immune system** is the body's defence system against diseases. White blood cells called **lymphocytes** play an important role in helping the body's immune system. **CD4** cells are a special type of lymphocyte.

In HIV infection, the virus attacks the immune system. HIV destroys the CD4 cells, and it is the loss of CD4 cells that leads to the weakening of the immune system and which means that people infected with HIV can become sick. **AIDS** is the name given to a group of illnesses in HIV positive people.

AIDS stands for:

- **Acquired** means a disease you get during life rather than one you are born with.
- **Immune Deficiency** means a weakness in the body's immune system.
- **Syndrome** means a group of health problems that make up a disease.

The progression of HIV to AIDS refers to the time from HIV infection to the time when PLHIV develop AIDS. The progression of HIV to AIDS is never the same in every person. The progression of HIV to AIDS consists of six major phases:

1. HIV infection
2. Window period
3. Seroconversion
4. Asymptomatic stage
5. HIV-related illness
6. AIDS

As time progresses, CD4 cells decrease and HIV increases, and when the CD4 count goes down and the virus goes up, more problems arise.

1.2 How is HIV transmitted?

Ask participants for ideas on the ways that HIV is transmitted. Record these ideas on a flipchart. Make sure that all of these methods of transmission are covered:

Unprotected sexual contact

- HIV can be transmitted during unprotected sexual intercourse or through contact with infected blood, semen, cervical or vaginal fluids of an infected person.

- HIV can be transmitted sexually through vaginal sex, oral sex and anal sex.

Blood transmission

- Receiving a blood transfusion.
- Sharing of contaminated needles, syringes, razor blades or other sharp objects.
- Infected blood entering the body through open wounds.

Parent-to-Child Transmission

- Mothers can pass HIV to their babies during pregnancy, during delivery, or after birth, through breastfeeding.
- It is important to note that during this period the infection may pass from the father to the mother and then the child and thus it is known as parent-to-child transmission since it is not only the responsibility of the mother.
- If a pregnant mother is HIV-positive there, is approximately a 1 in 3 chance that her baby will become infected. However, there are ways to decrease this possibility. Mothers can take ARVs and use special feeding practices that will help reduce the chance of passing HIV to a child.

Now ask participants for the ways that HIV is **NOT** transmitted and record these on a flipchart.
These will include:

- Hugging, kissing.
- Shaking hands.
- Breathing the same air.
- Sweat, contact through sport.
- Tears, consoling someone who is crying.
- Toilet seats.
- Food utensils or drinking cups.
- Clothes.
- Public baths or swimming pools.
- Mosquito bites.
- Any biting insect or animal.

1.3 How can HIV transmission be prevented?

To complete the discussion on HIV and AIDS basics, ask participants for the ways that HIV infection can be prevented and record these on a flipchart.

They include:

a) Safer sex

- Correct and consistent use of male and female condoms.
- Abstinence (not having sex at all).
- Having sex in a faithful monogamous (one partner only) or polygamous relationship.
- Avoid having multiple partners and/or casual sex.
- Being aware of your partner's HIV status and taking necessary precautions.
- Non-penetrative sex with no fluid exchange (mutual masturbation, kissing, cuddling).

b) Prevention of Parent-to-Child Transmission (PMTCT)

- Educating parents (both mothers and fathers) about their options, and the implications for the health of the mother and the baby.
- Educating parents on the importance of using condoms to prevent passing the infection to the other partner if only one partner is positive.

Prevent unintended pregnancies among HIV-infected women through family planning

Activity 3

Participants will now have gained, or reminded themselves of a lot of basic information relating to HIV, but it is important for them to have confidence in sharing this information with others. For this activity, divide the group into pairs. One member of the pair will play the role of a traditional leader in their community who has just returned from a meeting with other leaders, where they discussed the issue of members of their communities not having the basic information on HIV and AIDS. The traditional leaders have decided to call meetings in their communities, where they will present this information in a simple way.

Those playing the role of traditional leader should role-play their talk to their partner, and the partner should listen to this talk. After five minutes of role play, the partner can then give the 'leader' feedback on some other points that they could have included in their talk based on the information in Handout 1.

At the end of this role play activity, bring the group back together and lead a debriefing discussion on what were the most important points that each 'leader' presented in their talks with their communities.

Session 2: Children living with HIV (1 hour)

Purpose:

The purpose of this session is to provide knowledge and skills to participants about HIV in children (including transmission, progression and testing).

Objectives

By the end of this session, participants should be able to:

1. Explain how HIV infects and progresses in children.
2. Understand guidelines for testing children living with HIV.

Materials required: Handout 2: Children and HIV

2.1 Facts about Children and HIV

In plenary, distribute Handout 2 and review facts about children and HIV as given below. Take time to respond to any questions or concerns raised by participants.

a) How is HIV transmitted to children?

The majority of children living with HIV are born to parents with HIV. Mothers and fathers can pass on HIV to their newborn children during pregnancy, delivery or breastfeeding.

In developed countries, pregnant women with HIV are given **antiretroviral drugs (ARVs)**, so that they do not pass on the virus to their unborn child but prevention of mother-to-child transmission efforts in developing countries have been far less successful. Some children are infected by HIV through blood transfusions or sexual abuse.

b) What is the progression of HIV in children? Is it the same as adults?

Children experience a different response to HIV infection than adults. This is mainly because a child's immune system is still developing.

About 20% of children develop serious disease in the first year of life. Without treatment, the majority of these children die by age four. The remaining 80% of infected children have a slower rate of disease progression and do not develop serious symptoms of AIDS until school entry or even adolescence.

The key factors responsible for the wide variation in progression of HIV in children seem to be the mother's health and the child's health at birth, in particular:

- The mother's vitamin A level and status of CD4 + T-cells count during pregnancy seems to influence whether a child will experience rapid or slow disease progression.
- Equally, the child's viral load and CD4 + T-cell counts in the first months of life are also indicators.

c) Signs and symptoms of HIV in children

Many children with HIV infection do not gain weight or grow normally. They are often slow to reach important development milestones such as crawling, walking and talking.

Children with HIV tend to experience the usual childhood infections more frequently and more severely than uninfected children. These infections can become life-threatening when accompanied with seizures, fever, pneumonia, recurrent colds, diarrhoea and dehydration.

Like adults with HIV infection, children with HIV also develop life-threatening opportunistic infections (OIs). Ask participants what these infections may be, and introduce:

- **Pneumocystis carinii pneumonia (PCP)** is the leading cause of death in HIV infected children with AIDS.

- **Toxoplasmosis (a parasitic disease):** While this is seen less frequently in HIV infected children than in HIV infected adults, serious bacterial infections occur more commonly in children than in adults.

- A lung disease called **lymphocytic interstitial pneumonitis (LIP),** rarely seen in adults, occurs more frequently in HIV-infected children. This condition, like PCP, can make breathing progressively more difficult and often results in admission to hospital.

- Severe **candidiasis (thrush):** A yeast infection that can cause unrelenting diaper rash and infections in the mouth and throat that make eating difficult, is found frequently in HIV infected children.

- **Chronic diarrhoea**: As children with HIV become more sickly, they may suffer from chronic diarrhoea due to opportunistic pathogens.

d) How can you know if a child is HIV positive?
Similar to an adult, you can only know that a child is HIV positive if a blood test has been done. Unfortunately, the standard HIV test used on adults cannot identify whether a child under 18 months has HIV or not. This is because the standard test measures the amount of antibodies in the bloodstream, yet until 18 months old, an infant's bloodstream carries its mother's antibodies. Therefore, the test will reflect the mother's status and not necessarily that of the child. There are tests available which can identify HIV in a child. However these are very expensive and not available in most developing countries. As a result, many children go undiagnosed or their diagnosis comes too late to treat them.

Activity 4
It is easy to know the signs and symptoms of HIV and opportunistic infections in children. But it is difficult as an adult to think about how a child may feel when they experience these as they may not understand what is happening to them. In this activity, ask participants to write down a sentence that a young child, five or six years old would use to describe how they feel when they experience:

- Many bouts of diarrhoea.
- Thrush in the throat.
- Lung disease that makes breathing difficult.

Give participants 5-10 minutes to write down these sentences and then ask several of them to share what they have written.

Session 3: HIV and TB co-infection in children (1 hour 15 minutes)

Purpose:
The purpose of this session is to provide knowledge and skills to participants about TB and HIV co-infection and its implications for children living with HIV.

Objectives
By the end of this session, participants should be able to:

1. Explain how HIV and TB co-infection affects children living with HIV.
2. Know when to refer a parent or child for testing and treatment of TB.

Materials required: Handout 3: TB and HIV co-infection

3.1 What is TB and HIV co-infection?
Ask participants for their understanding of what it means to be co-infected with TB and HIV, and then present the following information, which is also in Handout 3.

TB can take two forms:

1. Pulmonary - TB affecting the lungs;
2. Extra-pulmonary - TB affecting organs of the body other than the lungs.

TB can only be diagnosed at a health facility and people who have these symptoms should visit a health facility as soon as possible:

- Cough for longer than two weeks;
- Fever that does not go away;
- Unexplained weight loss;
- Severe under nutrition;
- Swollen glands for a long period of time;
- Night sweats.

Other members of the family who should also be encouraged to go for testing where a person is suspected to have TB include:

- **All children under two years** who can have preventive therapy and/or an immunisation (called a BCG vaccine).
- **All children under five years** who can also have preventive therapy.
- **Other household members who have a cough.**

To get participants to review or find out about basic TB information, use the following chart to go through an activity where the facilitator plays the role of a parent or caregiver who has questions on TB, and the participants play the role of service providers, who can give the answers. Use the responses in the chart to add to the responses that participants give you.

3.2 TB co-infection in children living with HIV

Next, ask participants what they think are the key issues around TB/HIV co-infection in children that parents and caregivers should be aware of. Some of these include:

- Tuberculosis presents a serious risk to children's health, particularly if they are suffering from a weak immune system due to HIV infection.
- While the basic principles of TB treatment are the same in HIV positive children, the situation is complicated by drug interactions between ARVs and drugs that are used to treat TB. The interaction can lead to increased risk of side-effects.
- For HIV-positive children who are not yet receiving ARVs, it is recommended that TB treatment ideally be initiated some weeks before ARV treatment. For children who are diagnosed with TB while already receiving treatment, ARV regimens need to be carefully reviewed, and may need to be adjusted in accordance with official guidelines.
- In order to avoid late diagnosis of HIV, it has been suggested that all TB-infected children should be considered for an HIV test.

Key Questions	Responses
1. What is TB and what causes it?	Tuberculosis, or TB, is an illness caused by a germ that is breathed into the lungs. When the lungs are damaged by TB, a person coughs up sputum (mucus from the lungs) and cannot breathe easily. Without correct treatment, a person can die from TB.
2. But can TB be cured?	TB can be cured with the correct drug treatment. The patient must take all of the recommended drugs for the entire treatment time in order to be cured. Drugs for treatment of TB are provided free of charge and treatment can be done without interrupting normal life and work.
3. How does TB spread?	TB spreads when an infected person coughs or sneezes, spraying TB germs into the air. Others may breathe in these germs and become infected. It is easy to pass germs to family members when many people live close together.
4. How can I stop other members of my family from being infected?	Take regular treatment to become cured. Cover the mouth and nose when coughing or sneezing. Open windows and doors to allow fresh air through the home, using a fan.

Activity 5

One issue in communities is that there may be a lack of awareness about TB infection in children and what this can mean. Divide participants into groups and provide them with a flipchart and markers. Their task is to design a poster that will give key messages for their community on how TB is spread, symptoms in children, and what parents can do if they think their child might have TB. The emphasis is on the thought behind the poster and not on the artistic merits. After 20 minutes of 'design time' give each group a chance to briefly present their poster to the rest of the group.

Session 4: Growing-up with HIV (2 hours)

Purpose:

The purpose of this session is to provide participants with knowledge of the developmental needs of children, in particular children living with HIV.

Objectives

By the end of this session, participants should be able to:

1. Identify the developmental needs of children.
2. Explain the special considerations for children living with HIV.
3. Understand the influence of a child's social and cultural environment on their developmental needs.

Materials required: different colour pieces of paper, copies of Handout 4 and 5

4.1 "A child is a child"

A child who is living with HIV is first and foremost a child. Parents have different ways of raising their children but it is useful to think about what ALL children need so that they grow into healthy, happy adults who contribute to our society.

a) Walking the Gallery of A Child's Needs (20 minutes)

Pass out five coloured pieces of paper to participants. Ask participants to write in one or two words the needs of children living with HIV. Emphasise that it should be one idea per paper. Ask participants to stick the coloured pieces of paper on the wall. Once everyone has posted their ideas, ask the group to stand near the wall and review all the ideas.

Ask participants to discuss the following:

- Which of these ideas represent the developmental needs of all children?
- Which are unique to children with HIV?

b) Distribute Handout 4: Speech from Nkosi Johnson. Ask a volunteer from the participants to read the speech by Nkosi Johnson. Ask participants for their initial impressions and then discuss the speech with respect to the development needs of children living with HIV **(20 minutes)**

4.2 Growing UP with HIV (45 minutes)

Introduce participants to the concept of 'families and communities in crisis'. What this refers to is that to fully understand the special needs of a child living with HIV, it is important to understand the social and cultural context of the child, their family and community context. The families and community in which the child lives may be influenced by additional burdens, concerns and challenges.

For example, a child with HIV is most likely to have a mother, father or other family members who are also HIV positive or who have died of AIDS-related illnesses. In high prevalence and countries, communities extended families are struggling with and are often overwhelmed by the vast number of children orphaned by AIDS. Stigma and discrimination remain barriers for families and communities seeking help related to HIV. Children living with HIV, like all children, need a sustained, supportive environment in which they can access quality medical, social, psycho-social, and educational care.

Distribute Handout 5: Growing-up with HIV, and review it together with participants. Go through each of the 10 points that cover the needs of children living with HIV. Ask participants why each of these needs is important, and ask for ways that parents and caregivers could ensure that these needs are met.

Activity 6

One difficulty in working to support children living with HIV is that they may not talk about how they are feeling because they do not know how to express themselves. Adults need to encourage them to talk or to find another way of expressing their feelings and concerns.

Divide participants into **four** groups and assign each group one of the topics below. Each of these topics is a feeling that a child living with HIV may experience and may not be able to talk about. Each group should discuss what this feeling means, and if they were parents, how they would talk to their child about this issue. A recorder in the group should note down **five** key points that the parent would use in talking about this issue, and then present this to the rest of the group.

Group 1

Fear – children may fear death, their own or a carer's, or they may fear pain and suffering, isolation or rejection.

Group 2

Shame – children may feel ashamed because of the sexual nature of HIV transmission and the stigma associated with that. They may also be embarrassed by physical signs of illness such as skin rashes or thin hair.

Group 3

Anger – Anger is one of the hardest feelings to deal with because children are often told not to be angry. They may feel anger towards a parent who has passed the virus on to them but at the same time they love and need that parent so they are very confused about what they feel.

Group 4

Guilt – Children can blame themselves, even when their illness is not their fault. They may have been sexually abused, for which they may see themselves as being responsible. Older children may feel guilty about their sexual behaviour.

Module wrap-up

Following the completion of the four sessions, draw participants' attention to the purpose of the session, which was to provide participants with the knowledge and skills to impart information on:

- The basic facts of HIV and AIDS.
- The effects of HIV infection on children.
- Development needs of children living with HIV.

Respond to any outstanding questions and prepare participants for Module 3.

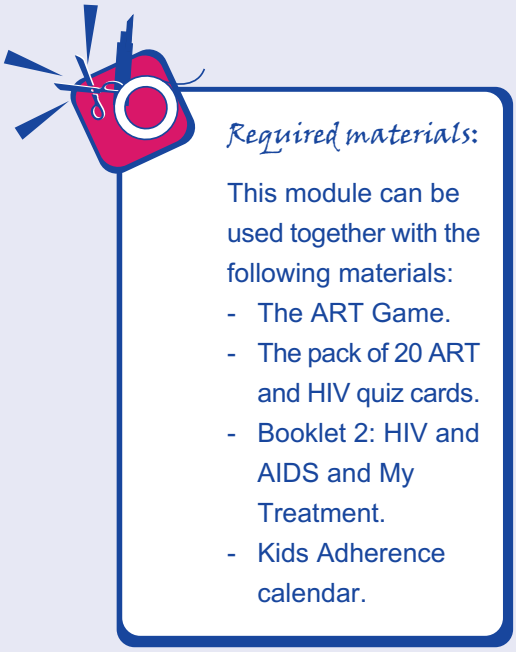
Ask participants to take time as individuals to write and reflect on their learning from the Module in their journals. They should respond to the following questions:

1. What new information did I learn?
2. What information will I share with parents and caregivers in my programmes?
3. What information will I adapt in my own life?

MODULE THREE

Antiretroviral Therapy (ART) for Children

Duration:
6 hours 30 minutes



Required materials:

This module can be used together with the following materials:

- The ART Game.
- The pack of 20 ART and HIV quiz cards.
- Booklet 2: HIV and AIDS and My Treatment.
- Kids Adherence calendar.

Session 1: Basic facts about ART (1 hour)

Purpose:

The purpose of this session is to review basic facts about ART, its goal, benefits and special considerations for adherence.

Objectives

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

1. Define ARV and ART.
2. Describe when a person should begin ART.
3. Explain the importance of adherence to ART.
4. Define positive living.

Materials required: ART Quiz and copies of Handout 6

1.1 ART Quiz (20 minutes)

Participants will have different levels of HIV knowledge and experience. The facilitator should anticipate that some will know more than others. This presents an opportunity to learn from each other. Begin the session by reading out the following quiz. Ask for a show of hands of who thinks each statement is true and who thinks it is false. The correct answers are given below. Give these to participants and encourage them to discuss and debate the statements.

	True	False
ART fights the virus directly	X	
ART can cure HIV		X
If a child is HIV-positive, HIV remains in the child's body	X	
ART helps to protect the child's immune system	X	
All children who are HIV-positive need to be given ART		X
One of the benefits of ART is increased weight gain	X	
Adherence means taking the medicine **exactly** as prescribed	X	
It is OK to miss tablets sometimes		X
The initial side-effects of ART usually last a short time if they are treated	X	
Carers should refer the child to the clinic if there are side-effects from ART	X	

Now move on to the basic information on ART in Handout 6 to clarify the key facts for participants. Encourage participants to read the handout in more detail later.

a) Defining ART and ARV

- **Antiretroviral Therapy** (**ART**) is a term used to describe giving ARV drugs in the correct way, with adherence support.
- **Antiretroviral drugs (ARVs)** are drugs used to treat HIV. Because HIV is a retrovirus, drugs used against HIV are called antiretroviral.

b) How do ARVs work?

ARVs help to stop HIV from making copies of itself (replicating) within the immune system of a child. If HIV cannot replicate, it is unable to damage the immune system and cause opportunistic infections that can lead to the progression of HIV to AIDS.

c) What are the goals and benefits of ART?

The goal of ART is to reduce the amount of HIV in the blood and to increase the number of CD4 cells in the blood as much as possible. ART improves the quality of life of the child.

CD4 and viral load counts are two terms health professionals will use in determining and monitoring someone on ART. **Viral load** is the amount of HIV in a person's blood. **CD4 cells** are a type of white blood cell in your body (called a lymphocyte or T4 cell) that fight infection. The more CD4 cells a person has, the healthier he or she is.

d) When to start ART?

Not everyone who is HIV positive needs to start ART. Different countries have different guidelines on when someone should start ART. For both adults and children, the decision to begin treatment can only be taken after one is tested for HIV and has consulted a health professional.

Activity 7

Parents and caregivers in communities may not be aware of what exactly ART is, and what its benefits are. Ask participants to imagine they are a community-based volunteer in an area where there is very low awareness of ART who is planning to visit a single mother with three children who are all living with HIV, to talk to the woman about her children's health. Participants should make a list of the things they would talk to her about, referring to Handout 6. The essential messages they should be trying to get out are:

- What is ART?
- What are the benefits of ART?

1.2 Adherence

Introduce participants to the concept of adherence by stating that everyone starting treatment needs to be aware that ART is a lifelong commitment. For all those on treatment it is essential to adhere to the treatment regimen. In ART, adherence involves taking medications in the correct amount, at the correct time and in the way they are prescribed. Ask participants to brainstorm around what a person needs to do to adhere to ART, and why it can be difficult. Record the discussion on the flip chart. Some points to cover include:

- Adherence means taking medications to treat other illnesses such as TB, as well as ARVs.
- Adherence means eating and drinking the right things with your pills, as prescribed by the clinical team.
- Adherence is different from simply following instructions.
- Adherence requires commitment and knowledge on the part of PLHIV. It is a partnership between the person taking ARVs, family and friends of PLHIV and the medical system supporting that person.
- Adherence requires the individual to be motivated and dedicated to improving their health. For PLHIV to achieve this motivation, they must understand their treatment regimen and be helped to overcome any challenges

Activity 8

After this discussion, to help participants understand the difficulties of adherence even further, go round the group asking them one by one to complete the sentence 'I think the most difficult thing about adhering to ART is…' Round off this activity by highlighting to participants that there are clearly difficulties in adhering to ART, and these will also be important for children.

1.3 What is positive living?

Positive living is a term used to describe steps taken by someone living with HIV, which enhance their lives and increase their health. Good nutrition, physical activity and prevention of HIV and opportunistic infections are all key components of positive living. Ask participants to brainstorm some of the components of positive living and make sure all of these are covered:

- Maintain a healthy and balanced diet.
- Ensure good personal hygiene and a clean working and living environment.
- Ensure that food is carefully prepared and stored.
- Avoiding new infections (STI, HIV or OI).
- Develop a regular exercise schedule.

Activity 9

To close this session, ask **three** participants to volunteer to each make a sentence about facts on HIV and ART, and in their sentence to include the following words: *positive living, side-effects, adherence, CD4 count and ART.*

Session 2: ART and Children (1 hour)

Purpose:

The purpose of this session is to provide knowledge and skills to participants to enable them to impart information to parents and caregivers of children on ART.

Objectives

By the end of this session, participants should be able to:

1. Give key information about how ART for children is different from ART for adults.
2. Describe the challenges and potential solutions to support adherence in children.

Materials Required: Distribute Handout 7: Children and ART.

Facilitator's note: Prior to the training, collect national guidelines to the use of ARVs in children. Share these with participants in this session.

2.1 Explaining ART for children to parents (30 minutes)

Divide participants into pairs and give them 10 minutes to go through Handout 7, with one member of the pair reading out sections to the other. Then ask the pairs to role play this scenario. Read the following case study aloud.

> Lucy has just begun taking ARVs. She has a three-year old daughter, who has recently been diagnosed with HIV, but has not yet begun ART. While her daughter has not been extremely ill for the past six months, Lucy suggests that she has considered sharing small portions of her ARVs with her daughter to keep her immune system strong. What do you say to Lucy?

After 10 minutes, ask **two** pairs of volunteers to share their role play with the whole group, and note the key issues that come out of the plays on a flipchart. To consolidate this session, summarise the facts on Children and ART from Handout 7:

a) ARV Regimens for children

The ARVs used in the first-line regimen are different depending on the age and weight of the child and will be determined by the clinical team.

The doses of some medications for infants and very young children can be individualised, and therefore, a parent or caregiver should **NEVER** attempt to share their medication with a child.

Children's ARVs may come in liquid or powder form. Others come in a granular form. Some pills can be crushed and added to food or liquids. Some clinics teach children how to swallow pills. Children who can swallow pills have more medication options.

Children's doses are sometimes based on their weight. Another method is body surface area. Several factors affect drug levels in children and hence it is important to anticipate that a child's dosing may have to be adjusted several times as a child develops. A parent should **NEVER** adjust the dose on their own. This should always be done in consultation with a knowledgeable health professional.

b) When to start ART in children

HIV positive parents should always be encouraged to have their children tested for HIV and seek consultation from health professionals on when to start children on ART (if it is necessary). HIV-related diseases show up much faster in untreated children than in adults.

c) Side-effects of treatment

Children respond differently to ARVs. They have larger increases in CD4 cell counts and more diverse CD4 cells. They seem to recover more of their immune response than adults.

Bones develop quickly during the early years of life. ARVs can weaken bones in adults. This has also been seen in children. Children are therefore more likely to experience bone disorders as a side-effect of treatment.

It is essential that parents and caregivers understand the kinds of side-effects that can be caused by ARVs. Before starting treatment, the parent or caregiver should discuss potential side-effects with their health care professional, and closely monitor their child's health to determine minor and major side-effects. Side-effects children may experience include:

- Nausea
- Vomiting and diarrhoea
- Abdominal pain
- Headache
- Fatigue
- Skin rashes
- Loss of appetite

2.2 Helping children adhere to ART

As discussed in the previous section, adherence can be a challenge for adults and for children and one of the main reasons for this is that children may not understand why they should put up with the side-effects of treatment. For parents and caregivers to be able to help their children, they need to understand the side-effects from the child's perspective, so that they can find ways to motivate and encourage them. Before starting ART, parents and caregivers should understand and accept that ARV drugs will cause side-effects and that they should contact their doctor or community health worker if severe or 'major' side-effects are felt and they should NOT change the way they take medications on their own.

Activity 10

For this activity, ask participants to put themselves in the shoes of a five or six-year-old child. Now go round the room for some of the side-effects they might experience (nausea, vomiting, diarrhoea, abdominal pain, etc) and ask participants to finish these statements:

'When I experience… I feel…'
'This makes it difficult for me to take my ARVs because…'

For example:
When I experience nausea, I feel sick and don't want to eat. This makes it difficult for me to take my ARVs because for some of them I need to eat before I take them.

To end this session, lead in brainstorming on how parents can make taking ARVs easier and top tips for reminding children to take their ARVs at the right time. Refer to handout 7 for some ideas.

Session 3: Preparing a child for treatment (1 hour 30 minutes)

Purpose:

To provide knowledge and skills to assist parents and caregivers to adequately prepare a child to begin treatment.

Objectives

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

1. Describe to parents and caregivers the necessary steps for preparing a child for treatment;
2. Explain steps for disclosing one's HIV status to a child.

Materials required: Handout 8: Disclosure

3.1 Starting towards Disclosure

Introduce participants to this session by explaining that disclosure of being HIV positive and taking ART can reduce fears and help a child to understand and take charge of their health, as well as protect others from getting the virus from them. Disclosing also helps families to find the right support. Each child has the right to decide what to tell people, although they can always consult others they trust about what to disclose.

After disclosure, the first step in preparing a child for ART is to designate a caregiver who will guide the child's treatment. The caregiver needs to be informed of:

- The child's HIV status
- What ART entails
- The possible side-effects of medication and interactions
- How to administer and store the medication
- The importance of lifelong adherence

Before starting treatment, the child and the caregivers must be ready to start treatment. The child should agree to cooperate and to take the required medication and the caretaker must be available to administer the ARV medication on a regular schedule.

Activity 11

Ask three volunteers to conduct a role play with the following characters: a child aged 12 years, a mother and a doctor (see role play guidelines).

- The scene is the first appointment with the doctor. Players should cover questions the family need to ask and information the doctor needs to know about the child and family.
- Ask for comments on the role play, with particular reference to how much the child was encouraged to participate and how the information was given.

Next, as a group, discuss the guidelines for disclosing to a child, in Handout 8. Get one participant to read out each of the sections and then spend some time discussing each section – when, who, how, etc. Also go through the tips for disclosing to others in a child's life, and as you go through each point, ask participants if they have any experience through their work or personal life that they would like to share for each point (e.g. someone may have experience of a child's status being disclosed by someone else when they did not want it to be.) Ask for volunteers to share with the group some examples of disclosing that had not gone well, or where they thought it could have been done in a more helpful way.

Session 4: Importance of Good Nutrition and ART (1 hour and 30 minutes)

Purpose:

To provide participants with skills and knowledge on how to assist parents and children living with HIV to maintain good nutrition.

Objectives

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

1. Understand the importance of good nutrition for children on ART;
2. Explain to parents and caregivers the importance of a healthy diet and food safety.

Materials required: Copies of Handout 9; photos or examples of various foods

4.1 Good nutrition and ART

Introduce the session by explaining to participants that a balanced diet is especially important for young children to ensure they grow properly, develop their immune system and are able to fight infection. This is especially true for children infected with HIV and on ART. Good nutrition also increases tolerance of ARV drugs. The general guidelines for nutrition for children with HIV are that if the child is still well give plenty of food; if the child is ill give more fluids. If the child is not well she will not want to eat so give plenty of fluids, including milk, fruit juices and supplement food drinks if the child is able to swallow. Patience, encouragement and good communication help to make sure that children eat what they can, even when they feel ill.

Activity 12

Refer participants to Handout 9 for examples of food groups that comprise a well-balanced diet. Ask each participant to draw one picture of a foodstuff available in their community that would fit into one of the different food groups energy-giving foods (carbohydrates), body-building foods (proteins) and protective foods (vitamins and minerals). Put all the food pictures into a pile. Divide participants into **three** groups. Each group is tasked with putting together different foodstuffs that would combine to make a balanced diet. At the end of five minutes the group with the most combinations will be the winner.

4.2 Food safety for children with HIV

Review the **seven** nutritional goals for children living with HIV in Handout 9. As you go through each goal, ask participants for ways that parents and caregivers could help to achieve these goals. Find out if there are any additional goals that should be considered, as learnt through the experiences of participants. Highlight goal four and discuss why food safety is important for people living with HIV. Emphasise that bacteria in food or water can have a serious impact on people with reduced immune systems.

Activity 13

Break participants into **five** smaller groups. Each group is assigned to one of the food safety areas in Handout 10 as follows:

1. **Personal hygiene**
2. **Hygiene in the house**
3. **Drinking water**
4. **Food preparation**
5. **Food storage**

Each group is tasked with coming up with a simple and entertaining two-minute song that gives the information on food safety for their section. Participants can imagine that they are a band or group who has been asked to write this song to air on national radio. After 15-20 minutes ask each group to come up and 'perform' their song. Emphasise to participants that it is not about how good they sound; it is just a learning exercise that gives them the chance to be creative and have fun.

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Module Wrap-up

To conclude the module, the facilitator should emphasise that this module aimed to provide participants with the knowledge and skills on the basic facts of antiretroviral Therapy (ART) and the available treatment options for children living with HIV. It also aims to impart skills and strategies on how to give information on ART and to sustain positive living for the child and the parents. Respond to any questions from participants and then introduce the next Module.

Ask participants to take time as individuals to write and reflect on their learning from the Module in their journals. They should respond to the following questions:

1. What new information did I learn?
2. What information will I share with parents and caregivers in my programmes?
3. What information will I adopt in my own life?

MODULE FOUR

Caring for a Child on ART

Duration:
4 hours 45 minutes

Required materials:

During this module refer to the following pieces of the Children's Treatment Literacy Toolkit for Communities:

- Booklet 3: *My Family and My Treatment*
- Booklet 5: *People who Support Me with My Treatment*

Session 1: Circles of Care: Building support systems around the child on ART (45 minutes)

Purpose:

To outline the support systems that a child on ART needs to sustain their treatment and encourage his/her healthy development.

Objectives

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

1. Identify services to link a parent of a child on ART to access different aspects of care.
2. Identify support systems for parents and caregivers of children on ART.

1.1 Identifying the Circle of Care

Ask for a volunteer to act as a child.

- Place them in the centre of the room and ask them who would be their closest support person.
- When they identify the person (e.g. mother) ask for a volunteer to act as the mother.
- Ask the child to place the mother somewhere close.
- Then ask the mother to consult with the child who would be the next support person who could come up, and find a volunteer to play this person.
- Continue the exercise until the child is surrounded by supporters in a circle.
- When the support system is complete ask them how it feels, and ask remaining observers what they see, and what it tells them.

Following this exercise, introduce a discussion around the "circle of care":

Individuals in a child's circle of care can be:

- Family members/friends: partners, parents, siblings;
- Support group members;
- Friends, neighbours, teachers, spiritual guides;
- Community or workplace volunteers;
- Health facility staff;
- Trained community health workers.

It is important to understand that each of these individuals can play a role in supporting the child on ART as well as supporting/assisting the parent or caregiver.

1.2 Building the circle of care

Emphasise that each individual in the child's circle of care will have their individual role and responsibility. Some will overlap, and it is important that those in the circles of care:

1) are trusted by the child and caregiver;
2) understand the health issues;
3) place the child's health and well-being as the highest priority.

Ask participants to take time to list:

- people within their community who they would consider important in the care of a child;
- the kind of information they will share with them after this training course;
- ideas on how to work with parents and caregivers to assist them to identify and build the circle of care of their child.

Activity 14

Draw this diagram of the circle of care on a flip chart and get the groups to copy it onto their flipcharts.

Their task is to spend 15 minutes filling in the roles of each of these different members of the 'circle of care' in the corresponding section of the circle. After this time, bring the groups together and ask them to shout out what they have come up with for each role. Use these points to fill in your diagram at the front of the room, and end the discussion by asking participants what information they would need to share with each person so that they can fulfil their role.

Session 2: Home Care: Managing symptoms (1 hour and 30 minutes)

Purpose:
To provide knowledge and skills to participants to enable them assist parents and caregivers to manage a child's HIV symptoms.

Objectives

By the end of this session, participants will be able to:

a) Give basic information on how to manage symptoms related to HIV.
b) Explain to parents and caregivers when they should seek support from healthcare professionals.
c) Discuss with parents and caregivers the importance of universal precautions when caring for a child on treatment.

Materials required: Handout 11, 12, 13

2.1 Practical tips for carers

Introduce this session by talking about how children who are taking ART require close attention as they may still become ill due to HIV itself, or from reactions to treatment. Children do not always complain of symptoms and parents and caregivers need to look for signs that show they are sick. Because ART does not cure HIV the child remains infected and may still develop some illnesses because the immune system may still struggle to fight infections.

Although ART can significantly improve a child's quality and length of life, there may be some problems that also come with taking this medication that make a child feel unwell. For example, children can develop a rash or a neck ache in reaction to ART. When a child feels unwell she may become very quiet, have no energy to play, not want to talk or eat, may look sick and weak, and only be able to lie still.

Highlight to participants that the role of carers is to help a child on ART to be comfortable and pain-free while ensuring the ART is taken correctly. To do this, they need to assess how the child is feeling. They should also ask their health professional which symptoms are likely to be side-effects of ART and which ones are serious enough to bring the child back to the clinic.

Lead the participants in going over Handout 11 on steps to take when a child is sick, and how to manage symptoms. For each symptom, once you have covered what is contained in the handout, ask participants if they have used any other methods for dealing with these symptoms in their experience.

2.2 Pain Management (20 minutes)

Lead a discussion with the participants based on the following questions:

- Do you think pain is different for children compared to adults?
- How is it different?
- What do you think people believe about how children feel pain?
- Correct any myths.
- What signs in a three-year-old will show he is in pain?
- What can you do to assess pain in a child? Is it physical or emotional e.g. due to the burden of adherence or stigma?
- Apart from painkillers, what can you do to help with pain?

Distribute Handout 12 and review each section with participants by asking one participant to read out each section, and then taking any comments or questions.

Activity 15

It can be especially difficult to treat children living with HIV for pain because they may not be able to explain their pain. It is important that parents and caregivers build their skills in trying to understand the pain their child experiences. Divide participants into pairs. One will role play a young child who is experiencing pain (they can decide what type of pain, where, etc) and the other will role play the caregiver trying to find out about the pain,

The caregiver should use the pain grading system in Handout 12 and the following questions to try and understand the pain:

- Where is the pain?
- What makes the pain better or worse (e.g. hot, cold, darkness, elevation, pressure)?
- What type of pain is it (i.e. stabbing, aching)?

End the activity by getting feedback from participants on how easy or difficult it was to assess the pain in the role play. What does this mean for caregivers? It is important to build listening and observation skills to start to understand a child's pain.

Treating Pain

As outlined in Handout 12, medication and non-medicinal methods of pain control can help children cope with pain. It is important to remember that everyone feels pain and deals with pain differently. The non-medicinal method that works for some children may not work for others.

Activity 16

Divide participants into groups and ask them to discuss the different traditional methods for dealing with pain that they have come across in their communities for 10 minutes. At the end of the discussion, ask groups for their ideas and experiences in using these traditional methods and record the discussion points on a flip chart.

2.3 Universal precautions (45 minutes)

For parents and caregivers, it is important to understand the principles of universal precautions when caring for a child living with HIV.

What are universal precautions?

Universal precautions are simple infection control procedures that reduce the risk of transmitting **infectious agents** through exposure to blood, body fluids and **contaminated medical or other type of equipment** among clients, family members and health care workers. Parents and primary caregivers should take universal precautions when caring for their child, whether they know if they are HIV positive or not. Recognising that touch is important for all children, parents and caregivers need to find ways of maintaining universal precautions but ensuring that the child does not feel isolated. Universal precautions should not make the child feel bad (for example, wearing masks and gloves during caring activities where there is no chance of blood or fluid contact).

Activity 17

In their groups, refer participants to the Universal Precautions that are presented in Handout 13. Their task is to spend 15 minutes designing a simple and clear poster that can get across some of these messages to their community. After 15 minutes, get **two** of the groups to present their posters, and take feedback from the rest of the groups on the posters.

To end off this session, discuss with participants:

- Strategies that parents and caregivers can use to ensure universal precautions do not alienate the child.

Session 3: Addressing stigma and discrimination (1 hour)

Purpose:

To raise awareness among participants about the impact of HIV-related stigma and discrimination.

Objectives

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

a) Give knowledge and skills to parents and caregivers on strategies for addressing stigma and discrimination experienced by their child.

Materials required: From the Children's Treatment Literacy Toolkit for Communities: Booklet 5: *My Daily life and my Treatment*, three advocacy stickers, and the Interactive Poster.

Introduce this session by talking about how some people avoid people who they think are HIV positive. They may openly criticise or blame the parents or the sick person for the illness. This is called **stigma**. This can be very upsetting for a child. Discrimination means that a person with HIV is treated differently, and less favourably, than someone who does not have HIV. Parents and caregivers need to stand up for children if they are being teased, and show that they are there to protect them.

Everything possible needs to be done to keep children in school, especially girls who are often taken out of school to look after someone at home or do the household chores. School gives hope for the future and a chance to mix with others of the same age. If caregivers hear that a child is being rejected at school, they should meet with the teacher and see what can be done in the classroom to stop stigma. Teachers who are trained in dealing with HIV can protect children at school.

Activity 18

Ask participants to think about what they have seen or heard about in their communities with regard to children experiencing stigma and discrimination. Next ask them to write down one word or phrase that sums up what stigma and discrimination mean for children in their communities. Ask for several volunteers to share their word or phrase and to explain to the group why this is significant to them.

Activity 19:

Divide participants into groups. In this activity, they should imagine that they are teachers at a primary school in their community. They have come together for a meeting to talk about how they can support children in their classes by reducing stigma and discrimination. The groups should come up with **five** ways that they can use to reduce stigma and discrimination. These should be simple and practical things they can implement easily. After 15 minutes, allow **two** groups to present to the whole group their ideas, and take feedback from the whole group. Finalise this session by highlighting to participants that everyone in the circle of care has a role in reducing stigma and discrimination, but that parents and caregivers need to be watchful for how stigma and discrimination may be affecting their child.

Session 4: Preparing for death (1 hour 30 minutes)

Purpose:

To present strategies to help parents, caregivers and children living with HIV to consider issues around death and dying.

Objectives

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

1) Discuss the importance of preparing for death and dying.
2) List ways of preparing a child for their own death or that of a loved one.
3) Describe the development of a memory box as a coping strategy.

Materials: Example of Memory Box, and from the CTLT Booklet 7: *My Future and My Treatment*.

4.1 Talking about death and dying

Hand out the story below to participants and ask a volunteer to read it out.

A mother visits her daughter and grandson who is very sick and tells her story. “He was asking me some questions about what is happening to him that I found very hard to answer. I think if I tell him just how sick he is, he will give up and die, but it also doesn’t feel good to lie to him. I am his Grandmother but I don’t know what to say. I wish I could give my daughter some wise advice. Our caregiver visitor has told us that he will ask questions and that we should be honest with him, but how do I stop from crying when he starts talking about his dead father and grandfather and that he thinks he might be like them soon?”

Ask participants to share some of the fears they may have about talking to a dying child about his illness and record these on the flip chart.

Then lead a discussion on talking about death by highlighting that if death is not discussed or prepared for, families can experience great emotional, financial and spiritual distress. It is important for parents and caregivers to accept that death is a normal and natural process, and that the death of people living with HIV should not be a topic of shame or secrecy.

Lead a brainstorming session on some of the ways that parents and caregivers can prepare children for their own death or the death of a loved one, including:

- Be willing to talk and answer questions;
- Help the child feel loved and not alone;
- Ensure that family members are around to play when the child is able;
- Remember that children from about 18 months to five years can have “magical thinking”. They may fear they have somehow caused themselves or others to be ill by being 'naughty'.
- Allow children to express anger or fear and help the child to do so without harming themselves or anyone else;
- Acknowledge that a child's most natural reaction to the idea of death may be denial;
- Allow the child to express fears and ask questions when they are ready;
- Allow children to discuss how they would like themselves or their family member to be remembered.

4.2 Coping strategy - Memory Books and Memory Boxes

Introduce participants to coping strategies as going hand in hand with talking about death. Remembering a person is an important part of acknowledging their life. Memory books and boxes are like a treasure chest of family photographs, letters, stories or documents that help describe the history of a family. Parents and caregivers can create memory books or boxes with their children, family or friends, in which they can include things they want to be remembered and shared. Memory books and boxes are especially important for children. They encourage parents to tell their children important stories and create positive memories for the entire family to share later.

Parents and caregivers can help their children with memory boxes:

- If the child does not read or write well, help them to write down stories or letters they would like to include in the memory box.
- Encourage them to draw pictures to be included.

Activity 20

Ask participants to individually spend **five** minutes thinking about things or stories they would include in a memory box about their family. Encourage participants to write down these ideas in their diary, and explain in written form why each different thing is important to them. They will not be asked to share what they have written with the group, but rather they should spend time reflecting on these things that are significant for them, and why they are so meaningful. By understanding what would be important for their own memory boxes, participants should be able to give parents and care givers ideas and empathy to help them or their children to create memory boxes.

Encourage participants to ask themselves these questions:

- How does it make you feel to remember this thing/story?
- How do you think children in your family would benefit from knowing this story?

Activity 21

Ask participants to get into groups of **three** and practise using sections from Booklet 7 on how to take children and their caregivers and parents through the process of starting and keeping Memory Books.

Session 5: Communicating with children (1 hour)

Purpose:

To provide skills for supporting parents and caregivers to enhance communication/ within a family affected by HIV.

Objectives

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

1. Identify and practice ways of communicating effectively with children living with HIV;
2. Advise parents and caregivers on effective strategies for communicating with their children.

Materials: Handout 14

5.1 Talking and problem solving with children living with HIV

Highlight to participants that talking to children about their thoughts and feelings when they are living with something as life-changing as HIV and ART is an important part of supporting them.

Children need adults to help them process their feelings, such as sadness, frustration, worry or anger. These feelings then get 'stuck' inside where they can become too much for the child, making them sick or depressed. Thoughts and beliefs can become less frightening when they are turned into words and shared with people who understand what we are talking about and want to help us.

Go over Handout 14 with participants on the tips for good communication, and for each tip, ask participants to share some experience they may have of how this can help communication, even if this is not necessarily with a child.

Next, get participants to brainstorm some problems a child may be having, which could be solved through communication. For example:

- Experiencing bullying or stigma at school.
- Worrying that their ART isn't working.

5.2 Other ways of communication

Remind participants that there are many other ways through which they can encourage the child to share their feelings, ideas, thoughts and emotions if they are unable to verbally express themselves. All children enjoy play, so make communication fun. Discuss each of these ways of communicating with participants and ask for their ideas on how they might help children communicate.

Toys

Give the child toys to play with and watch to see the story that he or she makes up. The child may play 'hospitals,' or 'funerals'. The toy may have feelings like anger or sadness or act naughty. You can ask if the child sometimes feels like the doll.

Drawing

If you do not have paper and pencils, the child can draw in the sand with a stick. Her drawing can show you what she is thinking. A picture of a sick person can show what the child understands about the illness. Ask her to tell you about her picture but don't make guesses about what she has drawn.

Story telling

Story telling is a good way to help children. Perhaps use traditional stories or make up a story with the child. For example, start a story about a family with a child on ART and then ask the child to finish the story. If there is more than one child, they can all take turns adding to the tale.

Other Ideas

- Drama can give children the chance to act out real life situations.
- A child can write in a diary or make up a poem or a song. This may appeal to older children.
- Make up games to help get anger out, such as stamping feet, digging the field, beating the ground with a stick, tearing up paper, making mud balls and throwing them as far as they can, kicking a ball or punching a punch bag.

5.3 Listening skills

A very important aspect of communicating with a child (or anyone) is listening. Listening is not always easy and needs practice. It will be useful to teach parents and caregivers that they need to listen to their children more.

Ask for two volunteers to come to the centre of the room. One will be an interviewer and the other will be a child of 12 years.

The facilitator takes the interviewer outside, and explains what is required.

- When the child starts to talk, look at the floor or off into the distance, shift in your seat, clean your nails, and generally look bored. Do not offer any response that encourages the child to carry on talking. Just say 'yes, yes' or 'uh huh' in a bored way.
- After a few minutes start to interrupt them, talking over them if necessary. When they start again, make it difficult for the child to tell you their story.

Return to the room and ask the child to tell a story to the interviewer about something which happened to them in the last few days or weeks. It should be about something interesting but not too serious. Carry out the role play for **five** minutes.

Ask the group to comment on what they have just witnessed and whether they have encountered this in their own lives.

Repeat the role play with different instructions. This time:

- The child will describe in detail what they do for *the first two hours of the day*, from the moment they wake up in the morning.
- The interviewer asks questions about every detail mentioned: what time, what colours, where the water comes from, who else is awake, and so on.

Carry out the role play for **five** minutes

Share the experiences with the whole group. Ask what we can learn from this about asking questions.

Activity 22

Divide participants into pairs. Using all the skills they have learnt in this session about communicating with children, they should role play the following scenario:

'Mary is a 30-year-old woman with two children. The eldest of her children is a girl of 15, Grace, who is outgoing and fun-loving, and has been healthy on ART for the last year. Mary has noticed that Grace's friends have started to talk about boys and relationships, and when this happens, Grace becomes sad and distracted. Mary wants to talk to her about sex and relationships, and what this means for a young girl who is HIV positive.'

After 10 minutes of role playing, bring the participants back together and discuss:

- What were the key points that Mary needed to get across?
- How did it feel to be Grace when Mary communicated with her openly and honestly on this issue?
- What are some of the ways that participants brought the guidelines for good communication into their role play?

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Module Wrap-up

This module aimed to provide participants with the knowledge and skills on the role and responsibility of parents, caregivers and other members in a child's 'circle of care'. It presented strategies for addressing issues of managing symptoms, managing pain, stigma and discrimination and support for children. Ask and respond to any outstanding questions. Conclude the session by reminding participants that parents or caregivers are important because of the direct support they give to the child in their care. And they can be an advocate for better treatment – someone who speaks out to teach and persuade others to provide the right help to the child on ART.

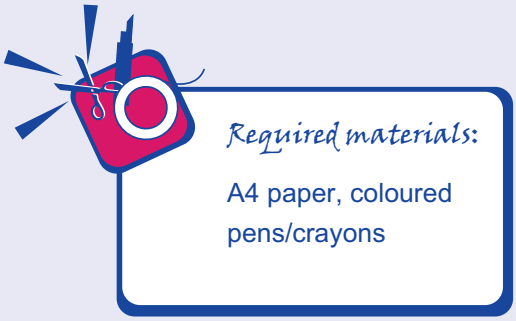
Ask participants to take time as individuals to write and reflect on their learning from the Module in their journals. They should respond to the following questions:

1. What new information did I learn?
2. What information will I share with parents and caregivers in my programmes?
3. What information will I adopt in my own life?

MODULE FIVE

Caring for the Caregiver

Duration:
2 hours



Required materials:

A4 paper, coloured pens/crayons

Session 1: Understanding emotions (30 minutes)

Purpose:
To provide participants an opportunity to reflect on how their feelings and emotions influence their work.

Objectives
By the end of the session, participants will be able to:
1) Describe how personal emotions build and influence an individual's work.
2) Identify methods of sustaining a positive outlook to one's work.

Materials required: A4 paper, coloured pens/crayons

Personal reflection
Ask participants to imagine that we have all our feelings locked tight in a 'feeling bottle'. It has a lid on it and we keep it tight on the mouth of the bottle. But then one day it bursts open, like a bottle of Coke.

We have different feelings at different times and in different places. Feelings come out, for example:
- When we cry
- When we shout
- When we sing
- When we pray
- When we talk with someone

Ask participants to draw a bottle on a blank A4 piece of paper. It should be large enough to fill all the space on the paper. Write these statements/questions out on the flipchart or board.

YOUR "FEELINGS BOTTLE"
- Think of the feelings you have inside you.
- What is the feeling which takes up the most space?
- What are the feelings which burst the bottle more often?
- What feelings are near the top and burst out?
- What feelings lie deep down and are more hidden?

Once they are done with filling in their bottles, ask them to look at the feelings in the bottle. Ask them to explore what the activity made them think and feel, and discuss in pairs how these feelings could affect their work.

Session 2: Facing the challenges of parenting and caring (45 minutes)

Purpose:
To explore challenges and concerns faced by parents/carers in caring for children on ART.

Objectives
By the end of the session participants will:
a. Identify circumstances that complicate caring for children on ART.
b. Identify strategies to overcome challenges faced by parents/carers of children with ART.

What makes it hard to care?
Introduce this topic by asking participants to draw on particular experiences of challenges in caring for children on ART, whether their own or those of others. List these examples on a flipchart. As a group, discuss how a parent's/carer's emotional and physical health influences their burden of care.

Feelings and the care for children on ART
Next discuss how **feelings** can influence the care a child gets. When children need special attention it is all too easy for the carer to forget about their own needs. Care of children needs to be balanced with care of the caregiver in order for that care to be sustained. Parents may be living with the knowledge that they transmitted HIV to the child without realising it during pregnancy, delivery or breastfeeding. Living with guilt can be constantly tiring and depressing. In these situations, we seldom feel that we deserve to be nurtured and cared for, and struggle to show love for ourselves.

Carers may feel unwilling to take care of a sick child that they may feel is forced upon them by circumstances. Sometimes it is difficult not to feel resentful. We have all heard stories of stepmothers or relatives treating children badly, giving them hard work to do, depriving them of food or beating them. This is wrong and unfair to the child.

Ask participants what parents and caregivers can do to deal with these situations. Some ideas to get you started include:

- Get enough support for themselves.
- Talk to someone, for instance others who find themselves in the same position as you about your feelings and see a counsellor if you can.

Health and care of children on ART

Now introduce participants to the idea that the **health** of a carer can influence the care that a child gets. If the carer is also HIV positive, taking ART, or living with another chronic health condition, it is even more important that they look after themselves carefully, especially when they are ill. Carers usually put their own needs last, especially when children require attention. But carers can be role models for the child on how to live with illness, showing them that it is possible to live a normal, happy life even though they are HIV positive. Ask participants what parents and carers can do to support their physical health. Some ideas include:

- Sharing ideas about how to remember to take ART pills.
- Sharing ideas for nutritious meals.

Child carers

Some children live in child-headed households. The eldest child becomes the main carer and takes on responsibilities far beyond their age. This is especially true if they are caring for a sick sibling who is on ART. Emphasise to participants that if they know a family like this, it is important to make sure they get support from their community.

Session 3: "Stress" and finding support for the parent/carer (1 hour)

Purpose:

To provide knowledge and skills to assist participants to support parents and caregivers to identify and deal with risks of caring.

Objectives

By the end of the session participants will:

1. Understand stress and burnout.
2. Identify coping strategies and resources.

Materials required: Handout 15

Introduce participants to the concept of the needs of the carer. When children need special attention, it is all too easy for carers to forget about their own needs. Ignoring their own health and well being is not helpful to anyone in the long term. Care of children needs to be balanced with care of the caregiver in order for that care to be sustained.

HIV lasts for life. Children living with HIV who are able to take ART need special care. This places demands on the carer. Over many months and years, this can be tiring and may wear people down. A regular self-care programme is necessary to help carers avoid feeling frustrated, resentful, exhausted and unable to carry on. If these feelings build up without being released, they may lead to what we sometimes call burnout or stress.

Activity 23

Divide participants into pairs and refer them to Handout 15. In their pairs, they should go through the physical and emotional signs of stress and burnout, and talk about any times in their lives when they have experienced these. They should also talk about what they did to cope with or avoid these feelings and symptoms. Then bring all participants back together and ask them for their ways of dealing with stress and what they would add to the list in Handout 15 of how to prevent or deal with stress and burnout.

Module wrap-up

This final session focuses on recognising the impact of caring on the carer and is aimed at providing participants with the knowledge and skills required to support parents and carers.

As a group, discuss how parents and carers living with HIV in your community are supported by addressing the following topics:

1. How are parents and caregivers currently being provided with support in your community?
2. What are the additional ways that parents and caregivers could be further supported?
3. How can parents and caregivers who do not know their status be supported to make use of HIV testing and counselling services?

Ask participants to take time as individuals to write and reflect on their learning from the Module in their journals. They should respond to the following questions:

1. What new information did I learn?
2. What information will I share with parents and caregivers in my programmes?
3. What information will I adopt in my own life?

MODULE SIX

Action Planning – Committing to Supporting Parents of Children on ART

Duration:
4 hours

Required materials:

Facilitator preparation:

- Make copies of Handout 16 – Hot Issues, Handout 17 – Action Plan
- Flipcharts required for noting down "commitment map"
- Make copies of Workshop Evaluation form

Session 1: "Hot Issues" (45 minutes)

Explain to participants that you are now going to go through an exercise that allows you to prioritise areas for treatment literacy-related support needs of parents/caregivers of children living with HIV or on ART.

Give participants Handout 16, and work through each of the issues in the table until you have reached a group consensus on what issues are 'hot'. Record the top three hot issues on your flip chart, and spend a couple of minutes reviewing why the group thinks they are important and that this is how they should take action.

Session 2: Developing Action Plans

Purpose:

This session will bring participants into the action planning mode for the cascading of information in the parents' handbook to their community, building on hot issues identified in the previous session.

Objectives

By the end of the session participants will:

1. Analyse the opportunities and challenges they may face as they roll out support to parents and caregivers of children on ART;
2. Prioritise the area(s) they have identified for action planning for promoting literacy levels among parents and caregivers;
3. Draft a plan of action for roll-out of knowledge and skills gained through this workshop.

2.1 Identifying challenges and opportunities – 30 minutes

Ask the participants to get into groups of three and identify the possible:

1) Challenges and
2) Opportunities, which they may come across as they cascade the knowledge and skills gained in supporting parents and caregivers of children living with HIV.

After completing their lists, ask all groups in plenary to share their points and list the challenges and opportunities on a flipchart. Together as a group, go over the challenges and drawing on experiences from the participants, discuss possible ways of overcoming each challenge. In this way, emphasise that nothing should hinder or discourage participants from:

- intensively sharing the knowledge and skills they have gained with others (their peers, family, friends, social groups), or
- finding ways to support parents and caregivers of children living with HIV or on ART.

2.2 Drafting the plan (1 hour 30 minutes)

Begin this session with passing out Handout 17 – Action Plan. Go through the section in the action plan table, and explain to participants how you would use it to systematically plan for taking action. Ask participants to get together with other members of their organisation or others who are from their community/area, and together think about the major activities that could be used to promote support and treatment literacy knowledge and skills for parents and caregivers of children on ART.

They can use the template for action planning to guide them to set their plans. Also remind participants that their plans need to reflect:

- The needs in their community, the 'hot issues' around needs of parents and caregivers;
- Practical activities which can be done with the resources available;
- Who they would work with in the community to make their activities work, e.g. women's groups, faith groups, traditional leaders, men's groups, health care workers;
- How the different pieces of the *Children's Treatment Literacy Toolkit for Communities* can be used creatively during planned activities.

Session 3: Commitment sharing

Purpose:

This is the final session of the workshop and is intended to bring participants together as a group committed to the way forward for supporting parents/caregivers of children on ART.

Objectives

By the end of the session participants will:

1. Share their action plans and commitments;
2. Recognise possible linkages and support needed to make their plans a reality.

3.1 Commitment mapping for promoting children's Treatment Literacy among parents/caregivers (45 minutes)

Ask each group to present their action plans. Emphasise that other groups can ask questions on what is presented and offer positive feedback.

As each presentation is concluded, the following should be addressed:

1. What is/are the target(s) for this action plan?
2. Does it address a hot issue for children's treatment literacy and the role of parents and caregivers in their community?
3. Are there possible linkages to other action plans presented?
4. Can others offer a form of support for these plans?

Facilitator's Note: *It is important to collect copies of the draft Action Plans developed by each group for inclusion within the workshop report. This action plan represents your most important output from workshop activities and will be used to guide participants in making targeted use of the training conducted in their communities.*

Facilitators Note *– A Commitment Map: Based on group presentations, facilitators should create a master "commitment map" which lists all the commitments made through action plans and how they are connected. For example, how can organisations/individuals in that community join forces in realising their commitment to promoting Children's Treatment Literacy in the community? This 'map' can be drawn up while groups are presenting their action plans, and then the facilitator can spend 10 minutes at the end of the session highlighting to participants the links between their plans.*

Workshop Closure

Workshop Evaluation: Participants (30 minutes)

Bring the workshop expectations flip chart from Day One to the front of the group and go through the expectations. Participants are asked to answer as a group whether the expectation was or was not met.

Next, ask each participant to complete a workshop evaluation form and collect these forms.

Closing remarks

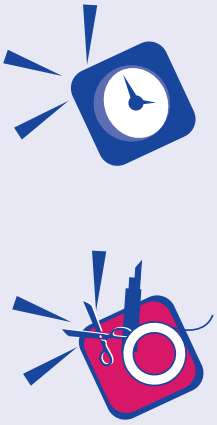
In closing the workshop, thank participants for their enthusiastic inputs and participation and encourage them to share their knowledge and skills with their peers, family members and others in their social circles when they return home.

Ensure that all participants have a complete copy of the *Children's Treatment Literacy Toolkit for Communities*, including a copy of this Handbook. Also ensure that participants have the contact details of the facilitators and other participants to enable them to communicate and support each other.

Facilitator's review meeting: At the end of the final day of workshop activities, facilitators should hold a review meeting to address:

- Workshop successes and challenges.
- Roles and responsibilities for workshop wrap-up (collection of information, writing of workshop report, and so forth).

ANNEXES



Annex 1: Guide for Facilitators

1. Adult learning principles

- Adults prefer learning experiences where they can participate in and influence the learning environment.
- Adults want to learn things that they can apply practically.
- Adults are motivated by knowing the planned outcomes of the learning and by seeing the way the learning will help them to solve specific problems.
- Adults benefit from having an opportunity and encouragement to practice what has been learnt.
- Feedback and reinforcement are critical for the learning to be implemented in practice.

The use of a variety of teaching methods – participatory group work, action role plays and dramas, as well as short presentations of information – is essential to reach your adult learners. As a facilitator, you need to be knowledgeable and comfortable with the material to adapt and respond to the group's needs.

2. Key Methods for Adult Learning

2.1. Guidelines for group work

- Decide how many groups are needed and divide the participants into groups.
- Tell each group what you want them to do. Give out flipchart papers and markers if they need them.
- Explain that each group should appoint a leader and a reporter. The leader is responsible for making sure that each person has a turn to speak, and the reporter takes notes for feedback and writes on the flip chart.
- Be clear how much time is allowed for the work. Be flexible if more or less time is needed.
- While groups are working, walk around and check that they are doing what is needed.
- Get feedback from each reporter, ask for anything extra from that group and then discuss the information with the whole group. This is when the facilitator needs to add in extra information and encourage the participants to think further.

2.2 Role play guidelines

- Once the scene has been set, go straight into the role play to allow it to develop naturally in interacting with the other players.
- Encourage participants to be natural, not to act. The main thing to remember about role plays is that they are an exercise in learning so participants should just try their best to learn from the problem and to have fun!

De-briefing*:*

At the end of a role-play the participants should come back to themselves in real life, especially if the person has acted a sad or worrying part. As a responsible facilitator, you can help them do this by:

- Asking each person who has played a part to stand up one at a time and to say to the whole group: "*I am not …… anymore" (the role played), "I am …… again*" (own name).
- Check that the actor feels alright after playing the part, by asking "*How do you feel now*?"

2.3 Using Energisers as facilitation tools

Energisers are activities which:

- Help people to get to know each other better. They are called '**ice-breakers'** and help people relax around other new people in their group;
- Increase energy and enthusiasm;
- Encourage team building.

Remember when choosing energisers:

- Avoid using competitive games. Use games which encourage appreciation of other people's strengths and abilities.
- Keep it short.
- Try and select an energiser that all your participants can be involved in and is sensitive to their culture and needs (e.g. physically disabled participants).
- Be careful when choosing energisers that involve touching, particularly between the sexes. These may not be appropriate within certain cultures.

Suggestions for energisers are provided in various sections during training, but it is useful to ask the group if they know any fun energisers they would like to conduct during training.

Practical aspects of training for facilitators

This section presents general tips for facilitators that will help to ensure a **successful** and **enjoyable** training experience for everyone.

Before you begin training:

- **KNOW** the topic you are facilitating and review the materials in the toolkit (check your knowledge using the questions in Box 1 below).
- Have a **PLAN** for each session, adding in individual touches you would like to make (e.g. ice-breakers).
- **PREPARE** your session well in advance.
- Learn about your **PARTICIPANTS.**
- Know the **VENUE** for the training and take care of practical considerations (i.e., seats for all participants, adequate supplies, flipcharts, markers etc).
- Have any **HANDOUTS** you might be using ready - with enough copies for each of your participants and some extras just in case.
- Choose your **EQUIPMENT** beforehand and make sure it is all available and working before your session.

Box 1. Check Your Knowledge

1. Do I understand ART and the challenges it poses for children who need treatment?
2. Do I know how it feels to care for a child on ART?
3. What are my own prejudices about ART?
4. Have I taken an HIV test? Am I comfortable talking about HIV?
5. What is the purpose of 'treatment literacy'?
6. Have I got the skills and personality to engage with and train participants in a workshop environment?
7. Is helping children on ART important to me?

During training:

- **FACE** your participants; make eye contact with them if appropriate;
- **SPEAK** audibly and pronounce your words clearly;
- **WRITE** legibly and in LARGE letters - use green, black and blue (avoid using red or bright colours which are difficult to read);
- Keep within your allocated **TIME;**
- Allow time for **QUESTIONS** and **INPUT** from participants;
- **INVOLVE** participants and acknowledge their experience and knowledge;
- **DRESS** appropriately, avoid tight, open and exaggerated clothing, too much make-up or jewellery;
- Do not make insensitive jokes or comments;
- Encourage shy and passive participants to participate.

Annex 2: Proposed Training Schedule

The following is a proposed schedule for implementing a five-day training of trainers. This programme may be altered or tailored depending on the knowledge and skill levels of participants.

Day 1	**Introduction to Training**	
Time	**Activity**	**Preparation**
8:00-8:15	Registration of participants	Registration forms, Participants' folders (name tag, brief on training, some sheets of writing paper)
8:15-11:15	Module 1: Session 1 - Introducing participants - Setting the ground rules - Expectations Module 1: Session 2 - Introducing Goals and Objectives of Training - Training structure overview and evaluation methods Module 1: Session 3 - Understanding the role of Parents and Guardians Session Wrap-up	Any tools used for introductory games e.g. ball, Copies of Handbook, SAfAIDS *Children's Treatment Literacy Toolkit* Evaluation Tools Flipchart
11:15-11:45	Tea	
11:45-1:00	Module 2: Session 1 Basics of HIV and AIDS	Copies of HIV and AIDS Quiz (Blank) and copies of Handout 1
1:00-2:00	Lunch	
2:00-3:00	Module 2: Session 2 Children and HIV	Handout 2
3:00-4:15	Module 2: Session 3 HIV and TB co-infection in Children	Handout 3
4:15-4:45	Questions and Answers from the day, wrap up	
5:00-5:15	Daily Journal Session	
Day 2	**Growing UP with HIV: Children on ART**	
8:00-8:30	Welcome and recap	
8:30-10:30	Module 2: Session 4 Growing-up with HIV	Handout 4 and 5
10:30-11:00	Tea	
11:00-12:00	Module 3: Session 1 Basic Facts of ART	ART Quiz and Copies of Handout 6
12:00-1:00	Module 3: Session 2 ART and Children	Handout 7
1:00-2:00	Lunch	
2:00-3:30	Module 3: Session 3 Preparing a Child for Treatment	Handout 8
3:30-5:00	Module 3: Session 4 Good Nutrition	Handout 9 and 10 Photos or examples of food groups
5:00-5:15	Questions and answers from the day, wrap up	
5:15-5:30	Daily Journal Session	

Continued...

Day 3	**ART: Caring for Children**	
8:00-8:30	Welcome and recap	
8:30-9:15 9:15-10:45	Module 4 Session 1: Circles of Care: Building support systems around the child on ART Module 4 Session 2: Home Care: Managing symptoms	Handout 11, 12, 13
10:45-11:15 11:15-12:00	Tea Module 4: Session 2 Managing Pain Universal Precautions	
12:00-1:00	Module 4: Session 3 Stigma and Discrimination	
1:00-2:00	Lunch	
2:00-3:30	Module 4: Session 4 Preparing for Death	Example of Memory Box
3:30-4:00	Tea	
4:00-5:00	Module 4: Session 5 Communicating with Children	Handout 14
5:00-5:15	Wrap up, Daily Journal Session	
Day 4	**Caring for Carer**	
8:00-8:30	Welcome and recap	
8:30-10:30	Module 5: Session 1 Understanding emotions	
10:30-11:00	Tea	
11.00-1:00	Module 5:Session 2 Facing challenges of parenting and caring	
1:00-2:00	Lunch	
2:00-3:00	Module 5: Session 3 Stress and Parenting	Handout 15
3:00-3:30	Tea	
3:30-4:00	Session Wrap-up	
4:00-4.30	Daily Journal Session	
Day 5	**Action Planning: Preparing for Training**	
8:00-8:30	Welcome and recap	
8:30-10:30	Community Action Plan	Handout 16, 17
10:30-1:00	Practice Sessions - Preparations	
1:00-2:00	Lunch	
2:00-4:00	Practice Sessions - Implementation	
4:00-4:30	Tea	
4:30-5:30	Wrap-Up and Evaluation	

Annex 3: Handouts

Handout 1: Basic Facts about HIV and AIDS

The following reflects the answers for HIV and AIDS quiz

Statement	True	False
AIDS is caused by HIV	X	
HIV is found in blood, semen, breast milk and vaginal fluid	X	
There is no way to prevent parent-to-child transmission of HIV		X
You can get HIV from changing a nappy		X
Once you are infected with HIV you are infected for life	X	
The only way to prevent the spread of HIV is to abstain from sex		X
HIV is spread through coughing and spitting		X
Wearing rubber gloves when wiping up blood prevents transmission of HIV	X	
Good nutrition is important for people living with HIV	X	
HIV can be passed from mother to an unborn child	X	
All babies born to HIV-positive mothers are HIV positive		X

1. Definitions

HIV and AIDS

HIV is the virus that causes AIDS. It attacks the immune system – the body's defence against disease. HIV is found in blood, breast milk, semen and vaginal fluids.

HIV is a virus that attacks the body and makes it weak. When the body is weak, it is easier to get coughs, diarrhoea, fever and other health problems.

The **immune system** is the body's defence system against diseases. White blood cells called **lymphocytes** play an important role in helping the body's immune system. **CD4** cells are a special type of lymphocyte.

In HIV infection, the virus attacks the immune system. HIV destroys the special CD4 cells, and it is the loss of CD4 cells that leads to the weakening of the immune system.

Once a person is infected with HIV, the virus remains in the body of the child or adult for life.

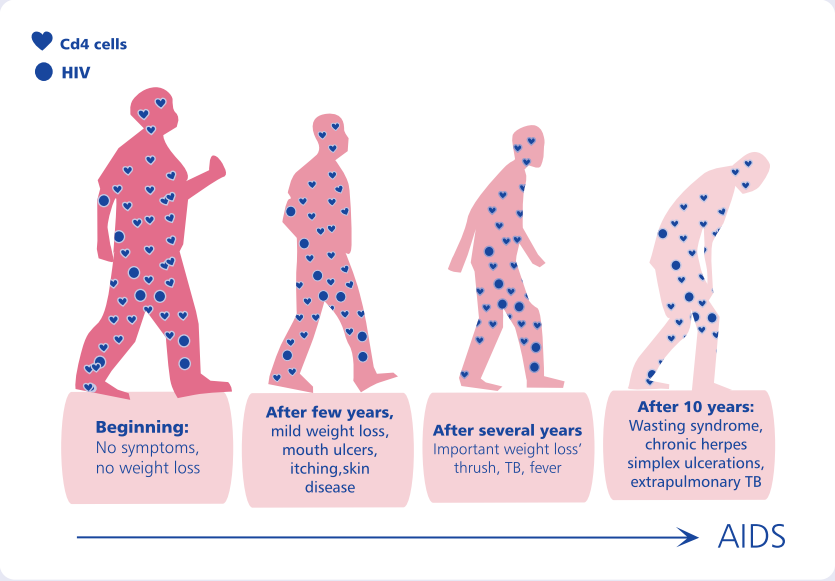
AIDS is the name given to a group of illnesses in HIV positive people. These are illnesses that arise when PLHIV are no longer able to fight off infection because of lowered immunity.

Understanding the acronym:

- **'Acquired'** means a disease you get during life rather than one you are born with.
- **'Immune Deficiency'** means a weakness in the body's immune system.
- **'Syndrome'** means a group of particular health problems that make up a disease.

The progression of HIV to AIDS refers to the time from HIV infection to the time when PLHIV develop AIDS. The progression of HIV to AIDS depends on individual circumstances and environment and is never the same in every person.
The progression of HIV to AIDS consists of six major phases:

1. HIV infection
2. Window period
3. Seroconversion
4. Asymptomatic stage
5. HIV-related illness
6. AIDS



As time progresses, the hearts (CD4 cells) decrease and the circles (HIV) increase. When the hearts go down and the number of circles goes up, more problems arise. When more circles exist, infections become more serious and last longer.

2. How is HIV transmitted?

HIV is transmitted through:

1. Unprotected sexual contact

- This is the most common means of transmitting HIV.
- HIV can be transmitted during unprotected sexual intercourse or through contact with infected blood, the semen, cervical or vaginal fluids of an infected person.
- HIV can be transmitted sexually through vaginal sex, oral sex and anal sex.
- The presence of other Sexually Transmitted Infections (STIs) increases the chance of contracting or transmitting HIV.

2. Blood Transmission

HIV infected blood gains entrance to the body through:

- Receiving a transfusion;
- Sharing of contaminated needles, syringes, razor blades or other sharp objects;
- Infected blood entering the body through open wounds.

3. Mother-to-Child Transmission

- Mothers can pass HIV to their babies during pregnancy, during delivery, or after birth, through breastfeeding.
- If a pregnant mother is HIV-positive, there is approximately a 1 in 3 chance that her baby will become infected. However, there are ways to decrease this possibility. There are drugs called ARVs that HIV-positive mothers can take, and special

feeding practices that will help reduce the chance of a mother passing HIV to her child.

HIV is **NOT** transmitted by the following:

- Hugging
- Kissing
- Shaking hands
- Breathing the same air, coughs, sneezes
- Sweat, contact through sport
- Tears, consoling someone who is crying
- Toilet seats
- Food utensils or drinking cups
- Clothes
- Public baths or swimming pools
- Mosquito bites
- Bed bugs
- Any other biting insect or animal

3. How can HIV transmission be prevented?

The following are factors that decrease the risk of HIV transmission:

1. Safer Sex

- Correct and consistent use of male and female condoms.
- Abstinence (not having sex at all).
- Delaying sex is important in young people who may not be prepared or able to negotiate for safer sex.
- Having sex in a faithful monogamous (one partner only) or polygamous relationship protects partners from contracting or transmitting HIV if they are not exposed to HIV through drugs or other activities.
- Avoid having multiple partners and/or casual sex.
- Being aware of your partner's HIV status and taking necessary precautions.
- Non-penetrative sex with no fluid exchange (mutual masturbation, kissing, cuddling).

2. Prevention of Mother-to-Child Transmission (PMTCT)

PMTCT involves methods that help prevent a mother from passing HIV on to her baby during pregnancy, child birth or breastfeeding. There is a need to:

- **Educate parents** about their options, and the implications for the health of the mother and the baby.
- **Prevent** unintended pregnancies among HIV-infected women. If family planning services are not available at your local clinic, refer the client so that she or he receives proper support and services to prevent unintended pregnancies.
- If only one partner is HIV positive, educate both parties on how important it is to use **condoms** to prevent passing infection to the other partner.

Annex 3: Handouts

Handout 2: Children and HIV

How is HIV transmitted to children?

The majority of children living with HIV are born to parents with HIV. Mothers and fathers can pass on HIV to their newborn children during pregnancy, delivery or breastfeeding. In developed countries, pregnant women with HIV are given **antiretroviral drugs (ARVs)**, so that they do not pass on the virus to their unborn child but prevention of mother-to-child transmission efforts in developing countries have been far less successful.

Some children are infected by HIV through blood transfusions or sexual abuse.

What is the progression of HIV in children? Is it the same as in adults?

Children experience a different response to HIV infection than adults. This is primarily because a child's immune system is still developing. HIV also progresses differently in different children.

Researchers have noted that there are two trends in HIV disease progression in children. About 20% of children develop serious disease in the first year of life. Without treatment, the majority of these children die by the age of four. The remaining 80% of infected children have a slower rate of disease progression and do not develop serious symptoms until school entry or even adolescence.

The key factors responsible for the wide variation in the progression of HIV in children seem to be the mother's health and the child's health at birth, in particular:

- The mother's Vitamin A level and status of CD4 + T-cells count during pregnancy seems to influence whether a child will experience rapid or slow disease progression.
- Equally the child's viral load and CD4 + T-cell counts in the first several months of life are also indicators.

Signs and Symptoms of HIV in Children

HIV infection tends to have a direct impact on a child's development. Many children with HIV infection do not gain weight or grow normally. HIV-infected children frequently are slow to reach important development milestones such as crawling, walking, and talking

Children with HIV tend to experience the usual childhood infections more frequently and more severely than uninfected children. These infections can become life-threatening when accompanied with seizures, fever, pneumonia, recurrent colds, diarrhoea, dehydration, and other problems that often result in extended hospital stays and nutritional problems. As the disease progresses, many children who have had minor symptoms may develop problems such as difficulty in walking, poor performance in school, seizures, and other symptoms such as brain disorders.

In addition, like adults with HIV infection, children with HIV develop life-threatening opportunistic infections (OIs), including:

- **Pneumocystis carinii pneumonia (PCP): This** is the leading cause of death in HIV-infected children with AIDS. PCP together with cytomegalovirus (CMV) disease, are usually primary infections in children, whereas in adults these diseases result from the reactivation of latent infections.

- **Toxoplasmosis (a parasitic disease):** while this is seen less frequently in HIV-infected children than in HIV-infected adults, serious bacterial infections occur more commonly in children than in adults.

- A lung disease called **lymphocytic interstitial pneumonitis (LIP),** rarely seen in adults, occurs more frequently in HIV-infected children. This condition, like PCP, can make breathing progressively more difficult and often results in admission to hospital.

- Severe **candidiasis (thrush)**, a yeast infection that can cause unrelenting diaper rash and infections in the mouth and throat that make eating difficult, is found frequently in HIV-infected children.

- **Chronic diarrhoea**: As children with HIV become sicker, they may suffer from chronic diarrhoea due to opportunistic pathogens.

How can you know if a child is HIV positive?

Like with an adult, you can only know that a child is HIV positive if a blood test has been done.

Unfortunately, the standard HIV test used on adults cannot identify whether a child under 18 months has HIV or not. This is because the standard test measures the amount of antibodies in the bloodstream, yet until 18 months old, an infant's bloodstream carries its mother's antibodies. Therefore, the test will reflect the mother's status and not necessarily that of the child.

There are tests available which can identify HIV in a child. However, these are very expensive and not available in most developing countries. As a result, many children go undiagnosed or their diagnosis comes too late to treat them.

Annex 3: Handouts

Handout 3: TB and HIV Co-infection in Children

What is TB and HIV co-infection?

Tuberculosis, or TB, is a disease that affects many PLHIV. TB can take two forms:

1. Pulmonary – TB affecting the lungs.
2. Extra-pulmonary – TB affecting organs of the body other than the lungs.

TB can only be diagnosed at a health facility. However, CBVs should encourage clients presenting with the following symptoms to visit their local health facility as soon as possible to have a TB test done.

- Cough for longer than two weeks
- Fever that does not go away
- Unexplained weight loss
- Severe under-nutrition
- Swollen glands for a long period of time
- Night sweats

Other members of the family who should also be encouraged to go for testing where a person is suspected to have TB:

- **All children under two years** should be referred to the local health facility where they can receive preventive therapy and/or an immunisation (called a BCG vaccine).
- **All children under five years** living in the household should be examined for TB symptoms at the local health facility. This is especially important because children under five years are at risk of severe forms of the disease. Young children may need preventive measures and should be referred to a health facility.
- **Other household members who have a cough.**

Key Questions	Responses
1. What do you understand tuberculosis to be? What do you think may have caused your illness?	Tuberculosis, or TB, is an illness caused by a germ that is breathed into the lungs. TB germs can settle anywhere in the body, but we most often hear about TB of the lungs. When the lungs are damaged by TB, a person coughs up sputum (mucus from the lungs) and cannot breathe easily. Without correct treatment, a person can die from TB.
2. Have you ever known anyone with TB? What happened to that person? Do you know that TB can be completely cured?	TB can be cured TB can be cured with the correct drug treatment. The client must take all of the recommended drugs for the entire treatment time in order to be cured. Drugs for the treatment of TB are provided free of charge. Treatment can be done without interrupting a person's normal life and work.

Key Questions	Responses
3. How do you think that TB spreads?	TB spreads when an infected person coughs or sneezes, spraying TB germs into the air. Others may breathe in these germs and become infected. It is easy to pass germs to family members when many people live closely together. Anyone can get TB. However, not everyone who is infected with TB will become sick.
4. How can you avoid TB from spreading?	To prevent TB from spreading: • Take regular treatment to become cured. • Cover the mouth and nose when coughing or sneezing. • Open windows and doors to allow fresh air through the home, using a fan. • Use UV lights. There is no need to eat a special diet or to sterilise dishes or household items.

TB co-infection in children living with HIV

Tuberculosis presents a serious risk to children's health, particularly if they are suffering from a weak immune system due to HIV infection. Co-infection with HIV and TB in children is increasingly becoming common in many areas.

While the basic principles of TB treatment are the same, in HIV-positive children, the situation is complicated by drug interactions between ARVs and drugs that are used to treat TB. The interaction can lead to the increased risk of toxic side-effects.

Ideally, for HIV positive children who are not yet receiving ARVs, it is recommended that TB treatment is initiated some weeks before ARV treatment, allowing the child to stabilise on this therapy. For children who are diagnosed with TB while already receiving treatment, ARV regimens need to be carefully reviewed, and may need to be adjusted in accordance with official guidelines.

In order to avoid late diagnosis of HIV, it has been suggested that all TB-infected children should be considered for an HIV test.

Annex 3: Handouts

Handout 4: Testimony of Nkosi Johnson

The following is the speech Nkosi Johnson, 11 years old, made for the opening ceremony of the 13th International AIDS Conference in Durban (2000):

"Hi. My name is Nkosi Johnson. I live in Melville, Johannesburg, South Africa. I am 11 years old and I have full-blown AIDS. I was born HIV-positive.

When I was two years old, I was living in a care centre for HIV / AIDS-infected people. My mommy was obviously also infected and could not afford to keep me because she was very scared that the community she lived in would find out that we were both infected and chase us away.

I know she loved me very much and would visit me when she could. And then the care centre had to close down because they didn't have any funds. So my foster mother, Gail Johnson, who was a director of the care centre and had taken me home for weekends, said at a board meeting she would take me home. She took me home with her and I have been living with her for eight years now.

She has taught me all about being infected and how I must be careful with my blood. If I fall and cut myself and bleed, then I must make sure that I cover my own wound and go to an adult to help me clean it and put a plaster on it.

I know that my blood is only dangerous to other people if they also have an open wound and my blood goes into it. That is the only time that people need to be careful when touching me.

In 1997 mommy Gail went to the school, Melpark Primary, and she had to fill in a form for my admission and it said does your child suffer from anything so she said yes: AIDS.

My mommy Gail and I have always been open about me having AIDS. And then my mommy Gail was waiting to hear if I was admitted to school. Then she phoned the school, who said we will call you and then they had a meeting about me.

Of the parents and the teachers at the meeting 50% said yes and 50% said no. And then on the day of my big brother's wedding, the media found out that there was a problem about me going to school. No one seemed to know what to do with me because I am infected. The AIDS workshops were done at the school for parents and teachers to teach them not to be scared of a child with AIDS. I am very proud to say that there is now a policy for all HIV-infected children to be allowed to go into schools and not be discriminated against.

And in the same year, just before I started school, my mommy Daphne died. She went on holiday to Newcastle- she died in her sleep. And mommy Gail got a phone call and I answered and my aunty said please can I speak to Gail? Mommy Gail told me almost immediately my mommy had died and I burst into tears. My mommy Gail took me to my Mommy's funeral. I saw my mommy in the coffin and I saw her eyes were closed and then I saw them lowering it into the ground and then they covered her up. My granny was very sad that her daughter had died.

Then I saw my father for the first time and I never knew I had a father. He was very upset but I thought to myself, why did he leave my mother and me? And then the other people asked mommy Gail about my sister and who would look after her and then mommy Gail said ask the father.

Ever since the funeral, I have been missing my mommy lots and I wish she was with me, but I know she is in heaven. And she is on my shoulder watching over me and in my heart.

I hate having AIDS because I get very sick and I get very sad when I think of all the other children and babies that are sick with AIDS. I just wish that the government can start giving AZT to pregnant HIV mothers to help stop the virus being passed on to their babies. Babies are dying very quickly and I know one little abandoned baby who came to stay with us and his name was Micky. He couldn't breathe, he couldn't eat and he was so sick and Mommy Gail had to phone welfare to have him admitted to a hospital and he died. But he was such a cute little baby and I think the government must start doing it because I don't want babies to die.

Because I was separated from my mother at an early age, because we were both HIV positive, my mommy Gail and I have always wanted to start a care centre for HIV / AIDS mothers and their children. I am very happy and proud to say that the first Nkosi's Haven was opened last year. And we look after 10 mommies and 15 children. My mommy Gail and I want to open five Nkosi's Havens by the end of next year because I want more infected mothers to stay together with their children - they mustn't be separated from their children so they can be together and live longer with the love that they need.

When I grow up, I want to lecture to more and more people about AIDS - and if mommy Gail will let me, around the whole country. I want people to understand about AIDS - to be careful and respect AIDS - you can't get AIDS if you touch, hug, kiss, hold hands with someone who is infected.

Care for us and accept us - we are all human beings.

We are normal. We have hands. We have feet. We can walk, we can talk, we have needs just like everyone else- don't be afraid of us - we are all the same!"

Source: http://www.simplytaty.com/bios/nkosi.htm

Annex 3: Handouts

Handout 5: Growing Up with HIV

For each stage in a child's development there are physical, social, mental and emotional needs:

Physical needs
Food, clothing, shelter, school-related expenses, health care and hygiene.
Emotional needs
Love, acceptance, security and encouragement.
Social needs
Learning within social situations – with our parents, families, friends and communities.
Skills and knowledge
Formal and informal education where children learn to be part of a community.
Spiritual needs
Beliefs that can give children a sense of hope.

Are there any special concerns for children living with HIV?

Yes – serious illness, such as HIV has great emotional impact on the whole family. Children living with HIV need:

1. **To be loved** simply for being his or her self. This means that a child does not need to believe she must be healthy, or clever or nice, in order to be loved. This 'unconditional love' builds the child's self esteem [the way they see themselves].

2. **To be forgiven**. Often a child may do or say things that they regret. It is helpful for the child to talk about it and be forgiven.

3. **To be heard and believed**. Children will express their feelings if they have someone listening to them who take the information seriously. Hear what the child says and ask more questions if you do not understand.

Kinds Of Care That Are Important For Chronically Ill Children

Social Interaction	Playing
Spiritual Care	Nutritional Care
Home Based Nursing	Tender Loving Care

4. **Reassurance**. A child may feel he has caused something to happen. For example, a sick child may think he is ill because he did not do his schoolwork well enough. He needs to be reassured that nothing he said or did caused the illness.

5. **To hope**. Children's hopes are often focused on the near future. Help the child choose something every day to hope for and eagerly anticipate.

6. **To feel safe and secure**. When illness and death affect a family, a child's main concern may be who will take care of him during the illness and after a death in the family.

7. **To know they are important to others**. Everyone, including children, wants to know that they have made a difference in other people's lives.

8. **To belong** to a family, a group of friends, a school a community. If children are unable to go to school or visit friends and family, they will lose contact with others and feel lonely and left out. It is important to encourage visits and activities with friends.

9. **Being part of living and dying**. Identifying what they believe in or making contact with their ancestors through prayer, talk or writing, may help a child make sense of life and death.

10. **To know oneself**. Children who are not well feel the loss of being whole, healthy people, able to enjoy life fully. They need help to look at who they are, not just at what they can do.

Annex 3: Handouts

Handout 6: Basic Facts about Antiretroviral Therapy (ART)

- **Antiretroviral drugs (ARVs)** are drugs used to treat HIV. Because HIV is a **retrovirus**, drugs used against HIV are called **antiretroviral**.
- **Antiretroviral Therapy** (**ART**) is a term used to describe giving ARV drugs in the correct way, with adherence support.

How do ARVs work?

ARVs help to stop HIV from making copies of itself (replicating) within the immune system of a child. If HIV cannot replicate, it is unable to damage the immune system and cause opportunistic infections that can lead to the progression of HIV to AIDS.

Important things to know about ART:

- ART involves a combination of antiretroviral (ARV) drugs.
- **ART is NOT a cure** for HIV and AIDS.
- While on ART, people living with HIV or AIDS **can still transmit HIV** and can still become re-infected with HIV.
- ARVs are **taken for life**.
- Not all people with HIV need to begin ART immediately.

What are the goals and benefits of ART?

The goal of ART is to reduce the amount of HIV in the blood and to increase the number of CD4 cells in the blood as much as possible. ART improves the quality of life of the child by:

- Helping prevent the progression of HIV to AIDS
- Helping reduce damage caused to the immune system by HIV
- Providing the immune system a chance to recover from damage caused by HIV
- Helping to reduce the number of opportunistic infections in children living with HIV

Benefits of ART:

By helping to respond to HIV and AIDS in our communities, ART has benefits for everyone and not just the child. Some of the following are the benefits of ART:

- Prolongs life and improves the quality of life of the child
- Helps households stay together by reducing illness and death caused by HIV and AIDS
- Increases the number of people accessing HIV testing and counselling
- Reduces the burden on health facilities
- Reduces stigma associated with HIV by proving that HIV is a chronic, manageable illness and NOT a death sentence
- Less time and money is spent treating opportunistic infections and providing palliative care

When to start ART?

Not everyone who is HIV positive needs to start ART. Different countries have different guidelines on when someone should start ART. For both adults and children, the decision to begin treatment can only be taken after one is tested for HIV and has consulted a health professional (doctor).

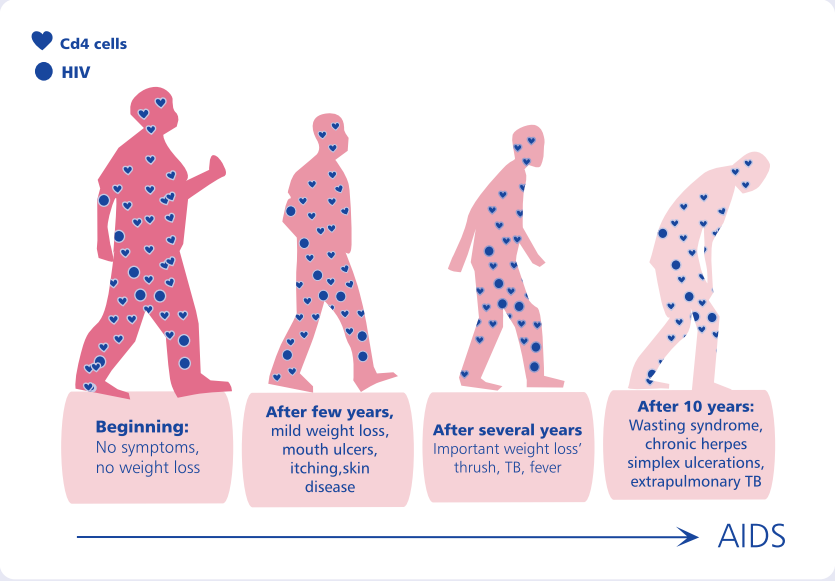
The decision to begin ART is based on an analysis of how HIV infection has progressed – so how many CD4 cells (CD4 count) and HIV virus particles (viral load) are present. Also known as “Clinical staging” doctors and other health professionals determine how far HIV infection has progressed by considering the signs and symptoms experienced by the individual (adult or child).

A **CD4 count** will tell a person living with HIV:

- How weak or strong his or her immune system is (a high CD4 count means the immune system is strong).
- Whether to start antiretroviral therapy: PLHIV with CD4 counts below 200 should start ART if it is available, though this figure may change depending on country protocols.
- Whether to change antiretroviral therapy: If a person is on ART and the CD4 counts begin to drop, the ARVs he or she is taking may have stopped working.

Viral load is the amount of HIV in a person's blood. A viral load test will tell a person living with HIV:

- How much HIV they have in their system
- Whether antiretroviral therapy is working



Understanding the Clinical Staging for HIV and AIDS

Stage 1 No need to begin ARVs at this stage

Stage 2 Health professional will monitor CD4 blood test to determine the need to start ART.

Stage 3 Based on results of tests, health professional may advise that an individual begins ARVs at this stage

Stage 4 Adults and children in Stage Four need ART and should receive immediate treatment for any illness.

Annex 3: Handouts

Handout 7: ARV Regimens for Children

Children and ART

When children have access to ART, they are known to respond very well. Until recently, few ARV formulations were available or adapted to the needs of children. Those that were available were considerably more expensive than adult versions. Yet, with increased access to reliable testing and treatment, it is important for parents and primary caregivers to understand the benefits and challenges of ART for children.

ARV regimens for Children

The ARVs used in the first-line regimen are different depending on the age and weight of the child and will be determined by the clinical team.

A parent or caregiver should **NEVER** attempt to share their medication with a child. Cutting adult tablets into smaller pieces for children may result in a dosage that is too low or unevenly distributed which can negatively affect the child's response.

Children's ARVs may come in liquid or powder form. Others come in a granular form. Some pills can be crushed and added to food or liquids. Some clinics teach children how to swallow pills. Children who can swallow pills have more medication options.

The correct doses are not always known. Several factors affect drug levels in children and hence it is important to anticipate that a child's dosing may have to be adjusted several times as a child develops. A parent should NEVER adjust the dose on their own – this should always be done in consultation with a knowledgeable health professional.

When to start ART in children

HIV positive parents should always be encouraged to have their children tested for HIV and seek consultation from health professionals on when to start children on ART.

- The World Health Organisations has a clinical staging of HIV and AIDS for infants and children, called the 'Paediatric Stages of HIV'. Children in Stage III of this system are recommended for ART regardless of their CD4 count.
- In children a percentage CD4 level is used for starting ART. Children with a CD4 cell percentage less than 20% are recommended to start ART.

Side-effects of treatment

Children respond differently to ARVs. They have larger increases in CD4 cell counts and more diverse CD4 cells. They seem to recover more of their immune response than adults.

Bones develop quickly during the early years of life. ARVs can weaken bones in adults and children. Children are therefore more likely to experience bone disorders as a side-effect of treatment. Before starting treatment, the parent or caregiver should discuss potential side-effects with their health care professional, and monitor closely their child's health to determine minor and major side-effects. Some side-effects children may experience include:

- Nausea
- Vomiting and diarrhoea
- Abdominal pain
- Headache
- Fatigue
- Skin rash
- Loss of appetite

Children adhering to ART

Many children do not understand why they should put up with medication side-effects. Many ARVs taste bad or have a strange texture. Parents and primary caregivers have a vital role in supporting children to take their medication.

How can parents and caregivers help a child on ART?

Although older children may find it easier to accept a routine of taking their medication every day at the same time, they may still need encouragement. A younger child, however, should be monitored and observed while taking ART. It can be helpful to explain that the child may feel tired when she or he starts ART as the body needs to get used to the drugs.

Tips for parents to make taking ARVs easier:

- Explain to even a very young child that you are giving her medicine that may help her by using simple language that the child will understand. Be reassuring.
- If the child does not want to drink the medicine, make up a game that will encourage her to take it.
- If the medicine has an unpleasant taste, prepare the child in advance so that she will know what to expect.
- If tablets are too big to swallow, crush them to make them easier to take.
- If the child vomits within 30 minutes, reassure her and give more medicine.
- Praise the child after taking the medicine. Tick on the chart that the child has been given the medicine. Let the child tick the chart herself, if possible.

Tips for parents to help a child remember to take ARVs everyday at the right time

- Make a timetable or chart with a list of the pills and time
- Work out how to tell the time at home, using:
  - A watch or clock
  - A cell phone
  - Listening to the rooster crowing at the same time every day
  - Watching the sun in the sky
- Carry some pills all the time in case something stops the child getting home on time.
- Store pills where they will be noticed at the right time, for example with a breakfast plate or toothbrush. Keep pills in a container with compartments if possible and fill this pill box once a week.
- If pills taste horrible, some pills can be broken or crushed or dissolved in water, juice or milk to make them easier to swallow. Follow pills with something sweet like honey or something salty.
- Family members can recognise the child's efforts with little rewards, like orange crush, a certificate saying, "..... is a champion!'', or a song congratulating the child. Make a star or sticker chart or use a calendar.
- The child can write in a diary about her difficulties and feelings about taking the medicines. She can share this with anyone she wants to, or keep it private.
- Make a plan to collect your supply of pills every 28 days.
- Have at least one family member who agrees to help the child take their pills.

Annex 3: Handouts

Handout 8: Disclosure

Depending on the age and knowledge level of the child, they may or may not be aware of their HIV status when they begin treatment. However, it is likely that they will be aware that they take medicine regularly to stay healthy. As the child grows, they may have more questions about their illness and at some point it will be important for the parent or caregiver to disclose their status.

Guidelines for disclosing to a child

- **When**? The child's age and mental and emotional maturity will help you decide when to tell a child she or he is HIV positive. You may be surprised at how much a young child can understand. In practice, children as young as five or six years old may be old enough to understand about living with HIV.
- **Who** should tell them? The parents are the best people to tell children their test result. Parents can always ask a counsellor for guidance and support in this difficult task. A carer who is with the child most often can also be the one to tell the child.
- **How?** Remember that you do not need to tell a child everything all at once. Talking about their HIV status is a process. Let the child lead you. First, find out how much the child already knows about HIV and AIDS and about testing. Ask whether they have any questions about HIV. Correct any wrong facts or myths they may have heard. Then bring the talk around to HIV and themselves. Talk in a loving, supportive way, showing the child that whatever happens they are accepted.
- **Afterwards,** let the child express whatever feelings they have. Give them time for tears, silence, anger or despair. Be sure to help them express fears and worries.
- Tell them all the things that can be done to help a person living with HIV stay healthy, including ART.
- **Acknowledge** to yourself that this is not an easy thing to do. Try not to let your own feelings stop you from disclosing to a child.
- **Congratulate** yourself when you have done it!

Disclosing to others in a child's life: points to remember

- Let the child decide if they want to tell anyone else about being HIV positive. Let the child decide who they want to tell. Help them think about the support they might get, medical, psychological or practical. This might be from people in the family, health carers or teachers.
- Help the child think what the results [consequences] of telling others might be. Not everyone can be trusted to react in a positive way.
- Help the child understand that when they share their HIV status with someone else, they need to give the person time to take in what has been said.
- Remember that not everyone knows a lot about HIV. Educating others before you decide to disclose your status to them can help.
- Young people who are becoming sexually active need to protect others from getting the virus from them. They will need to talk about disclosing to a sexual partner.

Annex 3: Handouts

Handout 9: Good Nutrition and Food Safety

For a well-balanced diet for a child on ART, parents and caregivers should choose food carefully from the three food groups below so that every day a child is eating food from all food groups.

Choose from:

Energy-Giving Foods (carbohydrates)
Maize meal, grains, sweet potatoes, sorghum, rice, millet, potatoes, oatmeal, pasta, wheat, whole wheat bread

Body-building foods (proteins)
Meat, fish, eggs, beans, groundnuts, milk and milk products, sesame, peas, lentils, peanut butter

Protective foods (vitamins and minerals)
Fruit, for example: pineapple, mango, bananas, watermelon, guava, apples, pears, plums, and indigenous fruits
Fruit is best when eaten raw and fresh

Select from Yellow, White and Green vegetables regularly
Yellow – pumpkin, carrot, butternut
White – cauliflower, white cabbage, onions, parsnip
Green – spinach, pumpkin leaves, or any dark green leafy local vegetable

7 Nutritional Goals for Children Living with HIV
Goal One Be aware of the importance of good nutrition if you are HIV positive
Goal Two Eat a healthy and balanced diet to keep your immune system strong
Goal Three Adjust food intake to deal with HIV-related symptoms
Goal Four Prevent food-borne illnesses by practicing good hygiene and food and water safety
Goal Five Manage the symptoms of HIV and AIDS that can affect food intake by getting early treatment for opportunistic infections
Goal Six Keep a healthy weight
Goal Seven Understand the ways that any medications you are taking (including ARVs) may affect your nutrition.

Annex 3: Handouts

Handout 10: 5 Easy Steps to Food Safety

1. Personal hygiene

- Always wash hands after using the toilet, before preparing food and before eating. Clean water with soap or ashes should always be used to wash hands.
- Wash hands carefully after changing a baby's nappy, or helping a child use the toilet.
- Keep nails short and clean. Wash under the nails each time you wash your hands.
- If you have a wound on your hand, cover it up with a bandage so that any infection in the wound is not passed on to food during preparation and handling.
- Hands should be washed under flowing water and not still water in a basin.

2. Hygiene in the House

- Always use a latrine or toilet. Keep the toilet and its surroundings clean and free from flies.
- Keep animals out of the house.
- Wash soiled linen with hot water and soap.
- After washing, soak in water with bleach (1 cup bleach to 10 cups of water).
- Keep garbage in a covered bin and empty regularly.
- Household vegetable gardens should not be grown near bathroom exits, garbage or open sewage.

3. Drinking Water

- Only use drinking water from a protected well or tap.
- If water comes from an unprotected well or river, boil water for at least 10 minutes before drinking it.
- Water in both rural and urban areas should be boiled.
- Store drinking water in a clean and covered container.

4. Food preparation

- Make sure all food preparation surfaces and utensils are clean
- Clean vegetables with running water (from a tap or poured from a cup or container) rather than soaking them in a bowl.
- Make sure meat is cooked 'all the way through'
- People should not eat eggs with runny yolks or uncooked foods prepared with raw eggs. Hard boil eggs.
- Wash cutting boards and knives well before using them on other food (especially after cutting meat like chicken, fish or pork)
- Do not use wooden cutting boards for cutting meat; use plastic boards or plates.
- Serve food immediately after cooking.
- Do not keep food for a long period of time, particularly if you do not have a fridge or cooler.
- Eat food while it is still warm.
- Food leftovers from the night before should be kept in a fridge.
- Cover food when not eating.
- Food should be reheated only once after it has been cooked.

5. Food storage

- Cover and store foods away from insects and pests.
- Fruits and vegetables should be checked regularly to see if they are 'over-ripe'.
- Store food according to the 'first in' 'first out' method to ensure that the oldest foods are used first.
- Prevent blood from raw meat from dripping on other foods.
- Do not thaw and then re-freeze what you have not eaten. Pack meat into smaller daily food portions before freezing to prevent wasting food.
- Thaw frozen meat inside a fridge rather than at room temperature.
- Food left over from the night before should be kept in a fridge and eaten within 24 hours. Those without a fridge should eat leftovers the same day.
- All leftovers should be re-heated thoroughly before serving.
  Left over chicken and fish should be avoided.

Annex 3: Handouts

Handout 11: Managing Symptoms

Some Signs and Symptoms of HIV and AIDS include:

- General weight loss
- Nausea and vomiting
- Mouth ulcers or pain swallowing
- Dry mouth
- Constipation
- Incontinence of urine or stool
- Rectal tenderness
- Diarrhoea
- Anxiety and worries
- Trouble sleeping
- Confusion
- Depression
- Itching
- Bedsores
- Cough or difficult breathing
- Fever
- Hiccups

When a child starts ART, many of these symptoms may reduce as they begin to feel better. Some ways to manage symptoms at home are given here, but parents and caregivers should always seek medical attention for the child if the symptoms get worse. Especially with diarrhoea and dehydration, it is important to consult a health care professional.

Symptom	Management
Nausea/vomiting	Give bland dry food Give small amounts of food at a time Avoid strong 'cooking' smells Give ginger tea or fresh ginger
Diarrhoea	Use Oral Rehydration Solution 8 teaspoons sugar with 1 teaspoon salt in 1 litre of boiled water Give fruit juice/rooibos tea
Dizziness	Adjust the child's medication time to just before bedtime
Tiredness	Give child lots of fluid Encourage child to rest
Nail discolouration	Visit your health care professional
'Pins and Needles' in hands or feet	Keep feet/hands clean Check for wounds Massage

Annex 3: Handouts

Handout 12: Managing Pain

a) Remember:

- Pain is what the child says it is, not what the parent or caregiver thinks it should be.
- Pain greatly affects the quality of life of the child.
- Pain should be controlled in a way that helps the child stay alert and active.
- If medication to relieve pain is not available, there are other ways to try to deal with pain.

b) How to assess pain

It is difficult to treat pain without knowing what is causing it. If a parent or caregiver is unsure of the cause of pain, they should refer their child to a doctor for a medical diagnosis. Parents and caregivers can use these questions to help determine the cause of pain:

- Where is the pain?
- What makes the pain better or worse (e.g. hot, cold, darkness)?
- What type of pain is it (i.e. stabbing, aching)?

Parents and caregivers also need to understand that it is often difficult for a child to understand and describe their pain and the parent or caregiver may under- or over-estimate pain in the child. It is important for parents to try to differentiate pain from anxiety.

- **Brief pain** can be shown by crying and distressed facial expressions.
- **Persistent pain** – also look for behavioural signs of pain:
    - Irritability
    - Not wanting to move
    - Lack of interest
    - Decreased ability to concentrate
    - Sleeping problems
    - Changes in how the child moves
    - Restlessness
    - Increased breathing rate or heart rate

When working with children, it is best to use a pain grading system like the one shown here. Parents and caregivers can also support children to record the grade of pain felt at certain times of the day and provide this information to their doctors during appointments.

Treating pain

For children, it is important to avoid intramuscular injections in pain control. Pain medication should be reviewed frequently by a health professional and increased or decreased when necessary. Non-medicinal methods of pain control can help children cope with pain without, or in addition to, pain medications.

Examples of non-medicinal methods of alleviating pain

- Emotional support (discussing their pain, providing support and understanding).
- Physical methods (touch, ice or heat, deep breathing).
- Prayer.
- Traditional practices.
- Other methods including swaddling, carrying infant, warmth, breastfeeding, feeding, stroking and rocking.

For children, parents and caregivers can also use cognitive methods to help relieve pain:

- Age-appropriate active distraction.
- Older children can concentrate on a game, conversation or special story.
- Music.

Annex 3: Handouts

Handout 13: Universal Precautions

What are Universal Precautions?

Universal Precautions are simple infection control procedures that reduce the risk of transmitting **infectious agents** through exposure to blood, body fluids and **contaminated medical or other types of equipment.** Parents and primary caregivers should take universal precautions when caring for their child, whether they know if they are HIV positive or not.

There is an extremely low risk of getting HIV through caring activities if the following Universal Precautions are taken:

- Wash hands with soap and water before and after caring.
- Wear gloves when touching blood or body fluids.
- Keep wounds covered (both those of the caregiver and the client).
- Clean up blood, faeces and urine with ordinary household bleach.
- Clean cutlery, linen, bath, etc with ordinary washing products.
- Keep clothing and sheets stained with blood, diarrhoea or other body fluids separate from other household laundry.
- Use a piece of plastic or paper, gloves or a big leaf to handle soiled items.
- Do not share toothbrushes, razors, needles or other sharp instruments that pierce the skin.
- Properly disinfect tools used for caring such as razors, needles and spit jars.
- Wash your hands with soap and water after changing soiled bed sheets and clothing and after any contact with body fluids.

Annex 3: Handouts

Handout 14: Communicating with Children

Rules and Skills for Good Communication

Don't repeat to others what the child has told you. Make sure to let children and adolescents know that their conversations with you are private. This will build their trust.

Accept what children tell you. The feelings and reactions of children are not "right" or "wrong." Children can be direct in what they say and have different ideas from adults.

Promote Independent Decision-Making. Children need to make their own decisions. Do not take over with advice and feel you know best. If adults always tell children what to do, they will not learn how to work out problems for themselves. Children need information and sometimes guidance in order to choose what they want to do.

1. **Listen.** Children will tell you as much as they can, depending on how they feel. They may tell you more later on. Do not rush to fill the silences too soon. Do not think of the next question as the child is talking. Look at the child when she or he is talking. That will show that you are interested and that what the child is saying is important. Sometimes children are more comfortable talking while you are busy together, preparing food or working in the fields. Sometimes they will need all of your attention. Then it is good to put down what you are doing, sit with the child and look only at him or her.

2. **Look at the problems**. Sometimes when there are lots of problems, a child can feel helpless. When you are helping a child, start with the problem the child sees as most urgent. It is easier to work with one problem at a time. Spend time together explaining different ways to solve the problem. Talk about what will happen in each scenario and then look at the different options and which ones will have the most favourable result. Give information and guidance, but do not tell the child what to do. Help the child make a decision that feels good for the child.

3. **Try to imagine how the child might be feeling.** Try to stand in her shoes and understand how the child might be making sense of her situation. Even a mother doesn't always understand the way her child thinks. Guess what she is feeling and ask her to tell you if your guesses are right.

   Those who live with a child can usually tell if something is wrong by noticing changes in their behaviour. Younger children will show unhappiness in different ways from older youths. Young children might
   - Become clingy not wanting to leave your side.
   - Cry over seemingly small things.
   - Throw temper tantrums.
   - Show physical signs like bed-wetting, thumb sucking or rocking.
   - Complain of ailments like stomach aches or headaches.

Older children might

- Withdraw, not wanting to talk to anyone.
- 'Act out' with bad behaviour.
- Run away from home.

Boys and girls will show feelings in different ways. Usually girls will find it easier to talk about what is worrying them, especially as they get older.

4. **Check that you understand correctly what she is saying.**
   Tell her in your own words what you think she is saying. Ask her if you are right or wrong.

5. **Be aware of body language.**
   - Look at the child to show you are listening. Nodding once in a while or making encouraging sounds also shows you are listening.
   - Be close enough to show you are with them but not so close that the child might feel crowded.
   - Look at how the child is sitting/standing to see if she is sad, uncomfortable, happy, relaxed or frightened.

6. **Talk in a helpful way.** Use simple language that the child can understand. Be natural and relaxed. Children are quick to pick up your discomfort with a topic. Before bringing up something you specially want to talk about, start by chatting generally about their day, school or friends.

   You can encourage the child to continue talking by saying things like:

   "It seems you feel..."
   "It sounds like you feel..."

7. **Help the child find the information they need.**
   The child needs correct information about how ART works, what happens if she stops taking ART, what can be done if she reacts badly to the medicine. It is important to ask health workers for up to date information on ART. Children and young people also may raise particular problems, such as how can they have sexual relationships or have children, or study for a career. Making it clear that you are available to discuss these difficult topics is the first step. Learn how to really listen well and give honest and correct answers to these kinds of issues.

Annex 3: Handouts

Handout 15: Caring for the Carer

HIV lasts for life. Children living with HIV who are able to take ART need special care. This places demands on the carer. A regular self-care programme is necessary to avoid feeling frustrated, resentful, exhausted and unable to carry on. If these feelings build up without being released they may lead to burnout or stress.

Symptoms to recognise burnout:

Physical

- Being ill often, getting injured or having accidents.
- Sweating, dry mouth, feeling sick, having a lot of colds, headaches, stomach problems, and tiredness.
- Tongue or lip biting, tense muscles, neck and back pain.
- Shallow breathing, pounding heart, high blood pressure.
- Difficulty in sleeping.
- Eating too much or too little.
- Irregular menstrual cycle.
- Abuse of alcohol, prescribed or illegal drugs.

Emotional and mental

- Anxiety, depression, confusion, crying.
- Feeling helpless.
- Being aggressive or overreacting.
- Feeling indecisive, insecure.
- Wanting to run away.
- Not trusting others.
- Having poor judgment or concentration.
- Having low self-esteem.
- Feeling like you are the only one who can do things and you can't rely on anyone else.

If you recognise some of these signs over a long period of time, you can then start to identify what is causing the stress and prevent it from happening again.

Preventing burnout symptoms

- Understand and express feelings.
- Speak to a good friend who is a good listener.
- Join a support group.
- Dedicate "quiet time" during the week.
- Pray, meditate or go for a walk.
- Avoid over-commitment; say 'no'.
- Eat nutritious foods, avoid alcohol, get enough rest.
- Take regular exercise.
- Reward yourself with nice things, such as chatting with friends, cooking and eating, playing sports, listening to the radio.
- Do not isolate yourself, but learn to recognise when you need to spend time alone.

Annex 3: Handouts

Handout 16: 'Hot issues'

List the degree to which of the issues in the table below are of concern in your community, using this scale. List any other important 'hot issues' in your community in the blank space provided.

1	2	3	4	5	6	7	8	9
Cold **(hardly heard of)**	Cool	Room temp.	Warm **(common, but not widespread problem)**		Too hot to handle	Burning		On fire **(serious problem)**

Possible Issue	**Rating (1-9)**
Adherence to Treatment	
Disclosure of HIV Status	
Stigma and discrimination	
Support systems	
Sexual and Reproductive Health and Rights	
Living Positively	
Side-effects of ART	
When to begin ARVs	

Agree as a group which 'hot issues' are the most important, and why.

Annex 3: Handouts

Handout 17: Action Plan

Activity	Objective	Staff	Date	Place	Resources required	Indicator
	Objective1:					
	Objective 2:					

References

1. IFRC, WHO, SAfAIDS.2006. HIV Prevention, Care and Treatment: A Training Manual for Community Based Volunteers

2. aidsinfonet.org Factsheet 612 Children and HIV Source: *http://www.aidsinfonet.org/factsheet_detail.php?fsnumber=612*

3. Médecins Sans Frontières. 2007. Fact sheet: Children and HIV. Sourced at: *http://www.accessmed-msf.org/main/hiv-aids/introduction-to-hivaids/children-and-hivaids/*

4. National Institute of Allergy and Infectious Disease.2004. HIV infection in Infants and Children Source: *http://www.niaid.nih.gov/factsheets/hivchildren.htm*

5. AVERT Fact sheet on Children and HIV. Source: *http://www.avert.org/hiv-children.htm*

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