

A Handbook for Community Health workers



Care for children infected  
and those affected  
by HIV/AIDS

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# ACRONYMS

AIC	AIDS Information Centre	LP	Lumbar Puncture
AIDS	Acquired Immunodeficiency Syndrome	NACWOLA	National Community of Women Living with HIV/AIDS
ARV(s)	Anti Retro-Viral(s)	ORS	Oral Rehydration Salts
BCG	Bacille Calmette Guerin	PCP	Pneumocystis Carini Preumonia
CDC	Centre for Disease Control	SSS	Salt, Sugar Solution
CHW	Community Health Worker	STI	Sexually Transmitted Infections
DPT	Diphtheria Pertusis Tetanus	TASO	The AIDS Support Organisation
Hep B	Hepatitis B	TB	Tuberculosis
HIV	Human Immuno-deficiency Virus	VCT	Voluntary Counselling and Testing
HiB	Haemophylus influenzae type B	WBC	White Blood Cells
Mls	Millilitres		
MTCT	Mother -to- Child Transmission		






Uganda has received international recognition for its fight against HIV and AIDS that has led to the reduction of HIV prevalence throughout the country. This positive trend is, however, continually threatened by the long-term impact of the epidemic on the lives of children. A majority of children affected by the epidemic are growing up unable to enjoy their right to education, good health and social protection and care. This curtails their capacity to develop into useful adults. This situation is precipitated by, among other things, the lack of access to quality guidance on how to care for, counsel and share information with children affected by HIV and AIDS. This handbook has been developed to help increase these children's access to proper care and support within the communities in which they live.

The guidance on paediatric HIV/AIDS care, counselling and prevention contained in this handbook will improve the quality of the lives of children infected or otherwise affected by HIV and AIDS. The guidelines are given from a community based approach and are intended for community based health workers who interface regularly with families affected by HIV and AIDS. It is my expectation that this handbook will increase the chances of children living with and those affected by HIV and AIDS to enjoy their right to proper growth and development.

I trust that the lessons that will be learnt through operationalising these guidelines will continue to inform and strengthen the fight against HIV and AIDS and its consequences. Their implementation should challenge policy makers and other key stakeholders at all levels of government and within communities to strengthen community-based initiatives and structures to respond more efficiently and effectively to the needs of children affected by HIV/AIDS.



**Zoe Bakoko Bakoru**  
**Minister of Gender, Labour and Social Development,**  
**Government of Uganda.**



Many people contributed information, ideas and practical guidance to the development of this handbook on care for children infected or otherwise affected by HIV/AIDS.

A list of individual persons who made an input is attached in appendix. However special thanks go to the two consultants Rachael Baggaley and Cathy Poulter for compiling the Community Health and Psychosocial sections of the book respectively.

Thanks also go to the following organisations and ministries for their participation in the reviewing of this handbook.

1. Ministry of Gender, Labour and Social Development
2. Ministry of Health
3. Ministry of Education
4. Mulago Hospital
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6. AIDS Information Centre
7. Mildmay Uganda
8. AIM Project
9. Save the Children UK
10. Centre for Disease Control and Prevention

Special thanks go to David Mawejje, the HIV/AIDS Project Manager, Save the Children UK - Uganda Programme, for his

hard work in coordinating the contributions and providing other support for the production of this handbook.

Finally, special gratitude is extended to CDC for providing funds and practical guidance for the development of this handbook.



Uganda has made great strides towards the reduction of HIV infection. For example, HIV prevalence rates among expectant mothers has continued to decline since the inception of HIV/AIDS awareness campaigns falling to 6.1%. The “good news” is however, outstripped by the increasing number of children affected by HIV/AIDS. For example, the current cumulative number of AIDS orphans in Uganda is estimated to be around 2.3 million.

HIV/AIDS is one of the greatest threats to children’s development in many parts of the world. Families in Uganda are overwhelmed with the increasing numbers of children living with HIV/AIDS; those orphaned by the pandemic and the special needs of these children. Adults are faced with the obvious challenges of providing these children with nutritional, health and educational needs- not to mention the importance of social protection and ensuring the development of mental capacities of these children. Stigma and the sense of hopelessness associated with HIV/AIDS greatly undermine the provision of care to children infected or otherwise affected by HIV/AIDS. Discrimination, neglect and isolation of these children became eminent.

Most children affected by HIV/AIDS end up having limited access to health, education and welfare services. Accessible public health services are just one part of the broad developmental

approach needed to support such children; their psychological support and acceptance in a non – discriminatory environment is just as important as their material needs to food, shelter and clothing.

While those challenges need to be faced holistically, the production of this handbook is aimed at contributing to provide guidance to various stakeholders in providing care to children infected and affected by HIV/AIDS.

The production of this handbook has gone through a long process. It started with a study collecting baseline information, where the Creative Research Centre was commissioned by Save the Children to conduct a study in the districts of Arua and Kasese. The aim of the study was to assess the community’s perceptions of care for children infected or otherwise affected by HIV/AIDS. The findings of the study revealed gaps in the accuracy of people’s knowledge about HIV/AIDS. Discrimination and rejection of children affected by HIV/AIDS was reportedly influenced by the prevailing stigma associated with the conditions. Community based health care workers were found to lack some of the skills and understanding necessary for the support of children suspected to be infected with HIV. Households affected by HIV/AIDS were found to face socio-economic problems that challenge their capacities for managing HIV/AIDS.

Therefore, this handbook aims to address some of the prevailing inadequacies in skills and understanding among community based health workers and other carers who support and care for children infected or affected by HIV/AIDS.

### **Use the Handbook**

The operationalisation of the information in this handbook is intended to contribute to the goal of mitigating the psychosocial impact of HIV/AIDS on children in Uganda. Given the difficulties in accessing medical care, coupled with the stigma and unsupportive attitudes towards persons living with HIV/AIDS that are prevalent in communities, home based care and counselling remain the most appropriate form of intervention for improving the quality of lives of children infected by HIV/AIDS. In addition to providing basic information on HIV/AIDS, this handbook is primarily designed to assist carers for children affected/infected by HIV/AIDS in providing home based care and counselling.

This handbook can also be used as a resource for community health workers and other carers within communities. It provides guidance on how to confidently provide care in a manner that will alleviate the physical and psychological pain inflicted by HIV on children affected by HIV/AIDS. It can also be used as a source of information for people living with HIV/AIDS. The Ministry of Gender, Labour and Social Development oversees the use of this handbook and is a reference point for any

questions related to its use. It is hoped that this handbook will contribute to guiding the provision of care and support to orphans and other vulnerable children as appropriate.

### **Key information contained in this handbook includes:**

1. Basic facts about HIV and AIDS, including definition, transmission and prevention of HIV/AIDS.
2. Information on HIV care and treatment and where it can be obtained.
3. HIV counselling and testing, with a special focus on children.
4. Nutrition and feeding, with a special focus on sick children.
5. Maintaining the general health and sanitation in homes.
6. Immunisation of children.
7. Nursing care for children with HIV disease, with special attention given to fevers, cough, diarrhoea, tuberculosis, mouth sores, skin problems and pain.
8. Emotional health of children affected by HIV/AIDS.

The handbook further introduces communication skills that can be applied in all aspects of care by family members and health workers, that are intended to increase psychosocial support for children traumatised by HIV/AIDS.

We believe that through this handbook, family members, health service providers and the general community will gain confidence and skills in improving care and alleviating the suffering of children affected by HIV/AIDS.

It is our intention that this handbook becomes widely available to the communities that need it the most and lessons learnt during the implementation are planned to be incorporated in future editions of the handbook. Translating of the handbook or parts of it into local languages are also planned in the near future.

**Dr. Hussein Mursal**  
**Country Director, Save the Children (UK)**  
**Kampala, Uganda.**





# Background information on HIV and AIDS

This chapter will tell you the following:

- Basic facts about HIV/AIDS
- How HIV is transmitted
- How HIV is NOT transmitted
- How HIV can be prevented
- The medical problems faced by children with HIV

## 1.1 What is HIV?

HIV stands for **Human Immunodeficiency Virus**

HIV is a germ that attacks human beings and weakens their bodies' ability to fight off other germs that cause illnesses and infection.

## What is AIDS?

AIDS stands for **Acquired Immuno Deficiency**

**Syndrome.** AIDS is a final stage of the HIV infection. HIV has destroyed the person's ability to fight off germs and other causes of disease so that he/she is inflicted by ill-health. The period between HIV infection and development of illness takes about 2-15 years.

### HIV

H- Human

I- Immunodeficiency

V- Virus

### AIDS

A- Acquired

I- Immune

D- Deficiency

S- Syndrome

## Information about the Immune system

The immune system is the means by which a person stops germs e.g viruses from establishing themselves in his/her body or fights off established germs

Viruses are very small living organisms that cause many different diseases in human beings. Poliomyelitis (polio) and measles are examples of diseases caused by viruses.

Viruses cannot reproduce on their own; they depend on the living things that they infect for reproduction

When a person becomes infected with a virus, the white blood cells try to fight the virus by producing *antibodies*.

## What Happens when HIV enters the Human Body

- When a person becomes infected with a virus, the virus begins to live and reproduce itself in the white blood cells found in the blood. The virus quickly multiplies in millions.
- The white blood cells respond by making *antibodies* that begin to fight the HIV virus from about 4 to 6 weeks after a person was infected with HIV.
- The *antibodies* produced by the body CONTAIN the viruses for along time(2-15 years) before the white cells that produce them are completely destroyed by the HIV.

- When a person with HIV frequently falls sick, from one or many illnesses, he or she is said to have AIDS.
- There are certain common diseases that attack people infected with HIV. The most common examples include tuberculosis (TB), pneumonia, diarrhoea and skin infections.
- The HIV slowly weakens the person's ability to fight off the germs that cause diseases and the person gradually begins to fall sick from common illnesses.

People infected with HIV look healthy and remain healthy for quite some time.

Nobody can know that he/she has the HIV virus, unless he/she has had an HIV test.

It is estimated that most people may look well and healthy 2-15 years after getting infected with HIV.

From the time an adult gets infected with HIV, their body's ability to fight germs that cause disease begins to gradually weaken.

Most children born with HIV show signs of HIV/AIDS within the first 2 years after birth.

## Important things to understand about HIV and AIDS

### 1.2 Transmission of HIV

There are many misconceptions and myths about how HIV is and is NOT transmitted. HIV is passed from one person to another through **sexual contact**, from **a woman to her baby** during pregnancy, delivery and breastfeeding and through **blood-to-blood** contact. HIV is known to be in the following fluids:

- Blood
- Semen
- Fluid from the vagina
- breast milk
- Other body fluids containing blood, for example if someone vomits and there is blood in the vomit

“I am worried about him ever since I took him over in my family. His mother died of AIDS last year. My children are fond of always carrying him. This creates a lot of anxiety and fear in me, thinking that possibly my children may contract AIDS. You never know!”

Guardian of a young child, Arua.

HIV is not passed on by casual contact such as kissing, hand shaking, hugging, playing together, sharing toilets or bathing together and many hundreds of other everyday events. Casual contact means when there is body contact but without exchange of potentially infectious body fluids like blood, semen and vaginal fluids.

It is important to show the child love and care by playing, talking, and paying attention to his/her needs.

It is however, important to practice good hygiene.

If a child loses a parent due to AIDS, it does not necessarily mean that the child has HIV. However, all people should be cautioned not to touch the blood, urine, vomit or faeces of any person.

## Ways in which HIV is not transmitted

HIV is **not** passed on to others by **casual contact** such as kissing, handshaking, hugging, playing together, sharing toilets or bathing together and many hundreds of other everyday events. Casual contact means there is body contact but without any exchange of potentially infectious body fluids like blood, semen and vaginal fluids.

Parents, teachers and other carers of children must be reassured that there is no possibility of HIV being passed to others when children eat together, play together, touch each other or sit together.

Some people worry that mosquitoes or bedbugs could transmit HIV. HIV cannot be transmitted by any insect. Blood-sucking insects suck up blood from one person and do not inject blood into another individual. Insects will inject a small amount of saliva to prevent blood from clotting in the insect's feeding tube. This saliva does not contain HIV.

Some people believe that HIV can be caused by spells of witchcraft. This is not true. A person cannot get HIV through being bewitched. No witchdoctor can cure HIV and there is no known cure for HIV/AIDS yet.

You cannot get AIDS through the following ways



Bathing together



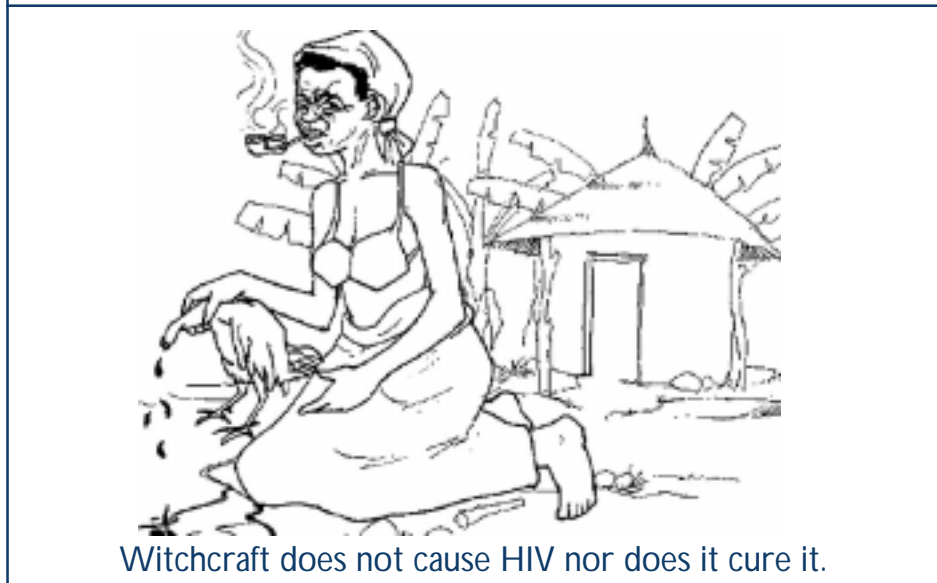
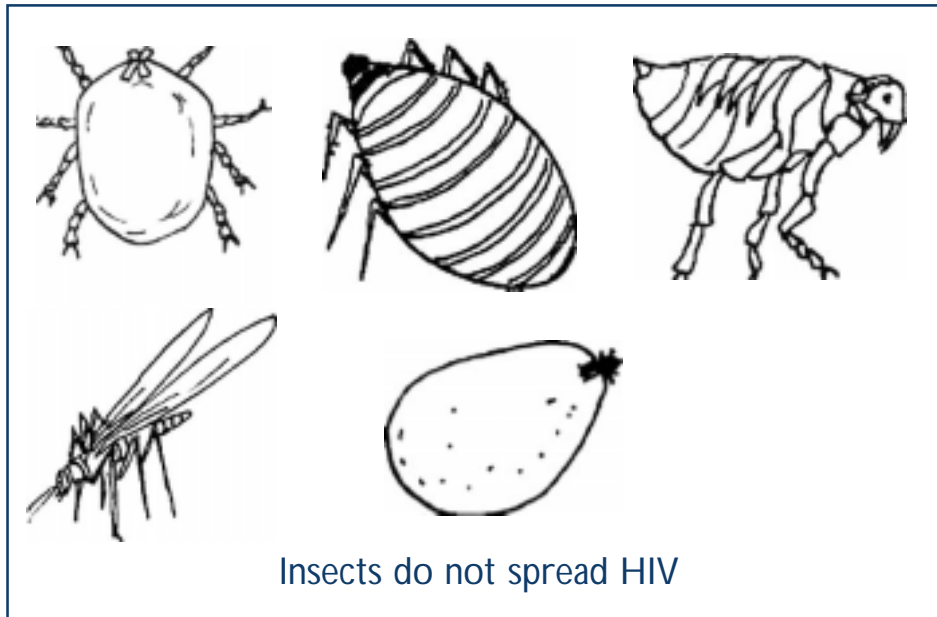
Mother carrying sick child



Playing together



Eating together



However, there are a number of practices associated with traditional healers that can transmit HIV. These include incising the body and ritual cleansing practices such as having sex with the healers, an albino or a virgin child.

Some cultural practices like widow inheritance, child marriages, female genital mutilation and circumcision can promote transmission of HIV.

## Ways in which HIV can be spread

HIV is passed from one infected person to another through **sexual contact**, through **blood-to-blood** contact and from **a woman to her baby** during pregnancy, delivery and breastfeeding. HIV is known to be present in the following body fluids:

- blood
- semen
- fluid from the vagina
- breast milk
- other body fluids containing blood; for example, vomit if there is any blood in it.

## Sexual transmission

Unprotected sexual intercourse with an HIV infected partner is by far the commonest means of spreading the virus in developing countries. **HIV can be transmitted through all forms of sexual intercourse including oral and anal sex.**

## Ways in which HIV can be transmitted

Through **unprotected sexual intercourse** with an HIV infected person. That is vaginal-penile sex without a condom

From an **HIV-infected mother to her unborn child** during pregnancy and delivery or her **newly born child** through breast feeding

Through **contact with infected blood**, for example by:

- the transfusion of HIV infected blood
- the sharing of skin piercing instruments, such as injecting needles that are not sterile or razor blades used by the traditional healer for cutting the skin

“My nephew is living with us and I know he has a girlfriend. I don’t want him to catch HIV. We have a good relationship and can talk about these things. But I am not sure what is the best advice. What can I tell him?”

Guardian of a young person, Entebbe

It is important to explain to your nephew how HIV is transmitted and how he can protect himself by abstaining from having sex or using a condom if sexually active. It is also important for him and his girlfriend to consider taking an HIV test and being faithful to each other. Try to refer him to the AIDS Information Centre, for further counselling on prevention.

## Prevention of HIV transmission through sexual intercourse

Most HIV transmission occurs through unprotected sexual intercourse. The main ways in which to prevent HIV transmission through sexual intercourse are:

### Abstaining or “Saying No to Sex”

Abstinence means ‘saying no to sex’. This is the best way for anyone, young and old, to be free from HIV. Abstinence is the surest way of preventing HIV infection. Children and young people are advised to abstain from sex until marriage.

### Being faithful

Being faithful means both partners in a relationship have sex only with each other, and usually means that the relationship is long term, as in marriage. If you are in a steady polygamous relationship (for example if you are in a family where the man has three wives) it is important that all members of the marriage remain faithful within the marriage and that all members have been tested for HIV and are HIV negative.

Couples wishing to use this strategy should have both **voluntary counselling and testing** (see chapter 2) to determine their HIV status.

### ABC of HIV Prevention

- **A**bstain from sex altogether, or
- **B**e faithful to one uninfected partner, who should also be faithful, or
- If you choose **C**ondoms: Use a new condom (female condoms are available) properly each and every time you have sexual intercourse.

The **ABC** is also known as **safer sex options**.

### Couple counselling



Counselling helps a couple to decide how to protect themselves against HIV infection



In reality, most couples have sex before getting married. It is always advisable for both of them to have an HIV test before engaging in sexual intercourse and going into marriage.

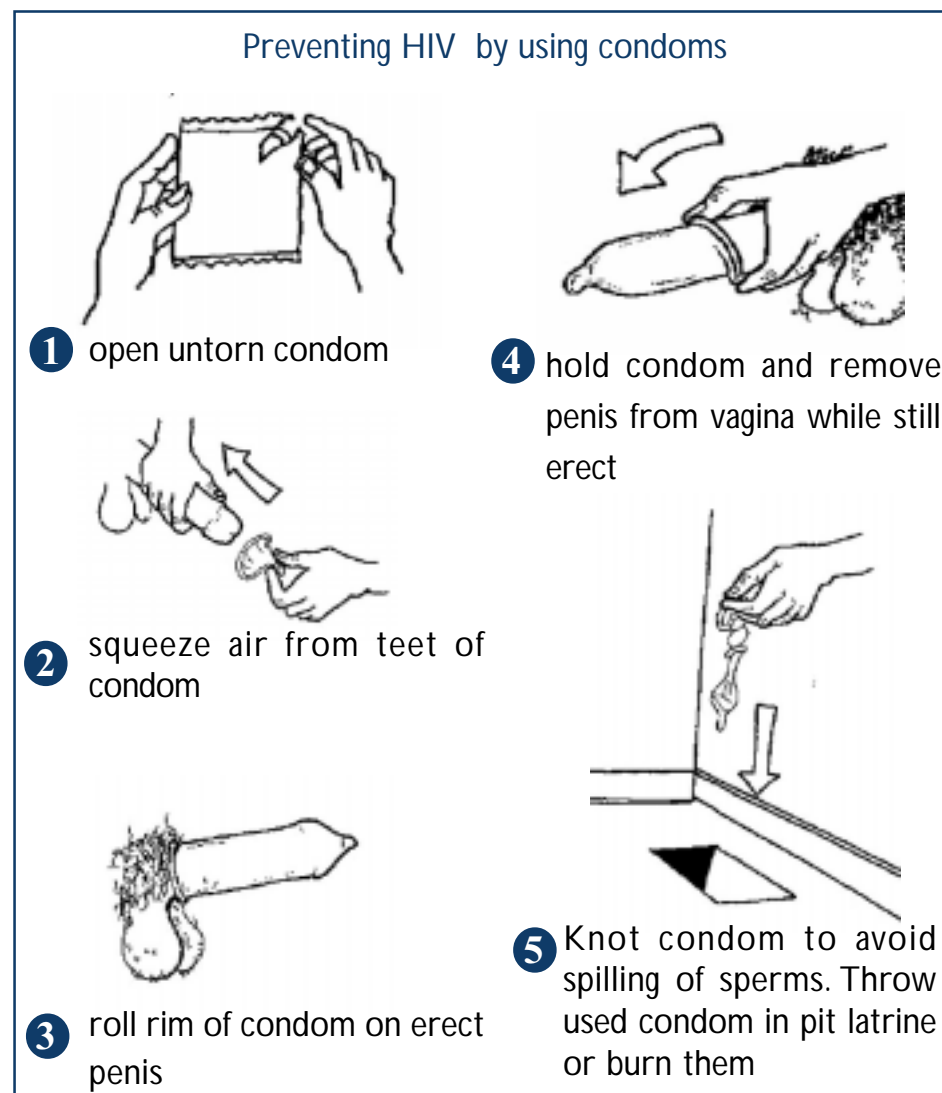
If only one partner has been tested, or one does not wish to be tested, or one partner is found to be HIV-positive, the best option for having sex is to use condoms.

## Condom use

### The Male Condom

- Using a condom correctly every time you have sex can prevent HIV transmission. Next to abstinence or being faithful to one partner (where both partners are known to be HIV negative), condoms are the best protection against HIV. Condoms also protect against other sexually transmitted infections (STIs) and pregnancy.
- Condoms should be used consistently and properly (ensure that the condom does not leak, tear or slip off and is not expired).
- Condoms should be stored properly; away from direct heat and light and should not be kept together with objects that can prick them. Condoms should not be kept in pockets or bras for a long time before being used.

- Never use a condom whose seal or cover has been broken or torn.
- Dispose used condoms by burning or throwing them in a pit latrine. Use condoms only once.



## The Female Condom

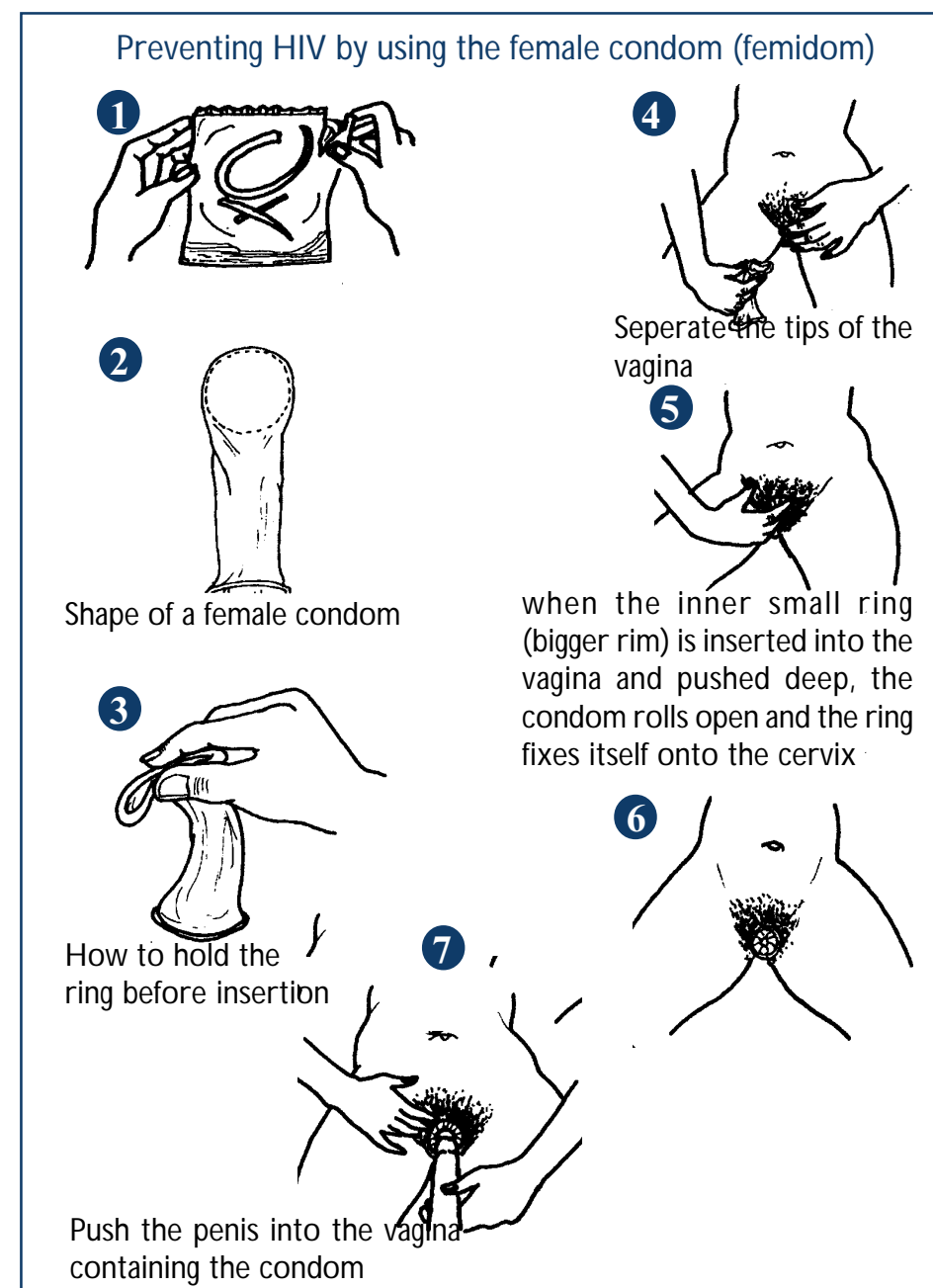
Female condoms are now available in Uganda. Like the male condom, the female condom is a barrier between a man's penis and a woman's vagina. The female condom is soft and thin and made of plastic. It fits into the inside of the vagina.

- The female condom, like the male condom, is for one time use only, and should be disposed of safely immediately after use, by burning it or throwing it in a pit latrine.
- Female condoms also protect against transmission of STIs, including HIV, and pregnancy. They serve the same purpose as the male condom, except that the female condom is inserted into the woman's vagina.
- The female condom can be inserted in the vagina up to eight hours before sex.

## Where to obtain both male and female condoms

Male and female condoms can either be obtained free of charge or bought.

- Free condoms are available at all Family Planning clinics, HIV counselling and testing centres and other HIV/AIDS service organizations.
- Condoms can be bought from pharmacies, drug shops and supermarkets.



## Non-penetrative sex

- Some people choose to express love, affection and sexual gratification by kissing, caressing and masturbating. There is no risk of contracting HIV in kissing, caressing and masturbating.

However, there is a risk of HIV transmission if you engage in oral sex with an HIV infected person.

**Caution:** penetration of vagina or anus by penis, finger or tongue carries a definite risk of HIV transmission.

## Mother-to-Child Transmission

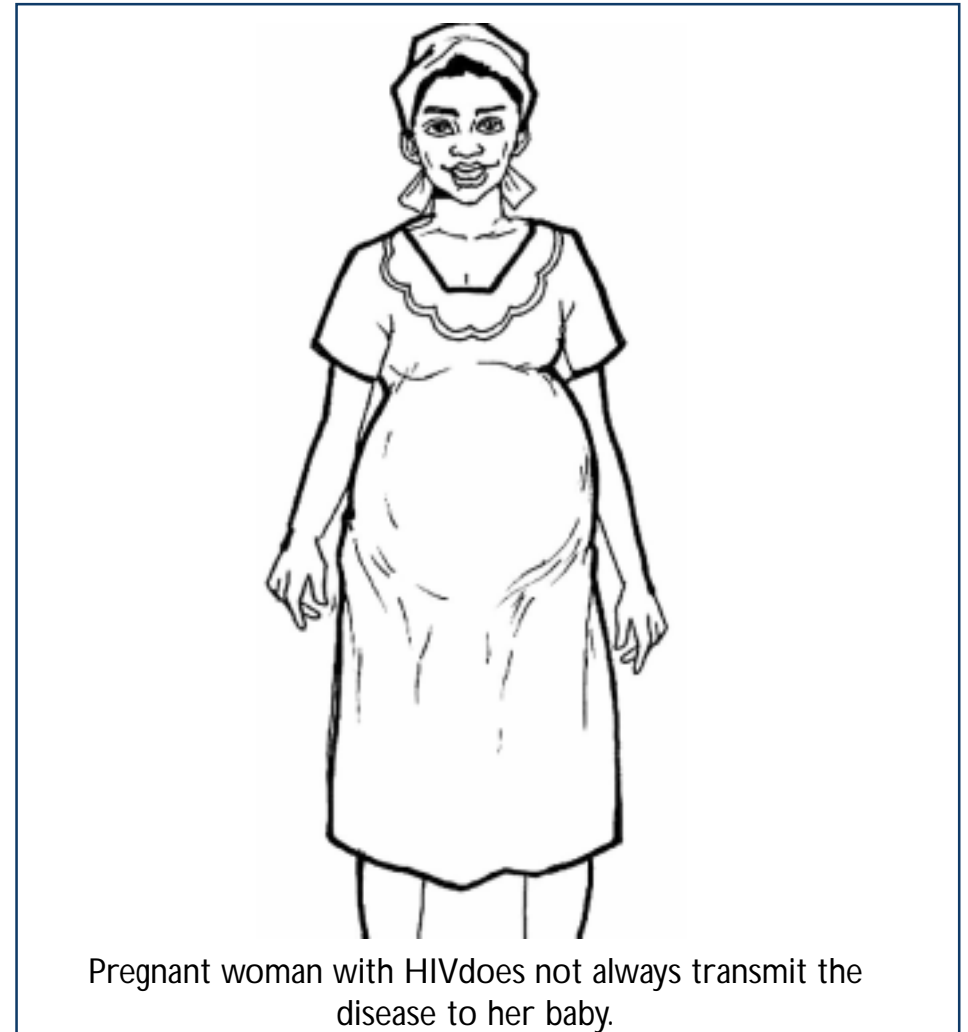
HIV can be passed from a mother to the baby during

- pregnancy
- labour and delivery, or
- breastfeeding

## HIV Transmission before and during birth

- In Uganda, it is estimated that *about* 3 out of 10 babies born to HIV-positive mothers will be HIV infected. That means that the majority of mothers with HIV will *not* pass the virus to their new born babies.
- Most babies do not contract HIV from their mothers while in the womb because the placenta acts as a barrier between the baby's and the mother's blood circulatory system.
- In rare cases, HIV can leak across the placenta to the unborn baby who will then acquire the virus.

At birth when the baby travels through the mother's birth canal, damage can occur to the baby's skin and HIV can be transmitted to the baby as it comes into contact with the mother's blood. This is why the time of labour and birth are the most common moments of HIV entering the baby's system.



## HIV transmission through breastfeeding

Some babies are infected after birth, through breast milk. HIV transmission through breastfeeding is more likely if the mother is very ill with HIV related illnesses.

Women who are very ill with HIV related illnesses need to consider substituting breast-feeding with animal milk or infant formula.

HIV transmission through breastfeeding is also more likely to occur if the mother has cracked nipples or breast abscesses.

Women who are breastfeeding should therefore seek more information from a health worker about good breastfeeding techniques.

Babies who have sores in the mouth or oral *thrush* (oral candida) are more likely to be infected with HIV through breastfeeding. Mothers should check their babies' mouths for the presence of thrush (white spots or patches inside the mouth).

Thrush also results into loss of appetite. If a mother sees that her baby has sores in the mouth, she should take him/her to a health worker for treatment and guidance.

- Couples who are considering having a baby are encouraged to have an HIV test to enable them make appropriate decisions based on their HIV results.
- If an HIV-negative woman gets infected with HIV during pregnancy or when she is breastfeeding, she is very likely to pass on the virus to her baby.
- Pregnant women who are HIV-negative should be counselled on the importance of remaining negative during pregnancy and breastfeeding because of the risk of **passing HIV to their baby and for their own safety**.

**Partners of pregnant women who are HIV-positive or have not been tested for HIV, should use condoms every time they have sex.**

## **Prevention of mother-to-child HIV transmission (PMTCT)**

There are several things that an HIV-positive mother can do to help reduce HIV transmission to her baby. The following are some of the useful tips on prevention of HIV transmission from mother-to-child.

### **Taking special anti-HIV medicines to prevent MTCT.**

The anti-HIV drug that is usually given is **nevirapine and it is given as a single dose at the onset of labour, and to the baby within the first 72 hours after birth.**

Since Nevirapine was proved to reduce transmission from the HIV infected mother to their babies markedly, the government decided to introduce it to all major hospitals and give it to pregnant women free of charge. At the time of writing, 20 districts had been covered.

"I really want to have a baby. I know that I am HIV-positive. Is there anything I can do to prevent my baby from getting HIV too?"

HIV positive pregnant mother

There is a chance to reduce HIV transmission to your baby by using Nevirapine during Labour, giving Nevirapine syrup to your newborn baby within 72 hrs of life and opt not to breast feed at all. Go to hospital for assistance.

Thinking about getting a baby



### **Making sure your baby is delivered safely**

Delivery is the time of greatest risk for HIV to be transmitted to a baby. It is very important for the mother to have her baby delivered with help from trained midwives who ensure that all necessary precautions are taken and that she and the baby are safe. Pregnant women need to start attending antenatal clinics at the nearest health centre as early as the 3rd month of pregnancy. Good antenatal care reduces MTCT in utero.

### **Making infant feeding as safe as possible**

As mentioned earlier, HIV occurs in the breast milk of an HIV infected mother and she can pass it on to her baby by breastfeeding.

### **Scenario Options for Discussion to Help Clarify Decision Making for HIV Infected Women Living in Different Circumstances in Resource Poor Settings [Source WHO]**

#### **Scenario A**

In settings where the water supply is generally unsafe without additional preparation steps, where infant mortality is high, where the cultural norms foster breastfeeding, and where social harms from not breastfeeding are substantial, then exclusive breastfeeding followed by weaning at around 6 months could be the general approach supported for most HIV infected women. However,

#### Antenatal Care



A pregnant woman should always attend antenatal care.

#### Breast feeding



An HIV positive mother who chooses to breast feed must do so exclusively for not more than 6 months or till when breastmilk is not enough for her baby

since it remains her individual choice, the HIV infected woman should also be told that formula is available if she chooses that option and be made aware of the preparation steps necessary to make water safe and how to use a cup for formula feeding. HIV infected women in such circumstances who choose breast feeding need skilled help including advice on feeding techniques, prevention of mastitis and cracked nipples, and general breast care. Once a woman makes her choice of feeding type, then she should be strongly supported in that choice.

### **Scenario B**

In settings where water supply is generally safe, infant mortality is relatively low but the social stigma associated with not breastfeeding remains high, then discussion with the HIV infected woman should include specific suggestions on possible ways to lessen the stigma attached to use of formula. HIV infected women in such circumstances should receive skilled help regarding safe formula preparation. Again the choice of feeding type remains with the individual woman and the counselor should support the woman in whatever choice she makes.

### **Scenario C**

In settings where water supply is generally safe and social stigma associated with not breastfeeding can be effectively dealt with, then HIV infected women should be encouraged to formula feed

from birth. As with other scenarios, the choice of feeding type remains with the individual woman and counselor should support the woman in whatever choice she makes.

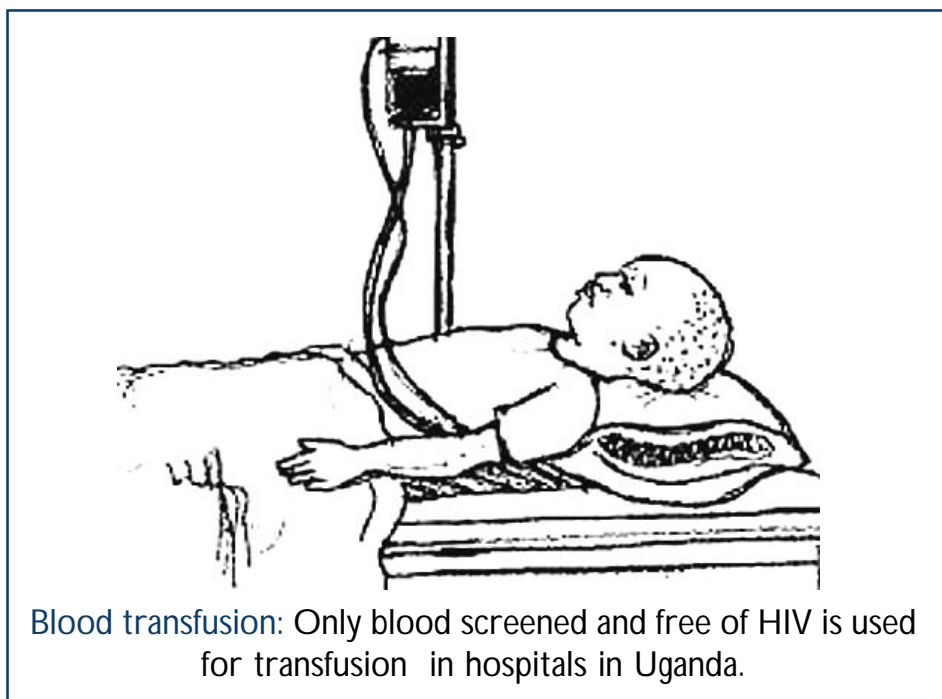
### **Blood transfusions**

It has earlier been mentioned that HIV survives in most of our body fluids, including blood. HIV can be transmitted through blood-to-blood contact, such as during blood transfusions. However, in many countries, including Uganda, blood obtained from hospitals and other health centres is screened for HIV and other diseases by national blood transfusion services. Once blood is known to be HIV free, it can be given safely to those in need of a transfusion. Blood transfusions are commonly given to children and pregnant women if they are found to be severely anaemic (having low hemoglobin levels), as a result of being sick for a long time, (for example with malaria) or of malnutrition.

### **Prevention of anaemia related transmissions**

Blood transfusion and therefore the risk of HIV transmission through blood transfusion can be avoided by:

- seeking prompt medical treatment from health centres
- feeding children on well-balanced, iron rich diets to prevent anaemia
- encouraging pregnant women to attend antenatal clinics where they will receive iron supplements that will help prevent



**Blood transfusion:** Only blood screened and free of HIV is used for transfusion in hospitals in Uganda.

anaemia during pregnancy. (See section 3.3 on nutrition for children.)

### **Skin piercing and scarification**

HIV can be transmitted through the use of needles contaminated with HIV; that is, unsterilised needles. HIV can also be transmitted if unsterilised razor blades are used for cutting the skin, as is often done in traditional healing instances for the application of cures.

“I took my young daughter to the private doctor recently and he said that she needed a vitamin injection. I was a bit worried because I don’t think the needles were new, so I refused to let him give her the injection. Was this the right thing to do?”

Mother of a 4-year-old girl

It is usually recommended to take children for medical treatment to health centres where health workers are trained to follow the necessary procedure and ensure that all injections and other equipment are properly cleaned and sterilised.

### **Prevention of transmission through skin piercing and injections**

Always use disposable needles and never share needles or skin piercing instruments for piercing ears or other parts of the body. Always go to a health centre for medical treatment. If you or your child needs an injection, ask if the needle and syringe are sterile. You can check to make sure that the health worker unwraps a new needle or syringe, or has facilities to sterilise reusable equipment.



## Prevention of transmission through body fluids.

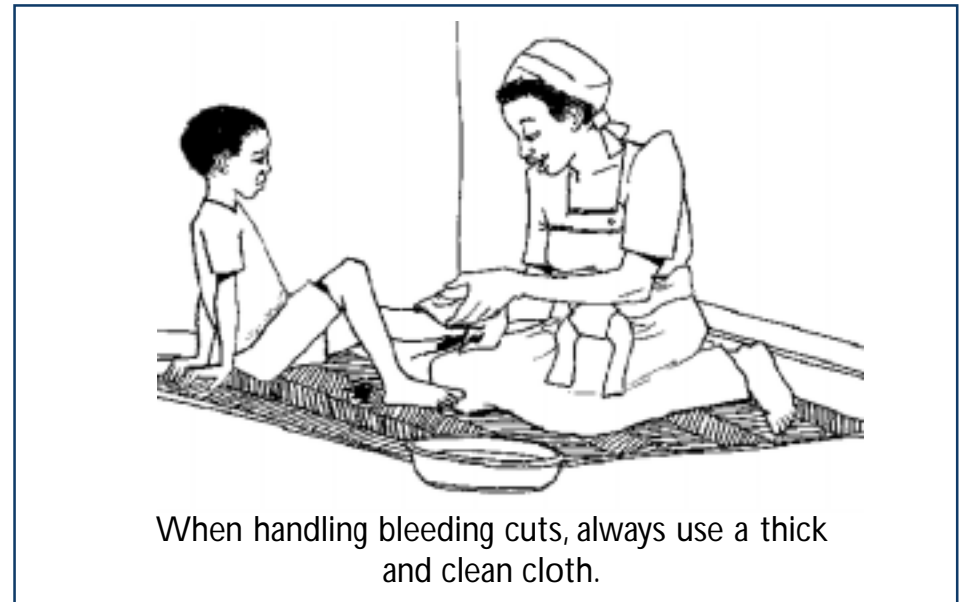
### Accidents

"I am looking after my sister's young son. I am sure he has AIDS, his mother died of AIDS two years ago and he has of recent been very sickly on and off. I worry all the time in case he has a cut and some of his blood got on my skin."  
Guardian

Sickly children born to HIV infected women are likely to be HIV infected themselves. Take your nephew to a hospital that cares for HIV infected children. Here you may have your nephew tested for HIV after you have been counselled.

Carers often worry about getting HIV from the person they are caring for, in case of an accident or any blood being spilled. When infected blood is spilled onto a skin which does not have any cuts there is no risk of HIV transmission. However if you have a cut on your skin and infected blood is spilled on to it, there is a *small* risk of HIV infection. You should cover cuts and sores as advised below.

- Carers should always cover any cuts and grazes on their and the patients' skin with a plaster or bandage when nursing someone with HIV.



- Do not touch blood-stained vomit or diarrhoea or blood with bare hands.
- Wear gloves or cover hands with plastic bags to handle body fluids and soiled cloth.
- If blood from a person with HIV is accidentally spilled on another person's skin it should be washed off with soap and water as soon as possible. If these precautions are taken there is probably no risk of getting HIV.

### 1.3 HIV infection in children

The point from which an **adult** becomes infected with HIV until he/she begins to become seriously ill with opportunistic infections is often about 2 to 15 years. This is often referred to as the **incubation period**. The incubation period may be as short as under two years, or as long as fifteen years or longer. In **children** the incubation period is often shorter than it is in adults. During this period, the person is normal and looks healthy. Despite this the person can infect others with the virus if he/she has unprotected sex with them or the infected blood is in contact with another's open wounds or donated. In Uganda many children who are infected with HIV at birth will become ill and die in the first two years of their lives. However, with improving care, many children with HIV will be well for much longer and some will live for many years, growing into teenagers.

#### Asymptomatic Stage

Several months, and often years, may pass before a child infected with HIV becomes unwell in any way. This incubation period is sometimes called the *asymptomatic* HIV stage. During this period few, if any, symptoms of illness occur. Despite the absence of signs and symptoms, HIV continues to weaken the immune system of the child.

#### Symptomatic Stage

As time passes, some signs and symptoms may occur. This period is called the *symptomatic* stage. Some of the non-specific symptoms or conditions that may occur in children include lingering colds and flu, chronic headaches, chronic diarrhoea, fever, weakness and tiredness, night sweats, loss of appetite, loss of weight, dry cough, swollen glands (particularly in the neck and axillae) or skin rashes. During this symptomatic period children may be very unwell for some time, then get better and stay well for many months before becoming unwell again.

#### AIDS

As time passes the cells that produce antibodies against HIV are depleted and the child's immunity is weakened even further. Opportunistic diseases and conditions, more serious than those during the symptomatic period, appear during this period. Currently, HIV antibody testing for children in Uganda is uncommon. Children with a series of opportunistic infections are considered to have AIDS and therefore are given the appropriate care. Take them to hospitals where they treat children with HIV/AIDS for proper diagnosis and treatment.

#### Opportunistic Infections

Opportunistic diseases emerge because the immune system is not working properly. A person with a healthy immune system

is less susceptible to these diseases than a HIV positive person. Once the body can no longer defend itself against diseases because its immune system is not working well, serious infections can occur.

### **Preventing opportunistic infections**

There are many opportunistic diseases and conditions associated with AIDS. Some of these can be prevented with **prophylaxis**, or a treatment to prevent these infections. Other conditions are only treated once the person is sick.

The common opportunistic diseases notable in children in Uganda are tuberculosis (TB), candidiasis (thrush in the mouth), and a type of pneumonia known as Pneumocystic Carinii Pneumonia (PCP).

The opportunistic infection that can cause pneumonia in babies and young children can be prevented by giving an antibiotic called cotrimoxazole (septrin) every day.

**Tuberculosis (TB)** is a bacterial infection that is spread through droplets by an infected person coughing or sneezing. **(See also the section on cough in 3. 4.)**

**Candidiasis** is a fungal infection, commonly known as

“thrush”.It appears as white, sometimes painful patches on the tongue and ulcers in the mouth that make it difficult for the patient to swallow.

**Pneumocystic Carinii Pneumonia (PCP)** is a protozoal infection of the lungs that can cause severe pneumonia. When a child has PCP he or she will have difficulty in breathing, fever and a dry cough. PCP is a common cause of death in babies with AIDS in Uganda. Because of this, HIV-infected babies and infants can sometimes be given cotrimoxazole (septrin) prophylaxis. **(See also Chapter 3 regarding special medical treatments for children with HIV.)**

# HIV Counselling and Testing

This chapter tells you about HIV counselling and testing. It explains what a counsellor does and what happens if someone wants to take an HIV test. It discusses the benefits of and cautions against HIV testing for adults, children and the meaning of HIV test results.

## Sources of counselling and testing

If you want to know whether or not you have HIV infection you can attend one of the many ‘**voluntary counselling and testing**’ (or VCT) sites in Uganda. The **AIDS Information Centre (AIC)** offers voluntary counselling and testing for adults and children who are over 12 years old at its many sites throughout Uganda. The Ministry of Health has plans for making voluntary counselling and testing even more widely available, with sites in every district, and is planning to train many more people to be HIV counsellors.

### 2.1 Who is a counsellor?

A counsellor is someone who is trained to help you understand your situation, think about possible solutions to problems and

answer questions you may have. He/she helps you make your own plans and decisions about what to do to enable you cope with your problem.

**Counselling** is talking to a counsellor about your situation and your problems and worries. The counsellor will help you make plans and decisions, give you information and help you find answers to your questions. Counselling is not about telling you what to do; it is about helping you decide what *you* think is best to do and giving you support for following your decisions through.

**Counsellors** have special training so that they can help you make decisions about HIV testing and then support you after you get your HIV test results. Sometimes HIV counsellors are nurses or teachers, but they can be *anyone* else who has had special HIV counselling training.

### 2.2 What is voluntary counselling and testing?

If you want to know whether you have HIV or not, you can

discuss this with a trained HIV counsellor. The counsellor will listen to you and discuss the advantages and disadvantages of being tested for HIV. She or he will discuss with you any worries you might have about being HIV-positive and how you could live better with the result if you tested HIV-positive. This is called **pre-test counselling**. During pre-test counselling, the counsellor will discuss with you issues about HIV prevention and your personal and family life. Once you feel that you are ready to go ahead with the HIV test a blood sample will be taken from you for **HIV testing**. Sometimes people will want some time to think about HIV testing or want to discuss it with their partner or family first. If this is your situation you can ask to come and see the counsellor again after a few days. You can come back on your own or you can bring your partner or a close family member. The counsellor will tell you that everything you have discussed is **confidential** and only the counsellor and you will know your test result.

If you decide to share your test result with anyone this will be your personal choice. In some voluntary counselling and testing centres you will not have to give your name. This is called **anonymous** testing.

When the HIV test result is ready you will meet the counsellor again for **post-test counselling**.

- During post-test counselling the counsellor will review with you information that you discussed during pre-test counselling and tell you your HIV test result.
- The result is being either HIV-positive or HIV-negative.
- The counsellor will explain to you what your result means.
- The counsellor will help to support you and will listen to the worries you want to express.
- The counsellor will help you make plans for the next few days and make sure that there is someone to support you at home if you need it.
- The counsellor will also help you decide whom, if anyone, you want to tell about your result.
- Often, when people have tested positive, they can not take in much information immediately after they get their test results, due to worry, confusion or anxiety.
- The counsellor may therefore ask you to come back in the next few days, to help you understand your result better and also guide you on what you need to do in order to live positively.
- The counsellor will help you identify organisations like TASO that can provide further counselling and support to you and members of your family.
- If your result is HIV-negative, the counsellor will discuss with you the options available for you to remain HIV-negative forever.

- Some people find it helpful to see their counsellor several times. This supports them to understand their situation and be able to live a better and meaningful life with their HIV result and plan for the future.

## 2.3 HIV Tests

When your blood is taken for HIV testing it will be checked to see if it has any **'antibodies to HIV'**. (See Chapter 1 for information about antibodies). Most HIV tests used in Uganda depend on detecting antibodies and not on detecting the viral load.

There is a time called the **'window period'** - from the time of infection to the time when the body has produced enough

### An HIV test can tell you:

- If you have HIV antibodies in your blood and are HIV positive.

### An HIV test cannot tell you:

- When you got infected with HIV
- Who infected you with HIV
- How you got infected with HIV
- Whether you have AIDS or not
- How long you will live with the HIV in your body

antibodies *to be detected on an HIV antibody test*. This period is usually less than six weeks. This means that a person who has just been infected may test negative for HIV because their body has not produced enough antibodies to be detected by the test. Such a person can still pass the virus to others if, for instance he or she donates blood or has unprotected sex, or to her baby if she becomes pregnant. There are two main methods of HIV antibody testing being used in Uganda. These are the ELISA and rapid testing methods.

### ELISA Tests

The enzyme linked immunosorbent assay or ELISA Tests is used in hospitals with laboratories. A blood sample is taken from your arm and stored in a glass tube. Results of the ELISA will be given to you within 3 to 7 days, however, some laboratories take up to two weeks.

### Rapid Tests

Rapid tests are much simpler to do and can be done in clinics. They are as accurate as ELISA tests. A very small sample of blood is taken from your fingertip and results can be availed in less than 10 minutes so that people can learn their HIV test result in one day. Some health centres in Uganda have trained counsellors who provide pre- and post-test counselling and laboratory technicians who carry out rapid testing. The AIC

centres in Uganda are also now using rapid testing. Some private clinics use rapid testing, but they may not always provide pre-test and post-test counselling.

## 2.4 Benefits of having an HIV test

### Should adults or young persons have an HIV test?

There are many good reasons why it is helpful for an adult or young person to know their HIV status.

#### Benefits for people who test HIV-negative

If you take an HIV test and you find out that you are HIV-negative,

- You then know that you do not have the HIV virus.
- Many people in Uganda worry that they are infected, but no one can be certain until they have had an HIV test.
- Even though HIV is a very serious problem in Uganda, **MOST** people do not have HIV. If you know that you are HIV-negative this can help you ensure practices that will make you stay HIV-negative forever.
- Often when people learn that they are HIV-negative, they take much more care to practise safer sex and protect their health. Many young people in Uganda decide to take an HIV test before they have sex with a new partner or get married.

#### Benefits for people who test HIV-positive

There are many benefits of knowing your status if you test HIV-positive.

- You can prevent transmitting HIV to your partner, if he or she is still negative.
- Disclosing your HIV situation to your spouse helps the two of you to make mutual decisions about prevention practices.
- People who test HIV-positive can do many things to help themselves keep healthy and live longer eg. adopt a positive life style with support from AIDS care organisations like TASO. In TASO, they can get earlier treatment of opportunistic infections and preventive therapies for HIV-associated infections. They may also be able to get social and emotional support to help them cope and plan for their own life and the future of their families.
- If women know that they are HIV-positive, they can decide against becoming pregnant so that they do not pass HIV to their babies. Pregnant women who test HIV-positive are advised to take anti-HIV medicines to reduce chances of passing HIV to their babies. Anti-HIV medicine for HIV-positive mothers can be obtained from all regional hospitals in Uganda, including Mulago, Mbale, Arua, Kabarole, Masindi hospitals.

Some people worry that they would not be able to cope if they were found to be HIV- positive. It is completely normal to feel upset, sad or angry following the announcement of an HIV- positive test result. But with time nearly everyone begins to accept the situation and to try to live better with it. Support from a counsellor or sharing the news with a close friend or family member is very useful for coping, particularly in the first few weeks after getting the test result. However, if you really felt unable to cope if you were found to be HIV-positive, the counsellor would support your decision not to test, or give you time to go and discuss it with a friend or family member.

“If I had an HIV test and I was found to be positive I would be too sad and I think it would make me die sooner. It is better not to know isn't it?”

Just like any other problem, knowing that you are HIV positive creates a lot of worry, anxiety and confusion and we feel that we are soon dying. However, with proper counselling guidance and support, you come to terms with the the situation and practice to live positively. Living positively means taking care of your health and mind and practising behaviours that will stop the spread of HIV to other people. When you know you are HIV infected, you do something about it and this makes you live longer.

## Support services for people with HIV

In Uganda there are many organisations that help and support people and families with HIV infection. Some of these are big organisations like TASO, AIC and Mildmay Centre. There are also HIV/AIDS home based care programmes in mission hospitals (in Kampala there are services at Nsambya, Rubaga and Mengo). In other district hospitals, there are other organisations that provide medical care or home visits and counselling. Mildmay Centre provides medical care and counselling for both adults and children. **(See details for available services on page 24.)**

## 2.5 HIV testing for babies and children

As pointed out earlier, HIV test kits detect **antibodies** for HIV. Babies have their mothers' antibodies in their blood for up to 18 months following birth. This means that testing babies under the age of 18 months using the HIV antibody test may not give the true result for the baby. In some large hospitals and research settings there are HIV tests which detect the HIV virus itself. These tests can detect HIV in babies when they are younger than 18 months. These special HIV tests are expensive and difficult to do, and are therefore very rarely available.

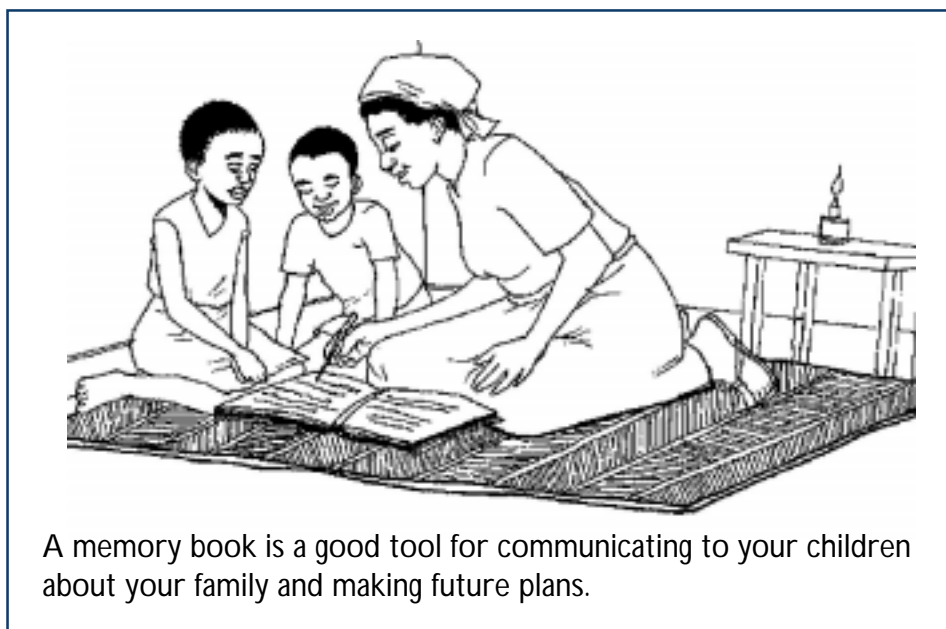
Although babies over 18 months and children can be tested for HIV, the advantages and disadvantages of HIV testing for them must be considered carefully. Counselling is essential for the



## Support services for people with HIV/AIDS

<p><b>The AIDS Support Organisation (TASO)</b></p> <p>TASO offers a wide range of support and care services for people with HIV, including medical care, on-going counselling, home visits, community programmes, day care centres and child support schemes.</p> <p>TASO has centres in Kampala, Jinja, Tororo, Mbale, Mbarara, Entebbe and Masaka. For more information you can contact any of these branches or the head office at TASO Kanyanya, P.O Box 10443, Kampala Tel: 041-11485 Email: <a href="mailto:tasomul@infocom.co.ug">tasomul@infocom.co.ug</a></p>	<p><b>AIDS Information Centre (AIC)</b></p> <p>AIC provides quality VCT, STD, family planning, TB and post-test clubs. AIC services can be got from nearly all hospitals and health centres in Uganda. For more information, you can contact the head office at Musajjalumbwa., Mengo-Kisenyi, P.O Box 10446 Kampala Tel:041 231528 Email: <a href="mailto:kiggundu@aicug.org">kiggundu@aicug.org</a></p>
<p><b>Mildmay Centre</b></p> <p>The Mildmay Centre in Kampala offers a wide range of medical and support services for adults and children with HIV. There is a special centre for children called <b>Jajja's home</b>. Jajja's home is a children's day care centre offering rehabilitation for children with HIV. A centre for adolescents with HIV will be opening there soon. The Mildmay Centre runs outpatient medical services for children with HIV. For more information contact Mildmay Centre at Kajjansi-Entebbe Road, P.O Box 200054 Email: <a href="mailto:mildint2@infocom.co.ug">mildint2@infocom.co.ug</a></p>	<p><b>National Community of Women living with HIV - Uganda (NACWOLA)</b></p> <p>NACWOLA is an organisation of HIV positive women and has branches in nearly all districts of Uganda.</p> <p>NACWOLA engages in self-resilience and sustainable activities, such as income generating activities. NACWOLA also supports mothers to write memory books for their children. A memory book contains family history, special events of the child as he/she grew up, wishes of the parents to the child, important people to the child and any future plans.</p> <p>Mothers of NACWOLA are empowered to communicate better with their children about sensitive HIV/AIDS related family issues. NACWOLA also creates awareness about HIV/AIDS in communities using personal testimonies and drama. For more information about NACWOLA, contact any AIDS care organisation, like TASO, in your district.</p>

NOTE: Each Community Health Worker should know support groups in their local areas



A memory book is a good tool for communicating to your children about your family and making future plans.

parent(s) or guardian(s), and other members of the family where appropriate, both before and after testing.



Medical care for children with HIV

### **Things to consider before testing babies and children for HIV**

#### **1. Are there any advantages for my child if we know his/her status?**

Yes, there are special medical treatments for children who are found to be HIV-positive, knowing their status could be of great benefit. For example if health workers know that the illnesses that the child is suffering are due to HIV, it will help them understand the best ways of treating the illnesses and controlling the pain. The health workers will also advise the carer the kind of food the child needs to eat.

“I can’t see the point in testing my baby. She seems very healthy. I might think about it if she became sickly.”

Mother with HIV

Yes, most children born to HIV infected mothers do not get infected. Test the baby if/when he/she starts falling sick.

Sometimes parents who know that their child has HIV can look after their child better. By seeking medical help more quickly improving nutrition, and providing emotional support.

Sometimes medicines can be given to prevent HIV-related illnesses. Children known to have HIV can be given therapies such as cotrimoxazole (septrin) to prevent pneumonia. This kind of treatment should be given under the guidance and supervision of a health worker.

If you know that your child has HIV you may also be able to support him/her better and be more understanding if he/she is frequently unwell or tired.

## **2. Are there any disadvantages for my child if she/he is tested?**

It is usually better to know if your child has HIV, because you can make sure that he/she has better medical care and is supported emotionally. However, if there is any possibility that a child will be discriminated against if he or she is found to be HIV-positive, an HIV test should not be done.

The HIV testing of babies and children should only be considered if knowing their HIV-positive status would help them get better care and not lead to neglect or discrimination.

Many mothers and fathers do not want their baby to be tested for HIV for genuine personal reasons, even if they know that they can easily get an HIV test to be done. Parents and guardians should be able to discuss HIV testing with a counsellor and if they decide that there are no benefits to be gained from HIV testing at the moment, this decision should be supported. They should be reassured that they can always discuss worries about their child with a counsellor in the future. If, for example, their child becomes ill and HIV testing could help in deciding the best medical care this could be considered at that time.

## 2.6 HIV counselling and testing for adolescents

Children over 12 years do not need the consent of their parents to be tested for HIV in Uganda. They may, however, choose to have a parent or any other adult with them when they are counselled and tested to give them the necessary support. Having another person attend counselling with the young person should be discussed and encouraged.

Adolescents should be treated with the same respect as any other person who seeks HIV testing and counsellors must be careful not to be judgmental about their situation. (See Chapter 4, sections 4.1 and 4.2 on communicating with adolescents).

Counselling adolescents will often take more time than counselling adults. They may need more information, but they may also be less willing or able to open up about their circumstances, as well as their thoughts and feelings. Counsellors should spend as much time as is necessary with young clients.

### Communicating with adolescents

Many parents and guardians have difficulty talking to young people about sensitive issues. Sometimes it can be helpful for the guardian or the adolescent to discuss things with a counsellor or health worker (*see section 2.6 on counselling adolescents.*) Adolescents between the ages of 10 and 18 go through a period of rapid

“My niece is an orphan and she has lived with me for the past 2 years since my sister died. She has had quite a few bouts of malaria and I think I should check her for HIV. She is 14 years old and very shy, so I don't think I could discuss it with her.”

You can encourage your niece to join any peer education group or visit a health unit that provides youth friendly services in your area. She will be helped to acquire more information about HIV and AIDS and other adolescent reproductive problems. She will also come to know how to prevent HIV and issues related to HIV testing.

emotional and physical growth. But they often lack the information, skills and maturity to protect their health and they continue to depend on adults for advice. In some parts of Uganda, there are clinics that offer ‘youth-friendly health services’. Health care workers and counsellors learn to make young people more comfortable about seeking services such as family planning, pregnancy testing, screening for sexually transmitted infections and counselling and testing for HIV.

Youth-friendly communication is supportive, non-judgmental and confidential. The most effective youth-friendly services depend on the participation of young people themselves as community animators and peer educators. When young people know that such services are available for them, they are more willing to talk

## Counselling Adolescents



Adolescents need consistent information about HIV/AIDS and if sexually active, advice on safe sex behaviour should be given.

about their problems and take better care of their health as they become sexually active.

Everyone in the community needs to learn to be open about the difficulties that young people face today. If parents or guardians find it difficult or awkward to discuss sensitive matters with their adolescent children, they can speak with a counsellor about this. Many counsellors are trained to talk with young people about sensitive issues such as sexuality and HIV prevention. They can help older people learn to talk more openly about these subjects or find other caring adults- such as other family members or religious leaders- to listen to and advise their youngsters.

# HIV Counselling and Testing

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## Sources of counselling and testing

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**Counsellors** have special training so that they can help you make decisions about HIV testing and then support you after you get your HIV test results. Sometimes HIV counsellors are nurses or teachers, but they can be *anyone* else who has had special HIV counselling training.

### 2.2 What is voluntary counselling and testing?

If you want to know whether you have HIV or not, you can

discuss this with a trained HIV counsellor. The counsellor will listen to you and discuss the advantages and disadvantages of being tested for HIV. She or he will discuss with you any worries you might have about being HIV-positive and how you could live better with the result if you tested HIV-positive. This is called **pre-test counselling**. During pre-test counselling, the counsellor will discuss with you issues about HIV prevention and your personal and family life. Once you feel that you are ready to go ahead with the HIV test a blood sample will be taken from you for **HIV testing**. Sometimes people will want some time to think about HIV testing or want to discuss it with their partner or family first. If this is your situation you can ask to come and see the counsellor again after a few days. You can come back on your own or you can bring your partner or a close family member. The counsellor will tell you that everything you have discussed is **confidential** and only the counsellor and you will know your test result.

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- Some people find it helpful to see their counsellor several times. This supports them to understand their situation and be able to live a better and meaningful life with their HIV result and plan for the future.

## 2.3 HIV Tests

When your blood is taken for HIV testing it will be checked to see if it has any **'antibodies to HIV'**. (See Chapter 1 for information about antibodies). Most HIV tests used in Uganda depend on detecting antibodies and not on detecting the viral load.

There is a time called the **'window period'** - from the time of infection to the time when the body has produced enough

### An HIV test can tell you:

- If you have HIV antibodies in your blood and are HIV positive.

### An HIV test cannot tell you:

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- How you got infected with HIV
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antibodies *to be detected on an HIV antibody test*. This period is usually less than six weeks. This means that a person who has just been infected may test negative for HIV because their body has not produced enough antibodies to be detected by the test. Such a person can still pass the virus to others if, for instance he or she donates blood or has unprotected sex, or to her baby if she becomes pregnant. There are two main methods of HIV antibody testing being used in Uganda. These are the ELISA and rapid testing methods.

### ELISA Tests

The enzyme linked immunosorbent assay or ELISA Tests is used in hospitals with laboratories. A blood sample is taken from your arm and stored in a glass tube. Results of the ELISA will be given to you within 3 to 7 days, however, some laboratories take up to two weeks.

### Rapid Tests

Rapid tests are much simpler to do and can be done in clinics. They are as accurate as ELISA tests. A very small sample of blood is taken from your fingertip and results can be availed in less than 10 minutes so that people can learn their HIV test result in one day. Some health centres in Uganda have trained counsellors who provide pre- and post-test counselling and laboratory technicians who carry out rapid testing. The AIC



centres in Uganda are also now using rapid testing. Some private clinics use rapid testing, but they may not always provide pre-test and post-test counselling.

## 2.4 Benefits of having an HIV test

### Should adults or young persons have an HIV test?

There are many good reasons why it is helpful for an adult or young person to know their HIV status.

#### Benefits for people who test HIV-negative

If you take an HIV test and you find out that you are HIV-negative,

- You then know that you do not have the HIV virus.
- Many people in Uganda worry that they are infected, but no one can be certain until they have had an HIV test.
- Even though HIV is a very serious problem in Uganda, **MOST** people do not have HIV. If you know that you are HIV-negative this can help you ensure practices that will make you stay HIV-negative forever.
- Often when people learn that they are HIV-negative, they take much more care to practise safer sex and protect their health. Many young people in Uganda decide to take an HIV test before they have sex with a new partner or get married.

#### Benefits for people who test HIV-positive

There are many benefits of knowing your status if you test HIV-positive.

- You can prevent transmitting HIV to your partner, if he or she is still negative.
- Disclosing your HIV situation to your spouse helps the two of you to make mutual decisions about prevention practices.
- People who test HIV-positive can do many things to help themselves keep healthy and live longer eg. adopt a positive life style with support from AIDS care organisations like TASO. In TASO, they can get earlier treatment of opportunistic infections and preventive therapies for HIV-associated infections. They may also be able to get social and emotional support to help them cope and plan for their own life and the future of their families.
- If women know that they are HIV-positive, they can decide against becoming pregnant so that they do not pass HIV to their babies. Pregnant women who test HIV-positive are advised to take anti-HIV medicines to reduce chances of passing HIV to their babies. Anti-HIV medicine for HIV-positive mothers can be obtained from all regional hospitals in Uganda, including Mulago, Mbale, Arua, Kabarole, Masindi hospitals.

Some people worry that they would not be able to cope if they were found to be HIV- positive. It is completely normal to feel upset, sad or angry following the announcement of an HIV- positive test result. But with time nearly everyone begins to accept the situation and to try to live better with it. Support from a counsellor or sharing the news with a close friend or family member is very useful for coping, particularly in the first few weeks after getting the test result. However, if you really felt unable to cope if you were found to be HIV-positive, the counsellor would support your decision not to test, or give you time to go and discuss it with a friend or family member.

“If I had an HIV test and I was found to be positive I would be too sad and I think it would make me die sooner. It is better not to know isn't it?”

Just like any other problem, knowing that you are HIV positive creates a lot of worry, anxiety and confusion and we feel that we are soon dying. However, with proper counselling guidance and support, you come to terms with the the situation and practice to live positively. Living positively means taking care of your health and mind and practising behaviours that will stop the spread of HIV to other people. When you know you are HIV infected, you do something about it and this makes you live longer.

## Support services for people with HIV

In Uganda there are many organisations that help and support people and families with HIV infection. Some of these are big organisations like TASO, AIC and Mildmay Centre. There are also HIV/AIDS home based care programmes in mission hospitals (in Kampala there are services at Nsambya, Rubaga and Mengo). In other district hospitals, there are other organisations that provide medical care or home visits and counselling. Mildmay Centre provides medical care and counselling for both adults and children. **(See details for available services on page 24.)**

## 2.5 HIV testing for babies and children

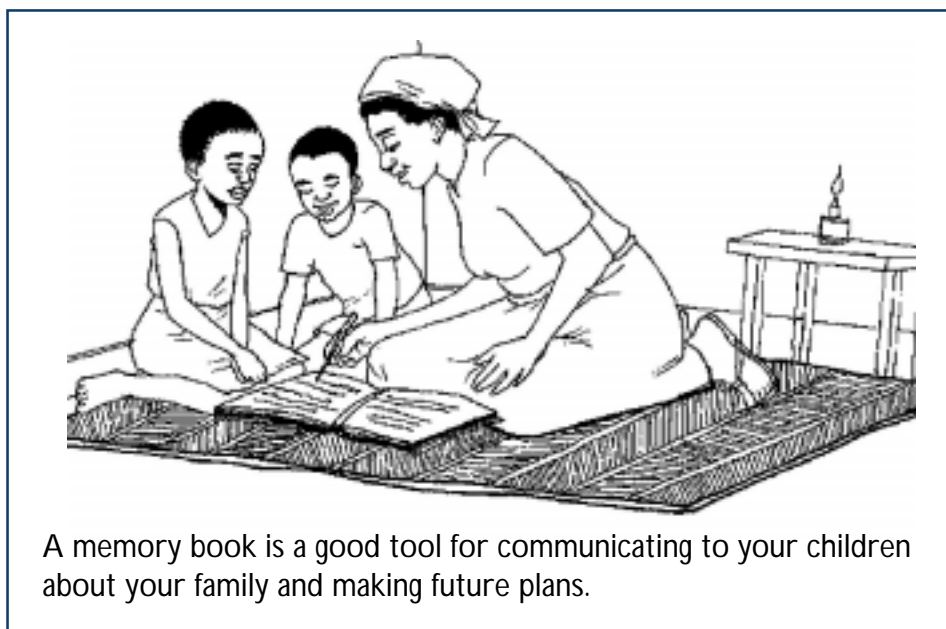
As pointed out earlier, HIV test kits detect **antibodies** for HIV. Babies have their mothers' antibodies in their blood for up to 18 months following birth. This means that testing babies under the age of 18 months using the HIV antibody test may not give the true result for the baby. In some large hospitals and research settings there are HIV tests which detect the HIV virus itself. These tests can detect HIV in babies when they are younger than 18 months. These special HIV tests are expensive and difficult to do, and are therefore very rarely available.

Although babies over 18 months and children can be tested for HIV, the advantages and disadvantages of HIV testing for them must be considered carefully. Counselling is essential for the

## Support services for people with HIV/AIDS

<p><b>The AIDS Support Organisation (TASO)</b></p> <p>TASO offers a wide range of support and care services for people with HIV, including medical care, on-going counselling, home visits, community programmes, day care centres and child support schemes.</p> <p>TASO has centres in Kampala, Jinja, Tororo, Mbale, Mbarara, Entebbe and Masaka. For more information you can contact any of these branches or the head office at TASO Kanyanya, P.O Box 10443, Kampala Tel: 041-11485 Email: <a href="mailto:tasomul@infocom.co.ug">tasomul@infocom.co.ug</a></p>	<p><b>AIDS Information Centre (AIC)</b></p> <p>AIC provides quality VCT, STD, family planning, TB and post-test clubs. AIC services can be got from nearly all hospitals and health centres in Uganda. For more information, you can contact the head office at Musajjalumbwa., Mengo-Kisenyi, P.O Box 10446 Kampala Tel:041 231528 Email: <a href="mailto:kiggundu@aicug.org">kiggundu@aicug.org</a></p>
<p><b>Mildmay Centre</b></p> <p>The Mildmay Centre in Kampala offers a wide range of medical and support services for adults and children with HIV. There is a special centre for children called <b>Jajja's home</b>. Jajja's home is a children's day care centre offering rehabilitation for children with HIV. A centre for adolescents with HIV will be opening there soon. The Mildmay Centre runs outpatient medical services for children with HIV. For more information contact Mildmay Centre at Kajjansi-Entebbe Road, P.O Box 200054 Email: <a href="mailto:mildint2@infocom.co.ug">mildint2@infocom.co.ug</a></p>	<p><b>National Community of Women living with HIV - Uganda (NACWOLA)</b></p> <p>NACWOLA is an organisation of HIV positive women and has branches in nearly all districts of Uganda.</p> <p>NACWOLA engages in self-resilience and sustainable activities, such as income generating activities. NACWOLA also supports mothers to write memory books for their children. A memory book contains family history, special events of the child as he/she grew up, wishes of the parents to the child, important people to the child and any future plans.</p> <p>Mothers of NACWOLA are empowered to communicate better with their children about sensitive HIV/AIDS related family issues. NACWOLA also creates awareness about HIV/AIDS in communities using personal testimonies and drama. For more information about NACWOLA, contact any AIDS care organisation, like TASO, in your district.</p>

NOTE: Each Community Health Worker should know support groups in their local areas



A memory book is a good tool for communicating to your children about your family and making future plans.

parent(s) or guardian(s), and other members of the family where appropriate, both before and after testing.



Medical care for children with HIV

### **Things to consider before testing babies and children for HIV**

#### **1. Are there any advantages for my child if we know his/her status?**

Yes, there are special medical treatments for children who are found to be HIV-positive, knowing their status could be of great benefit. For example if health workers know that the illnesses that the child is suffering are due to HIV, it will help them understand the best ways of treating the illnesses and controlling the pain. The health workers will also advise the carer the kind of food the child needs to eat.

"I can't see the point in testing my baby. She seems very healthy. I might think about it if she became sickly."

Mother with HIV

Yes, most children born to HIV infected mothers do not get infected. Test the baby if/when he/she starts falling sick.

Sometimes parents who know that their child has HIV can look after their child better. By seeking medical help more quickly improving nutrition, and providing emotional support.

Sometimes medicines can be given to prevent HIV-related illnesses. Children known to have HIV can be given therapies such as cotrimoxazole (septrin) to prevent pneumonia. This kind of treatment should be given under the guidance and supervision of a health worker.

If you know that your child has HIV you may also be able to support him/her better and be more understanding if he/she is frequently unwell or tired.

## **2. Are there any disadvantages for my child if she/he is tested?**

It is usually better to know if your child has HIV, because you can make sure that he/she has better medical care and is supported emotionally. However, if there is any possibility that a child will be discriminated against if he or she is found to be HIV-positive, an HIV test should not be done.

The HIV testing of babies and children should only be considered if knowing their HIV-positive status would help them get better care and not lead to neglect or discrimination.

Many mothers and fathers do not want their baby to be tested for HIV for genuine personal reasons, even if they know that they can easily get an HIV test to be done. Parents and guardians should be able to discuss HIV testing with a counsellor and if they decide that there are no benefits to be gained from HIV testing at the moment, this decision should be supported. They should be reassured that they can always discuss worries about their child with a counsellor in the future. If, for example, their child becomes ill and HIV testing could help in deciding the best medical care this could be considered at that time.

## 2.6 HIV counselling and testing for adolescents

Children over 12 years do not need the consent of their parents to be tested for HIV in Uganda. They may, however, choose to have a parent or any other adult with them when they are counselled and tested to give them the necessary support. Having another person attend counselling with the young person should be discussed and encouraged.

Adolescents should be treated with the same respect as any other person who seeks HIV testing and counsellors must be careful not to be judgmental about their situation. (See Chapter 4, sections 4.1 and 4.2 on communicating with adolescents).

Counselling adolescents will often take more time than counselling adults. They may need more information, but they may also be less willing or able to open up about their circumstances, as well as their thoughts and feelings. Counsellors should spend as much time as is necessary with young clients.

### Communicating with adolescents

Many parents and guardians have difficulty talking to young people about sensitive issues. Sometimes it can be helpful for the guardian or the adolescent to discuss things with a counsellor or health worker (see section 2.6 on counselling adolescents.) Adolescents between the ages of 10 and 18 go through a period of rapid

“My niece is an orphan and she has lived with me for the past 2 years since my sister died. She has had quite a few bouts of malaria and I think I should check her for HIV. She is 14 years old and very shy, so I don't think I could discuss it with her.”

You can encourage your niece to join any peer education group or visit a health unit that provides youth friendly services in your area. She will be helped to acquire more information about HIV and AIDS and other adolescent reproductive problems. She will also come to know how to prevent HIV and issues related to HIV testing.

emotional and physical growth. But they often lack the information, skills and maturity to protect their health and they continue to depend on adults for advice. In some parts of Uganda, there are clinics that offer ‘youth-friendly health services’. Health care workers and counsellors learn to make young people more comfortable about seeking services such as family planning, pregnancy testing, screening for sexually transmitted infections and counselling and testing for HIV.

Youth-friendly communication is supportive, non-judgmental and confidential. The most effective youth-friendly services depend on the participation of young people themselves as community animators and peer educators. When young people know that such services are available for them, they are more willing to talk

## Counselling Adolescents



Adolescents need consistent information about HIV/AIDS and if sexually active, advice on safe sex behaviour should be given.

about their problems and take better care of their health as they become sexually active.

Everyone in the community needs to learn to be open about the difficulties that young people face today. If parents or guardians find it difficult or awkward to discuss sensitive matters with their adolescent children, they can speak with a counsellor about this. Many counsellors are trained to talk with young people about sensitive issues such as sexuality and HIV prevention. They can help older people learn to talk more openly about these subjects or find other caring adults- such as other family members or religious leaders- to listen to and advise their youngsters.

# Nursing Care for Children with HIV

This chapter has been written to tell you about:

- Where you can get medical care and social support for a child infected with HIV
- The different things you can do at home to care for a sick child who is suffering from illnesses that are due to HIV infection.
- How to prepare a good meal to feed a sick child.
- Ways of preventing common illnesses and infections at home.
- How to deal with common conditions like fever, diarrhoea and cough and when to get help from a health care worker.

## 3.1 Where should children with HIV get medical care?

Children with HIV can receive medical care:

- In health centres and hospitals as **out-patients** or **in-patients**
- At home. This is often called **home care** or **home based care**.

“Sarah, 5 years old, has been constantly sick with on and off fevers and diarrhoea. I often take her to the hospital, but as you know it is costly and I leave my other children and my garden unattended to. Her condition has started to deteriorate, I am confused about what to do, more so with the fact that she will soon die.”

Aunt, Arua

Maybe your niece was infected with HIV and is now developing AIDS. Take her to a hospital where children with HIV/AIDS have a special clinic. She will be tested and be given appropriate treatment. This will improve the quality of her life and she will fall sick less often.

### What is home based care?

Home based care is a package that includes physical, medical, nutritional, emotional, social and spiritual care. Health workers can teach you how to provide home based care to a child with HIV infection.



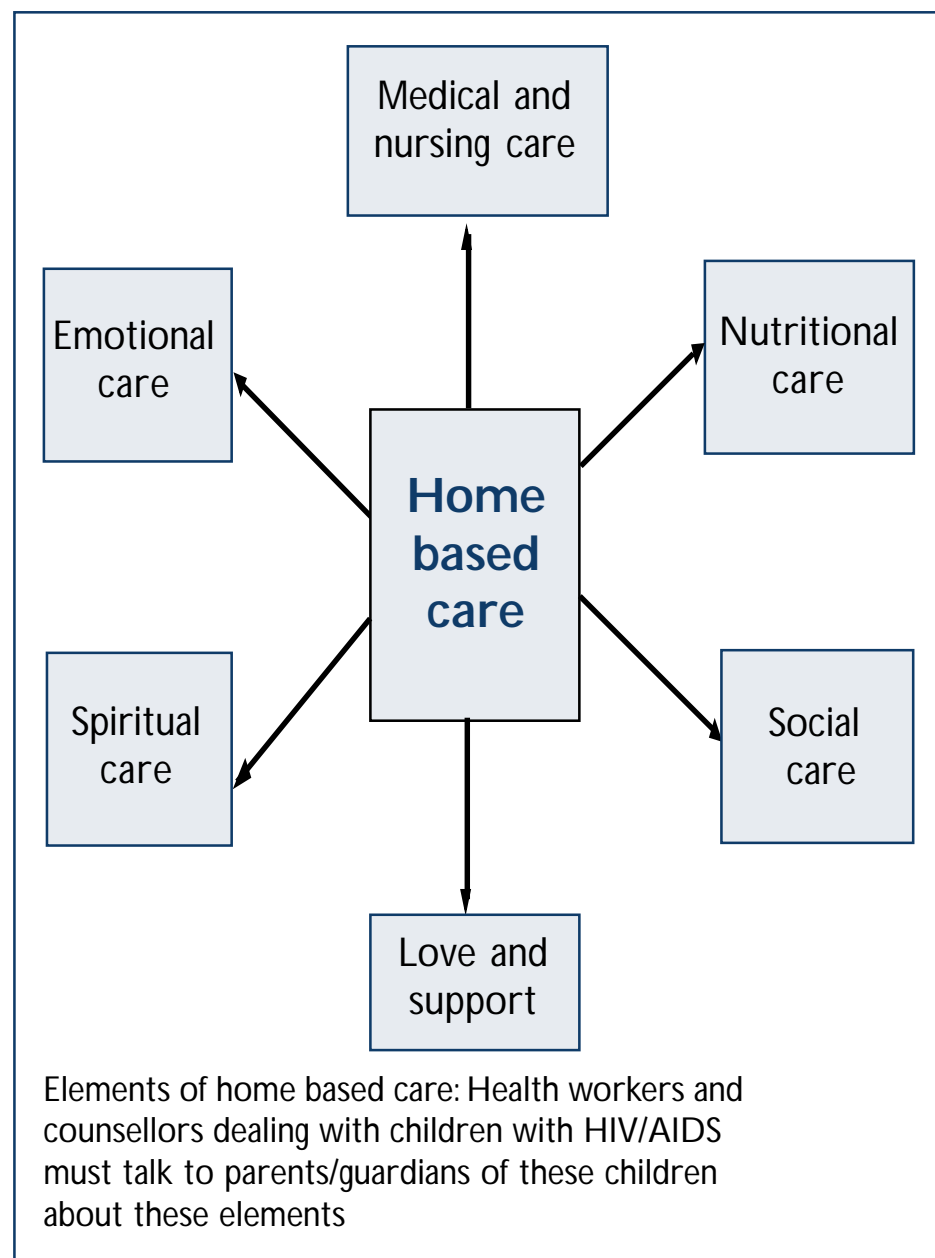
**Caring for terminally sick AIDS children at home has several advantages. Some of them are listed here,**

- Home care is less expensive for families because it reduces the transport costs and hospital expenses
- Parents or guardians who are caring for a sick child can do so more easily when they fit their care-giving tasks with other daily activities at home, including looking after other children and other members of the family
- Sick children usually feel much happier at home, in a familiar environment surrounded by family and friends
- The responsibility of caring for a sick child can be shared among all family members.

The disadvantages include the need to know when to consult hospital (staff) and questions regarding access to nursing care.

**Advantages of learning the art of Home Based Care**

- Parents/guardians will treat minor illnesses promptly and properly
- parents/guardians will prevent malnutrition
- parents/guardians will give comfort and confidence to their sick child
- parents/guardians will consult hospital/health care staff at the right time



## Kinds of care that can be given to children infected or affected by HIV/AIDS in a home

### Social interaction



A sick child always feels loved when left to interact with others. Involve HIV affected/infected children in all childhood activities.

### Spiritual care



Praying gives hope to the sick and also the carers. When strong, take sick child to his/her church.

### Nutritional care



Proper feeding improves the health of a sick child. Give frequent small amounts of soft foods to the sick child. Ensure regular meals.

### Emotional care



Playing brings happiness to children. Sick children need to play too or to watch others playing if they are too weak to join.

### Home based nursing



Sick children feel happier when nursed at home. Know when child is too sick to receive visitors. If available, consult [Hospices](#) for appropriate terminal care.

### Tender loving care



Showing love and affection to a sick child promotes fast healing. Touching, hugging eliminates/reduces stigma but avoid handling potentially infective material with bare hands.

## 3.2 Helping Children Stay Well

Children need to live in a clean environment with basic facilities which promote proper growth and development. Maintaining good hygiene and keeping the home environment sanitary helps children's who have weakened immune systems due to HIV infection.

### Keeping your home clean

Good hygiene (cleanliness) in the home is an important way of protecting your child from germs that can cause diarrhoea, skin infections, fevers and coughs. You can make your home more hygienic by sweeping and cleaning the house and airing the rooms during the day by opening the windows. Keep animals and birds outside the house and do not share rooms with them at night. You may need to build extra shelter for them attached to your house. Especially if you use firewood, it is best to cook in a different room from the one in which the children sleep. Smoke can be irritating and will make the children cough.

### Keeping your garden or compound clean

It is important to keep the area around your home clean and safe. You can easily achieve this by doing the following,

- Making sure that there are no broken bottles or sharp objects that could hurt children

'My living conditions are not the best. The house I live in with my grandchildren is old, it leaks and has holes that I cover with paper and old cloth. The kitchen collapsed and I cook in the main house. The goats and chickens are pushed into one corner of the room where the children sleep. The children who would have helped me clean the compound are sick like me, suffering from diarrhoea and fever.'

Grandmother carer

The fever and diarrhoea affecting the children can be prevented by improving the cleanliness and hygiene of the home.

The house needs to be roofed with new grass to prevent leakage and the walls need to be plastered afresh to block the holes and cracks.

The kitchen needs to be built again. You will need to build a small house in the compound where goats and chicken should live. You should maintain a clean compound.

Ask for assistance from your church (Mosque) or local leaders

- Digging a pit into which you can throw all rubbish and then burn it.
- Throwing sharp objects like used razor blades and broken glass into a pit latrine

## Keeping your home clean

### Home Resources



Homes have the necessary resources to care for the sick child

### Cooking place



The cooking place should be well aerated

### Clean home environment



A clean environment promotes health

### Burning Rubbish



Rubbish should be gathered and burnt

### Disposing sharp instruments



Sharp instruments should be thrown in the pit latrine

- Sweeping away animal waste everyday. Keeping the area around your water source (well, bore hole or a water tap) properly drained and protected from animals and waste water from bathrooms and latrines.

### Protecting the family from malaria

Malaria is a common illness caused by a germ passed on by the bite of mosquitoes. You can reduce the chances of malaria in your home by destroying the places where mosquitoes breed and protecting your family from mosquito bites.

#### You can destroy the breeding places of mosquitoes by

- Using insecticide sprays in your home
- Clearing any bushes around the home
- Draining stagnant water and destroying containers that trap water, such as discarded plastic bags, tins and broken pots
- Planting crops that encourage mosquito breeding far away from the house.

Maize for example has leaves that trap rainwater and therefore encourages mosquito breeding.

#### You can protect the family from mosquito bites by

- Using **bed nets** (mosquito nets), especially ones treated with insecticide which are more effective. Babies' cots or cradles should be covered by nets

### Mosquito Nets



A treated mosquito net prevents malaria. Bednets should be dipped/treated every 6 months. Do not wash them between dipping/treating.

- Using insect repellents
- Closing windows and doors in early evening to prevent mosquitoes from entering
- Using gauze nets in windows and ventilators

### Personal hygiene

Poor hygiene can cause health problems like diarrhoea, mouth infections, skin diseases, eye infections and many others. It is therefore important to observe and practise personal hygiene. The following are some very simple and yet useful habits to prevent infection.

- Washing hands with soap and clean water before preparing and giving food to the child
- Making sure that children wash their hands before they eat
- Making sure that everyone in the home washes his/her hands with soap and clean water after visiting the toilet
- Washing hands after changing soiled bedclothes
- Washing hands before giving the child medicine

### Brushing teeth

Giving one's mouth and teeth good care keeps them healthy and prevents tooth decay, gum infections and bad breath. Teach children to brush their teeth properly. Observe the following carefully,

- Teeth should be brushed after every meal where possible
- If a child is too weak to brush his/her teeth, help him/her to clean his/her mouth
- If a child has sores in his/her mouth, gently clean it with warm salty water and a clean piece of cloth or cotton wool.

It is important to discourage children from eating sweets because they attract germs in the mouth and cause tooth decay.

### Avoiding spitting on the ground

Spitting is a bad habit. It spreads diseases like chest infections

and flu. If a child has a cough which is producing a lot of sputum/phlegm (or mucus), he or she should be encouraged to spit into a container that can be covered. The sputum should then be thrown in a pit latrine and the tin washed for use again. A disinfectant such as jik should be poured into the container to disinfect it or kill the germs. In the absence of disinfectants from shops, ash can be used. The child should also be helped to cover his/her mouth with a clean cloth when coughing or sneezing.

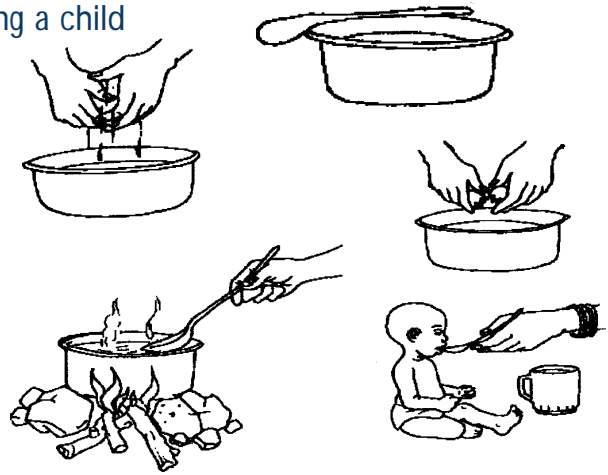
### Keeping finger and toe nails short and clean

Germs and worm eggs hide under the nails. This can cause worm infestation and diarrhoea. Keeping the child's finger and toe nails short and clean reduces chances of any such infection. Proper instruments must be used to cut the nails. The child must not bite his/her fingernails.

Cutting nails



Bathing a child



Washing children's clothes



Shaving hair



Washing hands after using the toilet



## Washing children's clothes and beddings

Hygiene must be kept everywhere. The child's clothes and beddings too need to be kept clean and safe. The following are some ways to ensure this,

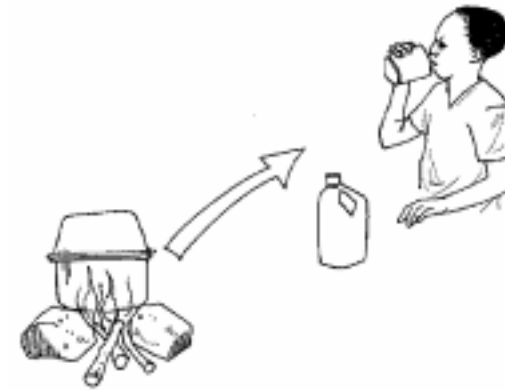
- Wash clothes and beddings regularly
- Hang them to dry out in the sunshine
- If beddings or clothes have blood or feaces on them, always rinse blood or feaces out of them before washing them with soap and hot water
- Always wash your hands after handling soiled clothes or beddings.
- Iron the clothes and beddings before the child uses them again.

## Preparing food and water

Food and drinking water should be prepared and stored in a clean and safe place in order to reduce the risk of infections, especially diarrhoea. Follow some of these tips to ensure safety of food and water,

- Always boil drinking water
- Drinking water should be stored in a clean container, preferably a small jerry can, kettle or water jug
- Always keep drinking water covered
- Food should be cooked long enough to kill any germs
- Cooked food should not be stored for more than 24 hours.

### Drinking clean water



Rain water, borehole water and water from protected wells need not be boiled . Keep it clean in containers with narrow mouths to avoid contamination by dipping dirty cups and / or hands into it. Boil water from other sources and keep it in clean containers

- Cooked food should be stored in a clean container with a cover
- Food that has been kept for more than two hours should be heated again before it is served to a child. Fruits and vegetables that are eaten raw should be washed in boiled water.



### Covering food



Food should always be covered to prevent germs getting on

### Eating in a clean environment



Children should eat in a clean environment

## Immunizations

Childhood immunisation is free in Uganda. You can take your child to any immunisation centre for immunisation. The World Health Organisation recommends that babies born to HIV-infected mothers should receive a 50,000 IU dose of vitamin A at birth and three other doses with a one month interval, preferably during the DPT immunisation dates of 6, 10 and 14 weeks. Thereafter HIV infected children should be given Vitamin A, and dewormed every three months.

### Carers should remember the following,

Children with HIV need protection from common childhood illnesses, just like all children. It is therefore important to make sure that *all* children, including those with HIV or suspected to have HIV, are immunised according to the Ministry of Health guidelines. These are shown in the box below,

### Ministry of Health Immunisation Schedule Guidelines

#### Uganda childhood immunisation schedule

Newborn	BCG and Polio 0
6 weeks	DPT 1 and Polio 1+HepB <sub>1</sub> +Hib <sub>1</sub>
10 weeks	DPT 2 and Polio 2+HepB <sub>2</sub> +Hib <sub>2</sub>
14 weeks	DPT 3 and Polio 3+HepB <sub>3</sub> +Hib <sub>3</sub>
9 months	Measles and Vitamin A

"I am looking after my sister's baby. She died of what we suspect was AIDS. I heard that it was dangerous to give immunisations to babies who might be infected with HIV. Is this true?"

Immunising children, even those suspected to have HIV, is safe. Immunisation protects children against dangerous diseases. Any child below 5 years should be taken regularly to an immunisation centre for immunisation.

Remember most of the children born to HIV infected women do not have HIV infection themselves.

### Immunization



Immunising your child is safe and protects the child against dangerous diseases.

- Children should be taken for immunisation at a health unit or immunisation outreach centre in the community.
- At the immunisation centre, your child will receive immunisations against TB, polio, measles and a combination immunisation against diphtheria, whooping cough, tetanus (DPT) and HiB Hep B
- He/she will also receive Vitamin A when he/she is nine months old and then every six months after that. For an HIV infected child, give Vitamin A every 3 months
- If you forget to have your child immunised on schedule, do not be afraid to go to the immunisation centre. **It is never too late!** Your health worker will understand.

### Regular check ups for your child

Children whose parent(s) or guardians are HIV positive are at great risk of growth failure, due to the deteriorating health and decreasing income of the parents or guardians. All children in Uganda should be taken regularly to an immunisation centre so that they can be weighed to monitor their growth and development.

At the immunisation centre, every child is given a **health card**. This card shows your child's growth record. The record is used by health workers to give you advice.

- This card shows the details of immunisation. The weight of your child is also recorded on the card on every visit



## IMMUNISATION

Immunisation protects your child against serious diseases.  
Follow and complete the immunisation schedule below:

	VACCINE	PROTECTS AGAINST	HOW GIVEN	DATE GIVEN
At Birth	BCG	Tuberculosis	Right Upper arm	
	Polio 0	Polio	Mouth Drops	
At 6 Weeks	Polio 1	Polio	Mouth Drops	
	DPT-HaBb+Hib 1	Diphtheria/Tetanus/Whooping Cough/ Hepatitis B/Haemophilus Influenzae type B	Left Upper thigh	
At 10 Weeks	Polio 2	Polio	Mouth Drops	
	DPT-HaBb+Hib 2	Diphtheria/Tetanus/Whooping Cough/ Hepatitis B/Haemophilus Influenzae type B	Left Upper thigh	
At 14 Weeks	Polio 3	Polio	Mouth Drops	
	DPT-HaBb+Hib 3	Diphtheria/Tetanus/Whooping Cough/ Hepatitis B/Haemophilus Influenzae type B	Left Upper thigh	
9 Months	Measles	Measles	Left Upper arm	

Take your child for immunisation even if the scheduled date is missed

AGE	VITAMIN A	DEWORMING	
	Date given	Date given	Medication
6 Months			
1 Year			
1 1/2 Years			
2 Years			
2 1/2 Years			
3 Years			
3 1/2 Years			
4 Years			
4 1/2 Years			
5 Years			
5 1/2 Years			
6 Years			

MOTHER	DATE VITAMIN A CAPSULE GIVEN

Source: MOH

REPUBLIC OF UGANDA



MINISTRY OF HEALTH

# CHILD HEALTH CARD

District:		Child's Registration No.:
Health Unit:		
Child's Name:		Birth Weight(Kg):
Sex:	Date of Birth:	Birth Order:
Mother's Name:		Mother's Occupation:
Father's Name:		Father's Occupation:
Where the Child lives:		
Sub County/Division:		
Parish:		
L.C.I:		

TICK REASONS FOR SPECIAL CARE:			
Birth weight less than 2.5 kg		Brothers or Sisters undernourished	
Birth defect		Mother dead	
Other handicaps or illness		Father dead	
Fifth child or more		3 or more children in family dead	
Birth less than 2yrs after last birth		Twin child	

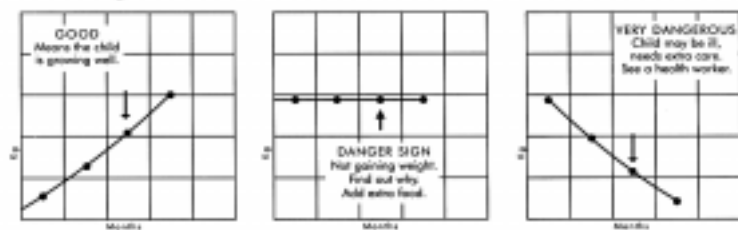
ANY OTHER REASON FOR SPECIAL ATTENTION:

Please carry this card every time you bring your child for care or attention.



### WATCH THE LINE SHOWING THE CHILDS GROWTH

The growth curve should continue to go up every time you have your child weighed.

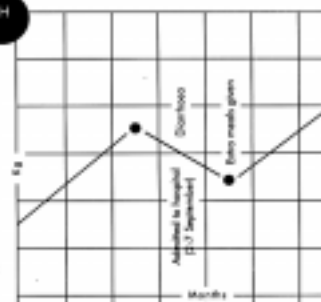


### RECORD ANY SPECIAL EVENTS WHICH MAY AFFECT CHILDS GROWTH

Write on the chart:

- Any illness e.g. diarrhoea
- Admission to hospital
- Solids introduced
- Breastfeeding stopped
- Birth of next child

like this:



### WATCH HOW THE CHILD DEVELOPS

<p>Lifts head, looks around, listens</p> <p>1 - 4 months</p>	<p>Sits with support, holds items, laughs and smiles</p> <p>5 - 8 months</p>	<p>Crawls and moves, becomes inquisitive</p> <p>8 - 12 months</p>	<p>Starts to stand, walk and say words</p> <p>12 - 24 months</p>	<p>Talks and walks</p> <p>24 - 27 months</p>
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Encourage development by spending time with the child, playing with him and encouraging him to learn.

### 3.3 Nutrition for children

#### Feeding babies

“I have HIV. I am worried that I might pass on HIV to my new baby if I breastfeed her, so I am thinking about bottle-feeding. What do you think?”

Breast milk is the best for the baby. HIV can also be passed through breastfeeding. However, you can reduce the chances of passing HIV to your baby if you exclusively breastfeed up to 3 months. This means that during this period, you should not give your baby any other foods apart from breast milk. In case you decide not to breast feed, then you should feed your baby on formula foods. Health workers at the health centre can give you more information about both options to help you decide.

If you are HIV-positive your breast milk contains the HIV virus and there is a chance that you could pass the virus to your baby. Unless you can afford to feed your baby with powdered infant milk or specially prepared cow or goat’s milk it is best to breastfeed exclusively. (See Chapter 1 on mother-to-child HIV transmission)

**Exclusive breastfeeding** is giving a baby no other food or drink, not even water, apart from breast milk, with the exception of drops or syrups consisting of vitamins, mineral supplements or medicines. Exclusive breastfeeding has less chance of HIV transmission than mixed feeding.

All HIV infected mothers should receive counselling to make an informed choice on the best feeding options for their situation.

If you choose exclusive breastfeeding, you should remember the following,

- You should care for the nipples to ensure that they do not crack
- You should breastfeed until your baby is 6 months old
- Stop breastfeeding immediately the baby becomes 6 months old or when milk is not enough for the baby and introduce animal milk or infant formula.

Mothers should also care for the nipples so that they do not crack.

HIV-positive mothers who breastfeed must drink a lot of liquids, eat plenty of nutritious food, rest and relax so that both mother and baby stay healthy.

## Preparing Children's Food

When preparing food for a child, you should make sure that everything, including water, cups, plates, spoons, sauce pans, your hands, the house, the kitchen and compound are very clean all the time. Remember the following as well,

### How to prepare infant formula for your baby

- Prepare the powdered infant formula with clean boiled water.
- Follow the instructions on the tin or packet. If you are not sure ask a health worker for help
- If your child does not finish a portion of formula, do not keep it to give to him/her later
- If your child remains hungry after finishing the measure suggested on the tin, give him/her some more.

### How to prepare animal milk for your 3-6 months baby

If you have pure, undiluted cow's milk, it is best to mix it using the following measurements,

- 1/2 tumpeco cup (a quarter litre or 250 ml) of clean boiled water
- 1 full tumpeco (a half litre or 500 ml) cow's milk
- 4 tea spoons of sugar

## Complementary feeding and weaning foods for babies

After 6 months, breastfeeding may no longer provide all nutritional requirements of your growing child. Therefore, all children 6-8 months should receive complementary foods. For women who are not HIV positive breast milk can still be given. For HIV positive mothers, rapid cessation of breast milk needs to occur as soon as breast milk is not enough or when the baby is six months old.

When you stop breastfeeding, make sure the baby receives one-two tumpeco cups (or half to 1 litre) of milk each day. The baby will need other foods in addition. The quality and quantity of food prepared for your child will affect his/her overall health status.

### Porridge

You can start the baby on weaning foods with posho (maize or millet), cassava or soya flour. Add pounded groundnuts, a teaspoon (small spoon) of vegetable oil for energy and milk.

### Mashed foods

Add a lot of milk when you are making porridge for your baby. Many children in Uganda are undernourished because they are given porridge made too thin with water. Porridge made with water only, will not give your baby the nutrition he/she needs.



### Preparing weaning food



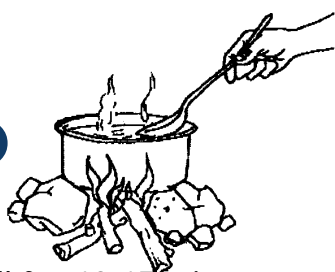
1

Wash your hands

2

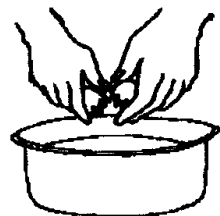
Mix water, maize flour,  
milk & vegetable oil

3



Boil for 10-15 minutes

4



Add an egg

5



Feed the baby

When your child is 6 months old, you can start feeding mashed staple like pumpkin, matooke, cassava, posho, rice, sweet or Irish potatoes. You can add mashed fish, groundnuts or simsim or mashed beans to add more protein for body building. Adding a small spoonful of margarine or oil will give extra energy to your baby. You can also add cooked and thoroughly mashed green leafy vegetables to provide vitamins.

### Feeding children

Children without sufficient nutrition are susceptible to various infections, including loss of appetite and diarrhoea. This in turn leads to poor growth. As with all children, children with HIV need a well balanced diet and should have three nutritious main meals a day. This diet should help them grow and develop in order to fight off infection. Greater attention needs to be given to children infected with HIV because their immune systems are weaker and they are likely to develop opportunistic infections.

Family foods can be made more nutritious and easy to eat. For example porridge can be made richer in energy by adding vegetable oil or groundnuts. You can also add body-building food such as milk, eggs or beans. Fermenting foods such as porridge can also make them more nutritious and easy to swallow.

### Feeding recommendations

- One cup enriched maize porridge with 1/4 cup mashed beans, handfull mashed fruit or vegetables is a healthy meal for your child of 6-8 months.
- Feed 2-3 times per day

#### A good nutritious diet includes:

**Foods rich in energy**, such as rice, cassava, mattoke, maize or millet porridge, bread, sweet potato and sorghum. These provide the main part of the meal and most of the energy. Sugar, animal fats, coconuts, groundnuts and vegetable oil are concentrated sources of energy.

**Body-building foods**, such as meat, chicken, liver, fish eggs, milk, simsim, peas, groundnuts, various beans including soya. These foods contain protein and help the body to grow and repair.

**Body-protecting foods**, are rich in vitamins and minerals. These include vegetables and fruits, for example green leafy vegetables (dodo, nakati and bbugga), pumpkins, tomatoes, carrots, mangoes, sweet bananas, avocados, passion fruit and oranges.

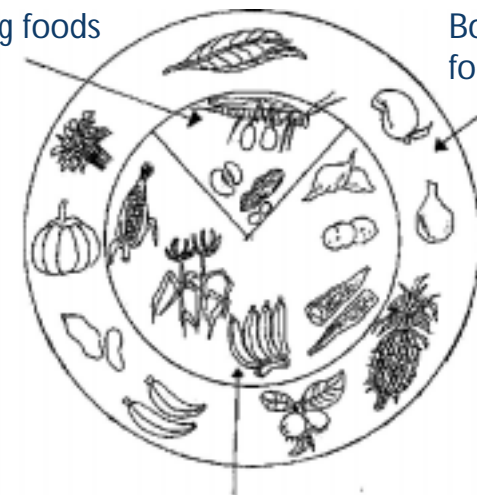
#### A well fed baby



A child needs a balanced diet to grow healthy and strong

#### Body Building foods

#### Body Protection foods (Vitamins)



#### Energy giving/rich foods (Vitamins)

A balanced diet is made up of energy giving, body building and body protecting foods.

### Special feeding needs of children with HIV

Children with HIV often lose weight or fail to grow well because their bodies cannot properly use the food they eat. They may also suffer from repeated attacks of diarrhoea and other infections. This can cause them to lose weight and have a poor appetite. HIV-infected children who are malnourished are very likely to fall sick. Special effort should be made to ensure that children with HIV have a good diet and do not become malnourished. Remember the following needs of the child,

- Give him/her a separate plate with his/her own food to make sure that the child eats enough food
- Feed your child before the rest of the family to make sure that he/she gets enough to eat
- If your child is still hungry and asks for more food, give him/her some more. Children should not feel hungry at the end of a meal
- In between meals you can offer your child a snack such as a piece of fruit

### Feeding sick children

Children who are sick often lose their appetite. They need to be encouraged to eat small meals of the food they like, more frequently than usual. You can do the following to ensure that the child still eats sufficient amounts of food,

- Give lemon juice in warm water or a ginger drink if the child

A sick child needs to be encouraged to eat.



feels he/she wants to vomit (feels sick). Avoid giving the child spicy or fatty foods because they increase the feeling of sickness

- Give yoghurt or other fermented foods like sour porridge. These can help children who have sore mouths due to thrush (candida) to regain some appetite
- Give well cooked locally available foods (staples) to children with diarrhoea. These can be easily digested. The food should be well mashed. Add a portion of food known to be a source of extra energy such as margarine or vegetable oil. (See section 3.4 on diarrhoea.)

Children who are weak or very sick may not be able to feed

themselves. You can either sit the child on your lap, supporting him/her to sit up, or support a child with pillows in a corner and feed him/her with a spoon or cup.

Feeding a sick child will often take time, especially if they are very weak or breathless. You must try and be patient and encouraging. You will need patience to do the following, for example,

- When the child is recovering, or after illness, give the child more to eat to help him/her build his/her strength
- Give the child an extra meal a day to help him/her regain weight and recover faster.

### 3.4 Common illness and health problems: What you should do

#### Fever

You will know that a child has a fever if he/she has a body temperature higher than 37.5°C. Fevers in children can be caused by different illnesses and it is often hard to determine if the fever is due to HIV, flu, malaria or other illnesses. Although colds and flu are the most common causes of fever in children, the Ministry of Health recommends that any child with a fever should always be treated with anti-malarial medicines. This is because **malaria** is common in Uganda and, if not treated quickly, it can cause serious illness and even death.

#### What to do if your child feels hot or has a fever

- Do not cover your child with warm covers such as blankets.
- Let the child rest where there is fresh air, preferably where there is a breeze.
- You can help to reduce the temperature by dipping a cloth into lukewarm (body temperature) water, squeezing out excess water, and then wiping your child's body gently with the wet cloth. This is called 'tepid sponging'.
- Make sure that you give your child plenty of fluids, such as water,

#### Tepid Sponging



















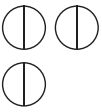
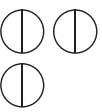


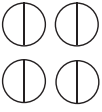
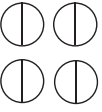


Reduce the child's body temperature by gently wiping the body with a wet cloth.

#### Paracetamol pain relief for children

Babies less than 6 months	$\frac{1}{8}$ tablet (62mg) 2-3 times each day
Children 6 months-2 years	$\frac{1}{4}$ tablet (125mg) 3-4 times each day
Children 3-7 years	$\frac{1}{2}$ tablet 3-4 times each day
Children more than 7 years	1 tablet 3-4 times each day

Source: MOH

## Anti-Malarial dosage

Age and weight	Day 1	Day 2	Day 3		Total Chloroquine
			Chloroquine	Fansidar	
3 months-1years					2½
1-2 years					3
3-4 years					4
5-7 years					5
8-10 years					7½
11-15 years					10

Source: MOH

juice or ORS to drink. This should help prevent dehydration which can easily be caused by fever

- You can give paracetamol (panadol) to reduce the fever.
- Give the first dose of malaria treatment. Remember to continue the course until it is completed
- add Fansidar on the third day
- Reassure and comfort your child. Children who are ill will often feel anxious or frightened
- Take your child to the nearest clinic if the fever lasts more than 3 days
- If the child has a stiff neck, is irritable or unconcious, has swollen anterior fontanalle severe pain or convulsions, take him/her **immediately** to a health centre to be examined by a health worker
- A **DOCTOR** may advise a Lumbar Puncture for your child which will help detect other serious diseases.

## Cough

Coughs are common among all children and particularly among children with HIV. Coughs are common with colds or flu but can also be caused by more serious illnesses such as pneumonia or TB.

## What to do if your child has a cough

- Give the child plenty of warm fluids to soothe the throat, ease the cough and replace lost body fluids.
- If a child has a constant cough or breathing problems, sit him/her up or raise his/her head on pillows to help him/her breathe more easily and comfortably. Give him/her cotrimoxazole tablets (or syrup if available)
- If your child has a blocked nose this can interfere with his/her breathing and eating and create a lot of discomfort. You can clear the nose by softening dry or sticky mucus using a cotton cloth soaked in clean salty water.

#### **Take your child to the clinic if he/she is**

- having difficulty in breathing
- finding it painful to breathe
- wheezing
- breathing faster than usual
- finding difficulty in drinking and swallowing
- coughing blood
- coughing up foul-smelling sputum or mucus

#### **Tuberculosis (TB)**

TB is caused by a germ which spreads through breathing in droplets coughed or sneezed from an infected person. It is difficult to diagnose in children and yet it is quite common in children who have HIV. The condition should be considered in

any child who has a cough for more than one month, recurring fever, poor weight gain or weight loss.

TB can be transmitted from parents or carers to children. If you or anyone else in the household has TB it is important that they receive treatment and take the children to the health centre or hospital to check whether or not they have TB.

The treatment for TB in children with HIV is the same as that given for any child with TB. It is given in two phases:

- **‘initiation phase’** where medicines are given for 2 months
- **‘continuation phase’** where medicines are given for a further 4 months.

#### **Carers should take note of the following**

- In order to cure TB, it is important that **children are given the correct medicines in the right dosage for the whole treatment period.**
- In most circumstances, once someone has been on TB treatment for at least two weeks, his/her condition is no longer infectious.

## Diarrhoea

Every parent or carer should be equipped with some basic facts about diarrhoea. This will help them detect the condition in children and give the necessary care.

- A child has diarrhoea if he/she passes loose stool more than 3 times in a day. Loose stool being stool that will take the shape of its container
- Diarrhoea can cause dehydration because of the loss of water and salts.
- Diarrhoea also reduces appetite, interferes with nutrient absorption and has serious implications for children with HIV.
- If there is no blood in the stool, the child's diarrhoea can be treated at home.

### What to do if your child has diarrhoea

These are the most important things to do,

- Give the child plenty to drink, especially clean boiled water.
- For a breast feeding child, increase the number of times you breastfeed to as many as possible.
- If diarrhoea persists or if it is very frequent and the child is unable to drink, take him or her to the nearest health centre or hospital.
- To replace the nutrients lost from the child's body, give any of the following fluids and foods as frequently as possible:

passion fruit juice, bananas, carrots, rice and rice water.

- Give one cup of **Oral Rehydration Solution (ORS)** or **Sugar Salt Solution (SSS)** every time the child passes stool.

### All those giving care to children with diarrhoea should remember the following,

- You should be patient when giving ORS or SSS to the child. If a child refuses to take any more fluids wait and give the fluids again after 15 minutes
- Always prepare fresh ORS or SSS each day. Never use ORS that has been kept from the previous day
- When you give ORS or SSS use a cup or a spoon because it allows the fluid to be given in small steady amounts which reduces vomiting
- Medicines are not necessary for most children with diarrhoea.

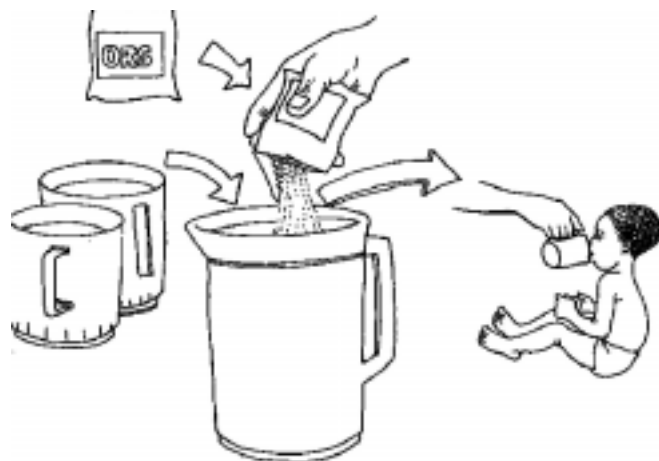
### Take your child to the clinic if

- there is blood in his/her stool
- after 3 days there are still many bouts of watery stool
- he/she vomits repeatedly
- his/her eating or drinking is poor.

### Vomiting

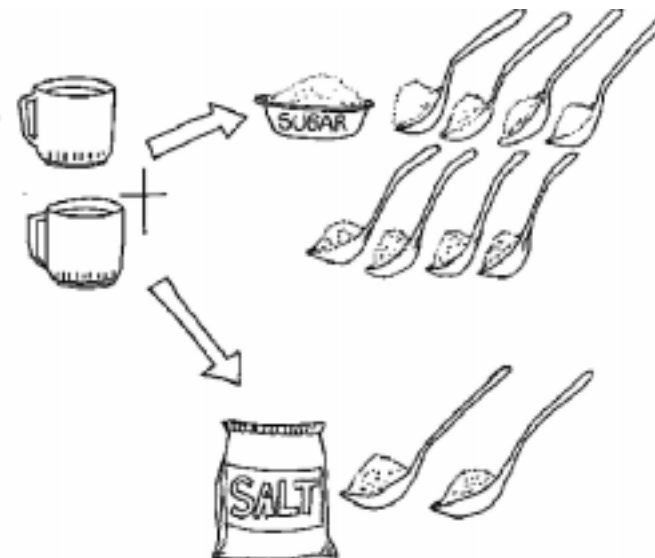
If a child is vomiting give him/her fluids and ORS or SSS, as in the case of diarrhoea outlined above. Start by giving small amounts, about one teaspoon every two to three minutes and then increase these gradually.

### Preparing ORS from sachets



- Measure one litre (2 tumpeco mugs) of cool boiled water into a clean container
- Open one packet of ORS and empty the whole sachet into the water
- Stir the ORS until it is dissolved
- For children **under 2 years** give 50-100mls (between a quarter and half a cup) after each loose stool
- For children **over 2 years** give 100-200mls (a half to one cup) after each loose stool
- Give to the baby whenever he/she wants to drink and give additional fluid every after a loose motion. Discard the remaining fluid after 24 hours

### Preparing SSS (Salt, Sugar Solution)



- Measure one litre (2 tumpeco mugs) of cool boiled water into a clean container.
- Add one teaspoon of salt.
- Add eight teaspoons of sugar.
- Stir the ORS until its dissolved
- For children under 2 years give 50-100mls (between a quarter and half a cup) after each loose stool.
- For children over 2 years give 100-200mls (a half to one cup) after each loose stool.



### **Take your child to the clinic if**

- he/she continues to vomit continuously for 24 hours or more
- his/her vomit is stained with blood
- besides vomiting, she/he has a stiff neck or severe headache.

### **Mouth and Throat Sores**

Mouth and throat sores are very common in children with HIV, often due to thrush (candida). Thrush causes white patches on the inside of the mouth. Herpes can also cause a sore mouth. Herpes is a virus, which makes painful blisters which can sometimes appear on the mouth and lips. A sore mouth or throat can prevent your baby from eating or drinking properly. It can also make him/her irritable and feverish.

### **What to do if your child has a sore mouth**

- Reduce the problem of sores by rinsing the baby's mouth with warm salty water in between and after meals. You can use a clean cloth soaked in salt solution to clean the mouth at least four times every day. If a child is old enough to manage it, encourage him/her to gargle the salty solution and then spit it out. To make the salt water solution, dissolve half a teaspoon of salt in a cup of clean warm water.
- Give fluids such as milk, yoghurt, soup and fruit juices. Fluids are good for a child with a sore mouth. They can be taken more easily with a straw.

- Do not give the child spicy or very salty foods and acidic citrus fruits (lemon and orange) because these can increase soreness.
- Give soft foods. These are easier for babies to chew and swallow when they have a sore mouth or throat.
- If the child has thrush, gently brush the tongue and inside of the mouth with a soft toothbrush several times a day.
- You can apply 0.25% gentian violet (purple) solution three times a day to help treat thrush or herpes blisters in the mouth.
- Reassure and comfort your child. The child needs this because a sore mouth can be very distressing.

### **Take your child to the clinic if**

- he/she is refusing to take any fluids because of very bad sores
- his/her mouth is too sore.

### **Skin problems**

Many babies and children with HIV will have skin problems at some stage time. These problems include rashes, itchy skin, painful sores and abscesses. They can also have skin problems such as ringworm and scabies.

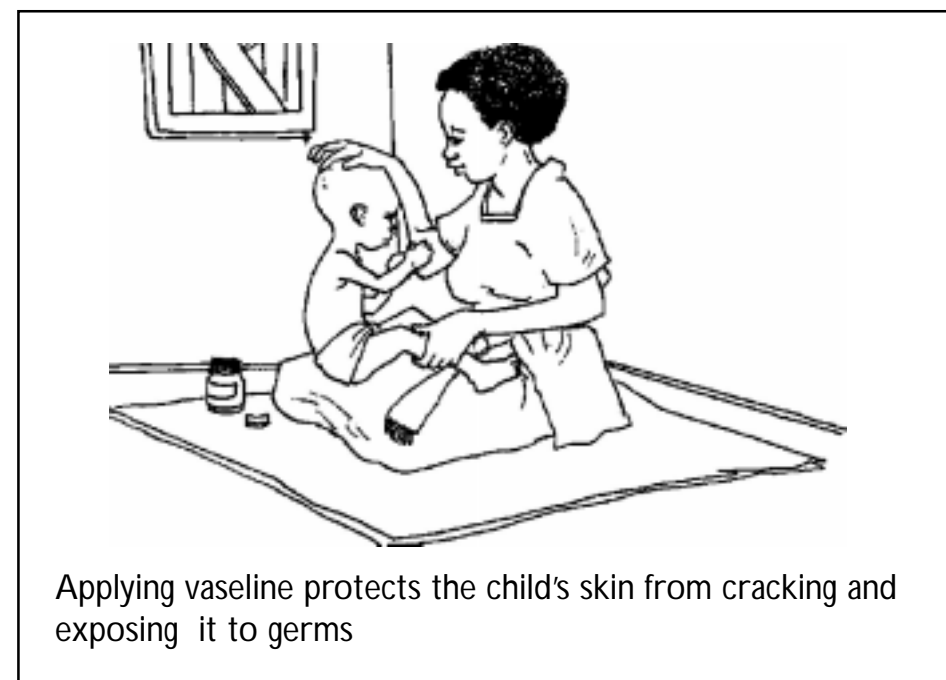
### **What you can do to prevent skin problems**

- Keep your child's skin clean by washing it once a day with soap and warm water.

- Keep the child's skin dry between washing.
- Keep the child's fingernails short to prevent skin injuries caused by rough scratching.
- Wash your child's skin less often if his/her skin is very dry because washing it with soap and water can make it worse. You can wash it two times a week or when the child's skin becomes dirty. You can also apply oils or creams such as vaseline or glycerine, or vegetable or plant oils such as coconut oil. **Avoid perfumed oils or perfumed soaps and creams as these may irritate the skin.**
- If your baby or child still wears napkins or if he/she has diarrhoea you should take great care of his/her skin. To prevent sores and rashes on your baby's bottom you should leave it exposed to fresh air as much as possible. When your baby's bottom is dirty you can wash him/her with warm water and use a barrier cream, such as vaseline. Leaving the baby in a wet or dirty napkin/cloth can cause rashes and sores.

### Shingles/Herpes Zoster

- Shingles is a skin condition caused by a virus and it results in painful blisters on the body. It is quite common in children with HIV. Shingles begins as painful skin 3 or 4 days before the blisters or painful rash appears. The blisters can take several weeks to go away. Severe shingles can be very painful and very difficult to manage at home without advice from the



#### How to make a 0.25% gentian violet solution

- Put half a 5ml spoonful (teaspoon) of gentian violet crystals into one litre of clean water.
- Stir well and leave to settle
- Pass the solution through some cotton cloth as this will remove any un-dissolved crystals.

Do not keep the gentian violet solution for more than seven days.

clinic. Unless the shingles is mild you should take your child to the nearest clinic for help and advice.

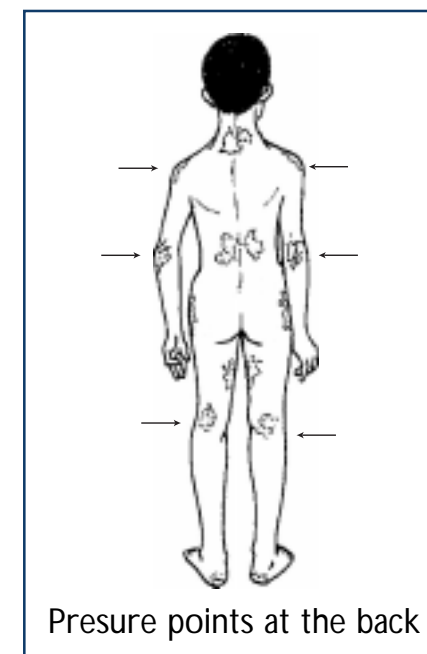
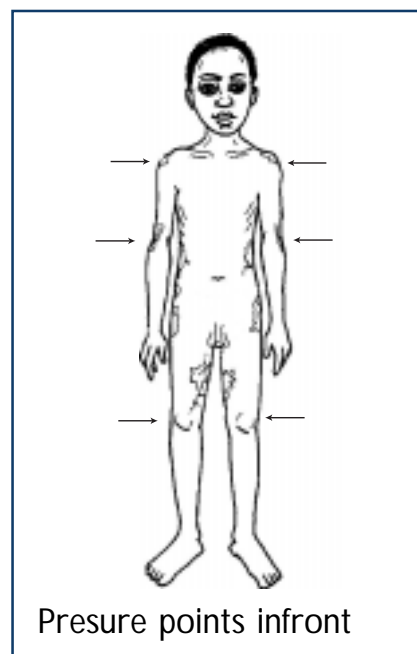
### What to do if your child has shingles

- There is a lotion called Calamine that is readily available at health centres
- Apply calamine lotion to the blistered skin. This is soothing and helps to prevent itching.
- Bathe the sore area in salt water or put gentian violet on the blisters to prevent infection.
- Crush one aspirin and mix it with two small spoonfuls of vaseline. Rub the mixture gently onto the affected area and repeat 3 to 4 times a day. Paracetamol (panadol) is not useful in this mixture.
- Keep the sore area dry.
- Give your child paracetamol (panadol) to relieve the pain.

### Bedsore

Children may get sores if they are very weak and stay in bed most of the time. Bedsore form because of breakdown of the skin due to poor circulation and resulting pressure, and they occur when children are too ill to roll over in bed. They form on the bony parts of the body, such as knees, buttocks, back, hips, elbows and shoulders.

### What you can do to prevent bedsore



- Encourage children to get out of bed or move around if they are strong enough to do this
- If your child is in bed most of the time you should shift their position in the bed every one to two hours. For example move your child from one side onto his/her back, from the back to the other side and so on. This will increase circulation to various parts of the body
- Move your child from his/her bed onto your lap and hold him/her there for 15-30 minutes before returning him/her to bed. This not only changes the child's position but makes him/her feel loved and secure
- Place cushions or pillows under the pressure area. Ask a nurse

to show you how to do this

- You can prevent bed sores by placing soft bed sheets and well aired extra padding at the pressure points. It is also important to make sure that the bedding is straightened and free from folds and wrinkles
- Always change bedding after it has become wet or dirty.

### What to do if your child has bedsores

- Make sure that the sores do not become infected. Clean them with warm salty water 3 times every day.
- Clean infected sores with an antiseptic solution like Potassium permanganate. Potassium permanganate solution makes a good antiseptic for soaking infected sores. Add a small pinch of potassium permanganate crystals to a tumpeco mug (a half litre) of clean water.
- Do (or continue doing) the things mentioned in the section on preventing bedsores, so that pressure areas are protected and sores have the best chance of healing.
- Honey placed onto the sore but not on the skin leads to a quick recovery (**see next page for picture**).

### Pain

Pain is common in children with HIV-related illnesses. It is often recurring and may become persistent and increase as children become more unwell with HIV. For some children in the later

stages of HIV/AIDS, pain may become part of daily life. Treatment of the cause of pain is important but in all cases pain relief is a priority. Children should not be left in pain and everything possible should be done to prevent pain or treat any pain promptly. No one should have to suffer from pain that can be otherwise controlled.

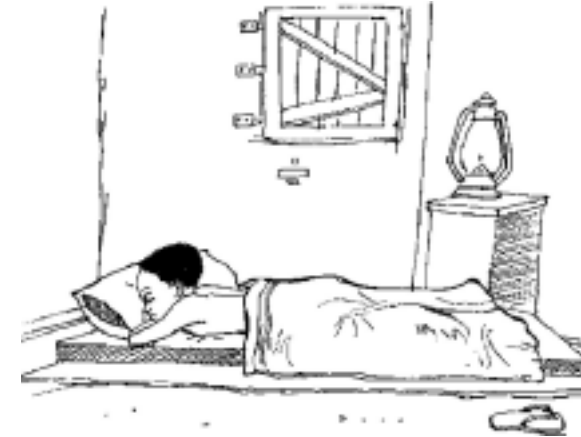
Children with HIV often have many fears and anxieties and may become depressed. This may make their pain worse. Pain is always worse if children feel frightened or alone.

Children should be supported and comforted by their carers and this can be a very important part of treating pain. You should talk with your child if he/she is in pain. This can be a distraction as well as a source of comfort and reassurance. You can also play music on the radio or tell the child stories. Putting a cool damp cloth on his/her head and giving massage can also be comforting.

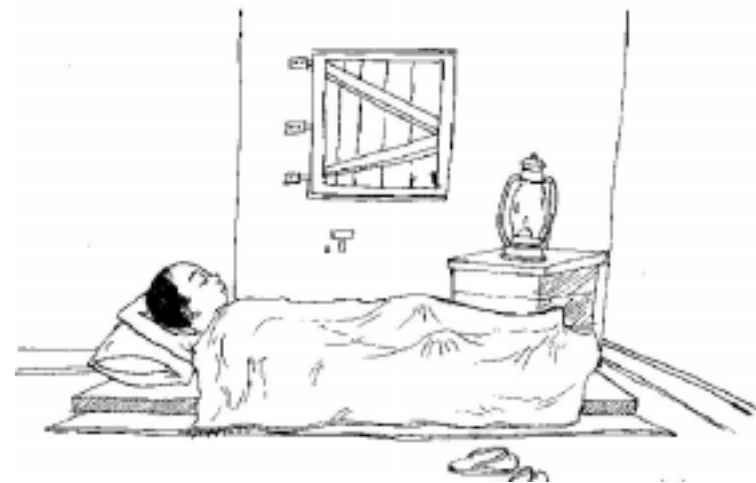
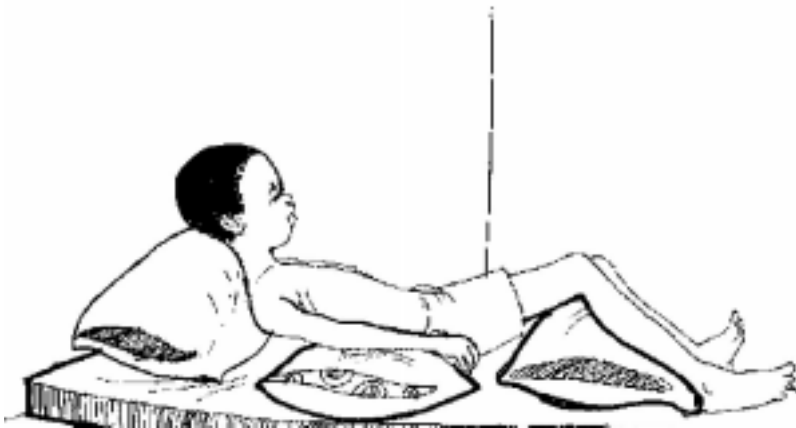
The following guidelines have been developed to help ensure that children get effective pain relief,

- **By mouth**-If possible, all pain killers should be given by mouth.
- **By the clock**-Pain killers should be given at fixed time intervals according to their instructions. The next dose should be given before the previous one has fully worn off. In this way it is

## Managing Bedsores



Turn regularly



Pad with pillows

possible to relieve pain continuously

- **By the ladder-**You can start to help relieve pain in your child by giving paracetamol. **Paracetamol is safer than aspirin in children.** If your child still has pain although he/she is taking paracetamol you must discuss this with a health worker who may give you a stronger painkiller.

#### Paracetamol pain relief for children (MOH/IMCI)

Babies less than 6 months	$\frac{1}{8}$ tablet (62mg) 2-3 times each day
Children 6 months-2 years	$\frac{1}{4}$ tablet (125mg) 3-4 times each day
Children 3-7 years	$\frac{1}{2}$ tablet 3-4 times day
Children more than 7 years	1 tablet 3-4 times each day

### 3.5 Special medical treatments for children with HIV

#### Prevention of opportunistic infections using septrin (cotrimoxazole)

Septin (Cotimoxazole) has been found to prevent some of the common chest infections such as pneumonia, particularly Pneumocystis Carinii Pneumonia, (PCP) in children with HIV/AIDS and infections of the brain (toxoplasmosis). It has also been found to reduce recurrence of diarrhoea in people with HIV.

#### Antiretroviral Therapies

“Can you tell me about these new drugs that you can get from the pharmacy that are supposed to cure AIDS?”  
Jane.

Yes there are medicines people with HIV infection can take in order to stay healthy and strong. However, they are not sold in pharmacies and they do not cure AIDS. You need to go to a professional health worker or visit an AIDS service organization like TASO for more information and guidance.  
CHW

Many drugs are being developed that are used to treat HIV directly.

These anti-HIV drugs are called antiretroviral drugs (ARV) or antiretroviral therapy. ARTs are currently expensive and only available privately in Uganda, although compared with earlier prices ARVs now cost very little.

### What you need to know about ARVs

- Antiretroviral drugs do not cure AIDS, but are used to reduce the amount of HIV in blood
- ARVs can make a person with HIV live longer and improve the quality of his/her life
- ARVs can be given to adults and to children
- There are many different types of ARVs. A single ARV drug does not work on its own and a person taking ARVs will usually have to take 3 or more different ARVs at a time. This is why this treatment is called “ARV combination therapy”.
- In order for ARVs to work, the patient MUST adhere to the treatment strictly.

When taken properly ARVs turn viral loads to undetectable levels, but do not cure HIV/AIDS

There are many difficulties with ARV drugs. The following are

some important ones to know,

- ARVs are expensive
- One has to be checked carefully before starting on ARVs, to know the right type for him/her and at specified intervals after

starting, to check if they are effective. These tests are very expensive

- Once a person starts on ARVs, he/she should take them for the rest of his/her life. If not taken as recommended they may fail to work or create body resistance
- For some people, the drugs may cause problems like vomiting, low blood levels, dizziness, skin problems, nerve problems and others
- ARVs may not work effectively for all people with HIV. Some people will not get better and will die despite having taken them.

At the moment most people in Uganda, both adults and children, will not be able to take ARVs because they are expensive and not widely available. However, there is hope that in future ARVs will be more affordable and also extensively available in hospitals.

### De-worming

A lot of children in Uganda have worms in their intestines. Children get worms by eating unwashed raw foods contaminated with faeces containing worm ova and cysts and through their feet by standing in dirty water or soil. The worms feed on their food in the intestines and also cause low blood levels (anaemia).

### To prevent worms do and observe the following

- Make sure children wash their hands before eating
- Make sure children do not eat unwashed raw food and fruits
- Where possible, children should wear shoes, especially when they use the latrine.
- Give children medicine to deworm them every three or six months. Ask the clinic about the de-worming medicine which you should give your child, especially when you see worms in the child's stool or if the child has a distended abdomen.

### Administering medicines to children

Children with HIV will often need to take medicines, sometimes every day. If you are given medicines by the health worker always check the instructions with the health worker so that you are sure how much your child is supposed to take and how often he/she must take it.

If you are given a liquid medicine or syrup you can squeeze it slowly into the side of your baby's mouth, using a dropper or syringe, or pour it in slowly using a spoon.

If the medicine is in tablet or pill form children can sometimes find it difficult to swallow. But you can do a few things to help the child take the medicine all the same. Here are some suggestions,

- You can crush the tablets and mix them with honey or jam to

"My little boy has to take lots of tablets for his cough and he finds it very difficult to swallow them. He is always refusing and I don't know what to do as the nurse said he must take them for 6 months."

Mother.

"It is normal for sick children to get tired of taking long term medicines. It is important to continue giving the medicine to him as instructed by the nurse. Try to crush it and mix it with honey or jam when giving it to him. It is also important not to intimidate or be harsh to him. Always comfort him".

CHW

make them easier to swallow.

- If your child is old enough explain to him/her why he/she has to take the tablets
- If the medicines have an unpleasant taste, tell your child this in advance so that he/she will know what to expect
- Always stay calm when helping children to take medicines. Do not threaten or shout at your child as he/she may refuse to take the medicine. It is better to praise him/her after he/she has taken the medicine
- If your child vomits immediately after taking the medicine wait a while and then give him/her the dose again
- If your child vomits more than 20 minutes after taking the



medicines there is no need to give the dose again

- If your child develops a skin rash after taking a medicine you should take him/her to the clinic as this may mean that he/she is allergic to it
- Remember to practice good hygiene when giving medicines. Wash your hands before giving medicines and make sure that you use a clean spoon.

### Storing medicines

- Store medicines in a clean dry place
- Do not keep medicines on the floor or under the mattress or anywhere where a child can take them by mistake. If a child takes medicine by mistake or if he takes an over doze, take him/her to see a medical person for advice

### Herbal remedies

- There are many herbal remedies that carers use at home. Although no research has been conducted to see if they are truly effective many have been reported by carers to give relief of symptoms for adults and children with HIV. If you choose to use a herbal remedy for a condition like skin rash or cough you should go to a health centre after 2-3 days if the herbal remedy is not working.

### Storing Medicines



Keep medicine in a clean dry place and where there is no direct sunlight.

## Children's Emotional Health

Health is a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity. In order for the child to be regarded as healthy, he or she needs care for both the body and the mind. Children who are neglected in either of these may have problems later in life.

### Emotional Care

Children need to feel loved and secure for them to be emotionally healthy. Emotional care starts with cuddling babies and making sure they are fed and clean. Older children also need to be hugged and comforted. Children can feel that they are loved from the look on an adult's face and the way they speak. Some children know very well that they are loved but some are not sure. They can be confused when an adult says kind things to them but uses a harsh voice. They do not know if they should believe the words or the tone of the voice.

Children need to feel valued. One way to make this possible is to give them tasks that suit their age. They will learn the skills they need when they are adults. The responsibility they are given tells

Involving children in household chores or domestic chores



Giving children appropriate tasks and responsibilities increases their value and self esteem

them that you trust them and think that they will do a good job. Praising them when they do well will help them develop their self-esteem, so that they value themselves. This will help them cope better with difficult times. Children with low self-esteem may do badly at school and not relate well to other people.

Children need to know what is right and what is wrong. The best way to teach a child this is by example and explaining why they should not do something. Young children may not understand what you say but if you start at an early age to use this way of teaching them, it will be easier later. Criticism and making the child feel stupid are not usually the best way to change the child's behaviour.

Children also need the chance to play. This helps them to learn the social skills they need to get on well with other people. Laughing and having fun is good for everyone.

Children who feel secure and loved can survive losses and hardships much better than those who have plenty of material support but feel unloved.

#### 4.1 Talking with children

"Talk to the child who is in despair, they have needs to express to us."- Adult in Kasese.

When children ask difficult questions or want to talk about subjects that are painful to adults, it is very easy to try and avoid discussion. Adults have many ways of doing this. They may pretend they haven't heard; deliberately misunderstand the

#### Playing together



Playing helps children to learn social skills. Encourage HIV infected/affected children to play with their friends and / or relatives

question; tell the child to ask them later; tell them to ask someone else; tell them not to talk about such matters. Although talking about difficult subjects with a child may not be easy, you will not help the child or yourself by avoiding problems.

This section makes some suggestions to help you communicate with children.

### Things to be aware of when talking with a child

- Before telling a child some difficult news, it will help to think about how the child will react to the news. Will they be upset, angry or not believe you? Think about how and when you will tell them the news
- How will you keep calm if they react in a way you find upsetting or shocking?
- What questions might they ask? It may be helpful to have this handbook with you in case they want to have some medical information
- How will you answer questions about where the infection came from or about death and what will happen in the future? You may find it helps to think about this and practice in your mind or even with another person how you will react. This will give you ideas about what you will say at the time. You may find that you do not say what you had planned to but preparing will help in the real situation
- Remember that answering questions honestly is usually the most helpful way to talk with the child
- A child will find it easier to communicate if they know that they can trust you and feel that you will understand how they feel
- A child may choose to talk to only one particular adult and ignore attempts by others to talk to them. Respect their right to choose

#### Loving Father



Talking to a child is a good way of identifying the child's concerns.

- A child may find it difficult to talk to an adult. You may have to try over some time to help a child talk about things that are troubling them. Give them opportunities to talk so that when they are ready, they will be able to.

## Where to talk

If you have something to talk to a child about, it is best to find somewhere quiet. Try and avoid disturbances. Sometimes children will start to talk about things that are troubling them in places you do not expect. For example, you may be doing a household task together or walking together to the market when the child starts to talk about his/her worries. If the child wants to tell you there, listen to him/her. Do not delay trying to find “right” place. The child may not want to tell you then.

## How to position yourself

Find somewhere to sit, so that you are at the same level as the child. This will make the child feel more comfortable and assured.

### Communication



Listen to the children. They always have meaning to what they say.

## Think about how you are sitting

It is important for the child to know that you are interested in what he/she is telling you. Do not turn away from the child. Leaning towards the child tells them that you are listening and want to hear what they have to say.

## Active listening

Closeness to the child also matters a lot. Some children may want to have their hand held or to have a hug. Others may want to have more space, especially if what you are talking about is difficult. Facial gestures and eye contact are also very important. If you look angry or uninterested, the child will find talking harder. Look at the child, even if they look away. This tells them you are listening to them.

### Active listening



Listen to children they have needs to express to us.

Let the child speak to you. It is very easy to talk for someone, and if the child has difficulty finding their words, you may be tempted to “put words in their mouths”. Be patient and allow them time to tell you in their own way.

To help, you can make encouraging sounds or repeat the last word or sentence that the child said. You can also ask “open” questions. These are questions that cannot be answered simply with a yes or no.

Do not assume you know what the child is trying to tell you. Tell him/her what you think you have heard from them so that they have the chance to tell you again if you have got it wrong.

- Talk to children in a language they understand. Using words that they have not heard before will confuse them. If you use a medical term, explain to the child what it means.
- Answer any questions they have with honesty. You may not be able to answer some questions. If this happens, you should tell the child that you do not know. It is better to do this than to pretend you know.

The child will find it difficult to talk if they are made to feel stupid or that they have done something wrong in saying certain

#### An open question

Child: “I am worried about my father’s health.”

Adult: “What is the problem?”

#### A closed question

Child: “I am worried about my father’s health.”

Adult: “Is this because he is always ill?”

things. They will find it easier to talk if they think you understand what they are feeling. If they have not understood something, do not criticise them. Help them to understand by explaining more simply.

### Simple language

Whenever you are discussing the facts of sexual reproduction or disclosing your HIV status to the child, it is important to be truthful and use simple language.

### Confidentiality

A child will not tell you personal information if they think you will tell anyone else. It may be right to tell other family members about how the child feels. Before you tell them think about how the child will feel if you share what they have told you with another person. It may help to explain to the child that you

### Understanding what the child has said

**Child:** I have a problem at school. My teacher was angry because I didn't have my book at school."

**Adult:** "Your teacher was angry because you forgot your book today?"

**Child:** "No. He was angry because we haven't bought the book."

want to tell someone else and why this is necessary. They can then tell you how they feel about it.

Young people are nearly adults. Talking to them as if they are small children is likely to prevent problems being solved. By the time they are young people they should be able to take responsibility for their actions. Shouting at them will not help them to do this. Show that you respect them as people. If you are worried about their behaviour, tell them why this is the case. Forbidding them to do something without explaining why may result in them doing it anyway. Young people will respect your advice if you give it in a reasonable, caring manner.

### Other forms of communication

Children may not be able to put into words what they wish to say. Some children can express themselves by drawing pictures. You can ask them if they would like to draw or paint a picture.

### Talking to adolescents



Always be calm when talking to adolescents about their problems.

### Talking to adolescents



Adolescents too need respect while talking to them.

When they have finished you can ask them to talk about what is in the picture. They may be able to use the picture to tell you what is troubling them.

Using toys or games is another way to help children bring out their feelings. Watching children play can help you to know how they are feeling.

Michael is 9 years old. He enjoys playing football and is a good team player. He was popular with the other boys. His uncle heard some of the boys complaining that they do not want to play with Michael any more. He won't let others have the ball and has hurt two boys by dangerous tackling. His uncle is surprised because this does not sound like Michael. He suddenly realises that this has happened since his father has been very sick at home.

He decides he must talk to Michael about what is troubling him.

Some children find it easier to talk about their situation through play. For example they may tell a story using a doll.

Sarah is 7 years old. She has a doll that was given to her when she was a baby. Her mother hears her talking to her doll, telling her that she shouldn't be so sad as her father will soon be well. Sarah's mother decides she needs to talk to Sarah about her own father's illness.

Watch the child for signs that they are unhappy and offer him/her the chance to talk to you.

## 4.2 Talking with children and young people about sex and relationships

"I think my daughter is having sex with a man. I am afraid to ask her but I worry that she will get the same infection as me."

HIV-positive mother.

Initiating young people into knowledge about sexuality can be a problem when traditional practices have disappeared. Adults sometimes feel unable, for both cultural and personal reasons, to talk to children and young people about sex, and hope they will find out some other way. The danger of this is that they may find out only by getting themselves into difficulties. Such sexual relationships and/or compromising situations. These should be prevented.

### **Some of the risks that young people face if they do not have information,**

- Unhappy relationships



- unprotected sex leading to: Sexually transmitted diseases, including HIV
- Unwanted pregnancy

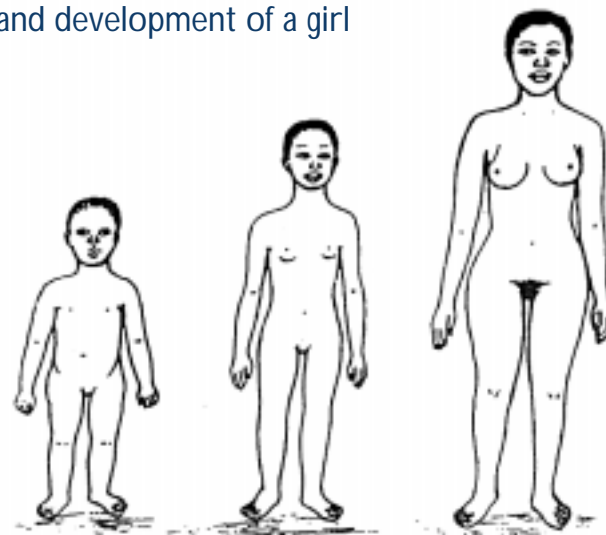
Youth, particularly girls, sometimes get involved in relationships at an early age. They may get married, or get involved in a serious relationship, or have casual relationships. They could be searching for someone to give them love, may want to leave the home they are living in, or may hope that the relationships will provide money or other material benefits. Unfortunately they may find that the relationship only adds more problems to the ones they already have. Unfortunately, orphans are also vulnerable to these high risk relationship.

### What you need to talk about with young people

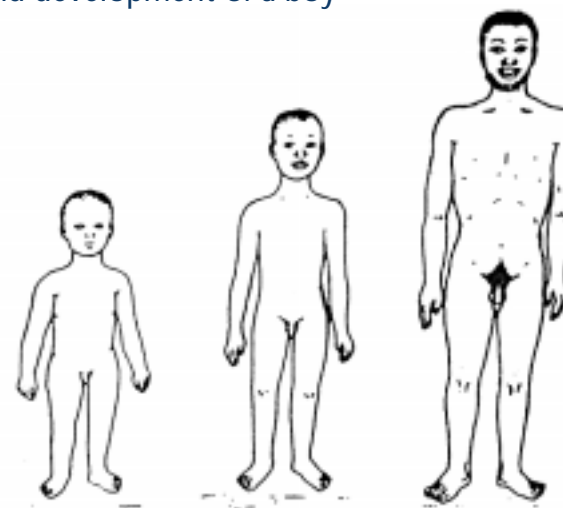
You should talk to young people about the physical changes that happen in their bodies at adolescence and about what happens when people have sex. Young people can be vulnerable if they do not know these basic facts.

Young people and you need to talk about relationships. Make sure they do not get forced into having sex; they should exercise personal choices. Help them to say “no” to relationships they do not want. This may sometimes mean that they tell you a neighbour or family member has defiled them. Knowing what has happened will be difficult but it will help you protect them.

Growth and development of a girl



Growth and development of a boy



Talk to young people about the problems associated with sexually transmitted diseases and unwanted pregnancies and how these can be prevented through safe sex.

### **When to talk to children**

Growing up and having a sexual relationship is normal. Try and be relaxed about discussing the subject.

Try to use the opportunities that arise every day to talk to children. Consider these three simple examples. The goat has a kid. You can talk about how this has happened and then arrive at how people have their young ones. Open a condom, do not look for opportunities to find a used condom. This is a chance to explain what it is for as well as its proper use and disposal. There is gossip about a girl having many sexual partners. Use this to warn your children about the dangers of this behaviour. The earlier you start talking with your children, the better. Start talking about how the body works when they are young. You do not have to talk about sex at an early age. But if you get used to talking about related matters, it will be easier for you when the children are old enough. You should find it useful to know that children may need knowledge at a younger age than you expect.

Children will find it easier to talk to you about sex if they know you will listen to them. If you show anger or great embarrassment when the subject is brought up, they will not ask you about the

things they do not understand. They will not ask for your advice either. You may therefore lose the opportunity to guide them and help them avoid problems.

One thing to remember always is that you have nothing to lose by talking to your children. You may not do it very well. However, if you talk to children, they will know that you care about their future.

### **4.3 Helping Children Cope with Sickness in the Family**

#### **Mishek's story**

"I am 11 years old. I live with my parents. Last year after my baby brother died, my mother started to be very tired. She often lies down. When I ask her what is wrong, she says she is just tired. I asked my father what was wrong and he said she was just fine. I heard some neighbours saying she has AIDS. I am worried that she will die soon."

#### **Mishek's mother's story**

"My baby died last year. They told me at the clinic that he had AIDS. I had the HIV test and I am positive. I have been ill at times since then. Mishek is a good boy. When I am ill he stays by my side. It will upset him too much to tell him that I am HIV-positive so it is better he doesn't know."

Adults usually want to protect children from news that they know will make them unhappy. Like Mishek’s mother, many adults decide that it is better to pretend there is no problem. This usually does not help the child. They may lose trust in adults and become angry if they are told all is well when they can see it is not. They have to keep their worries to themselves and may become unhappier as a result.

If you don’t discuss the truth with your children, they may hear the news from outside the family and this may include some untruths. It is better for the child to know the situation. Keeping it from them does not mean that children will feel less pain or that they will be protected from the effects of HIV.

### **Who should tell the child**

The best person to tell the child that a parent has HIV is someone they are close to and who they trust. This should be someone who will be there for the child to talk to when they need to. A relative who the child sees only once a year would not be a good choice, even if they get on well with the child.

### **When the child should be told**

Children should be told as soon as possible that parent(s) is ill. You need to remember that even quite young children often know when things are not well around them. They will notice if

adults are distressed or if they hear conversations between adults and can understand enough to know that there is a problem. They will feel tension in the home and be worried by what they know.

Adults should not wait for “the right time”, for this may never come. A child may want to know why the adult has waited a year or more to tell them such important news. Adults can find that telling the child becomes much more difficult as time goes on. Unfortunately, the sick person may die before the child is told.

### **What HIV positive adults should tell the child**

Adults may have difficulty deciding what to tell the child and what to leave out. You need not worry over so much detail. The key thing is to keep it to the facts, in simple language and in amounts that the child can take at a time. The following will be useful to remember,

- Keep things simple. Let them take in one piece of news at a time. Young children need to be told that something is wrong, but they will not probably need further information at once.
- You do not have to tell the child everything at once. You could start by telling them that a parent or brother or sister is not well. This may be all that some children will understand.

- Sometimes children may not want to listen to what you have to say. They may be frightened of what they think you are going to say. Do not try and tell them when they do not want to hear. You can tell them that they can talk to you about the subject at some other time. This will help them to realise that they can discuss the subject when they are ready.
- Children can ask questions that we do not have the courage to answer. One of these is whether the HIV-positive person will die. A child may think that death will come very soon. Unless it is likely that the sick person is dying, you can reassure the child that it may be a long time before they die. It is important to be truthful and it would be fair to say that no one knows when anyone will die.
- Some children will want to know about the illness. You can use the information in this book to explain to a child. Give them the chance to ask questions about information they do not understand. If they ask questions that you do not know the answer to, you can ask counsellors, people at the clinic or those working with home based care organizations.
- A child may want to ask the same questions many times. Try not to lose patience. Explain what they want to know; taking time to do this will reassure the child.
- A child may react in a way you do not expect. They may appear to be unconcerned about what you are telling them. They may feel angry with the person who is ill or with you who is telling them. Do not be angry with them or let yourself be distressed. The child could be shocked by the news or may want to deny its truth. Keep calm and give them time to take in the news. You may find that they need time to get over the initial shock before they can talk about what you have told them. You may need to tell them again, as sometimes people do not remember hearing bad news and may deny that they have been told. You need to allow the child to take in the information at his/her own pace.
- Sometimes children think that they may have caused the illness by doing or not doing something. They need reassurance that the illness has not been caused by them.
- Children are able to deal with illness more easily if they know what is happening. If they can talk about their fears they will be less worried. Adults in the family therefore need not worry about them finding out about the illness. The child will still feel the pain of seeing a loved one when they are ill.
- Children may have to cope with people they know treating them differently because of attitudes to HIV. There may be

less food in the home, and school fees may be hard to come by. The changes are difficult to live with. But children can find them easier to deal with if they understand the reasons for the situation.

- When the sick relative is in hospital, the child may want to visit them. This is particularly important if they need to say goodbye. Hospitals can be frightening places if children have never been to one before. Try and prepare the child for what the visit may be like. This could include telling them about the hospital and the ward. If the relative is very changed, you should tell the child about the sick person's appearance. The child may want to stay only a short time. They should not be forced to stay if the visit is distressing them.
- Keeping children informed helps them to get used to the situation and to be part of any plans for the future. This will help them adjust to changes in their situation. This will be particularly important when the close family member dies.

#### 4.4 Children and grief

"As human beings we die just like any other natural thing that God created. The causes of death are many, though the most common is illnesses."

Carer.

People are overcome with grief when they lose people or things that are important to them, eg. the chance to go to school, a good meal or good food, a better house or their own health. One can even start to express grief before a loss happens. When children lose someone close to them, the way they react will depend on their age and what they are like as people.

Reactions to grief change with a child's age and stage of development. Some children may not react in a way that is usual for their age. This is normal since not all children in the same age group will be at the same stage of development.

##### **Different ways of coping by children by age**

Babies below the age of 6 months are not able to remember people for long. They may not always know when someone close to them is missing. Babies therefore should not be upset by the loss of their mother if someone else is able to take good care of them.

Between the ages of 6 months and two years children are able to recognise their close family members and search for them when they disappear. They become very attached to the people caring for them. But they cannot understand what death means, even if they have actually seen their dead parent or dead animals. So they will not understand that the person they are attached to will not come back. You may observe some of the following behaviour in these children,

- They may protest, showing grief and anger with loud wailing
- They may refuse to be comforted by any person.
- They may become withdrawn and perhaps rock their body or sit still for a long time in despair.
- They may become very active and sometimes aggressive towards other persons or any objects they associate with the missing person.

Children between the ages of 3 and 5 years may not show grief openly, particularly if they feel secure in the knowledge that they will be cared for. They need to be given this assurance to prevent the fear that they will not be cared for.

Between the ages of 5 and 8 years children can understand the meaning of death. At this age they may blame themselves for the death. They can think that something they have done or failed to do has caused the death. The child may behave un-

pleasantly due to anger and the feeling that they deserve to be punished for their parent's death. They may deny that the death has happened. Some children will ask again and again where their missing parent is. Others will behave as if nothing has happened; they do not want to think that their parent will never come back.

By the age of 8 years, the child has a greater understanding of what death means. They know that death is a natural process. They know that it cannot be changed and that it can happen to anyone, including themselves. Children of 8 or 9 years and over react to death much like adults. They are tearful and withdrawn and are not interested in anything. They may be very angry, either with the dead person or with others. Anger in a child may seem very strange, but this is a common feeling in adults who have lost someone. Grief can occur in different stages. Some children go through all these stages, but in a different order. Others go through only some of the stages. These stages are described briefly below,

### **Denial or disbelief**

Children may not believe what they are told. They may behave as though nothing has happened. They may say that the person telling them is wrong. Sometimes they may deny ever being told that their parent has died.

### Psycho-social effect of grief on the child



A child under going grief may refuse to participate in social activities

### **Making sense of the loss**

The child may try and understand what has happened by asking many questions. They may feel guilty that they have caused the death or failed to stop it happening. Some things they say may be unreasonable. This is normal.

### **Anxiety and hopelessness**

The child may be very worried about what will happen next. They may fear that they have no future.

### **Anger**

The child may feel angry with the deceased person, feeling that they allowed themselves to die. They may feel angry with people

who they think caused the death or did not care for the deceased person.

### **Sadness**

The child may cry and it may not be easy to comfort them. They may be quiet and not want to do the things they normally do, or may isolate themselves from other children.

### **Accepting what has happened**

As time goes on, the child will look to the future when they have got used to not having the person they have missed. They will still miss them and will sometimes be sad, but not so often.

You may find that they complain of headaches or stomach pains. This can be the way they feel their grief. They may find it hard to concentrate and this can be a problem at school.

### **How you can help a child who is grieving**

It has already been noted that adults may have difficulty talking with children about problems. Here are some ideas on how to cope with the demands for supporting children who have to cope with grieving,

- Be honest with the child. Tell them what has happened. You need to tell them in a way they can understand. Some chil-

dren will want to ask questions about the death. Answer them honestly, in words they understand. If you do not know the answer to a question, tell them this and do not try to make something up.

- Accept the child's feelings. Understand that they will behave in a way that perhaps you do not expect but that this is normal. Allow them to cry. Do not be angry with them if they are angry with their dead parent. Do not be surprised if they behave as though the parent were not dead.
- Reassure the child. Allow them to ask questions and talk to them about the future.
- Try to keep as many things as normal as possible. The child will feel safer if they can do some things as usual.
- Talk about the deceased parent. Remember happier times. Laugh about good memories. But do not make the child talk about these if they are not ready for this. Allow the child to take part in ceremonies. This could include allowing them to attend the funeral or join in other rituals normally attended by adults. If this is not possible, you can hold your own ceremony especially for the child.
- Allow the child to use something belonging to their dead

parent. This could be something that their parent used or wore often that would remind the child of their life together.

- The child may like to have a box or a basket to keep small items that remind them of the deceased person.
- Some children are helped by writing or drawing about their deceased parent or the way they feel. They could write a letter to the deceased or draw a picture of them.
- Remember the deceased family member at special times. Traditional family celebrations and birthdays are good times to talk about the person.
- Grief can take a long time to pass. Be patient with the child. Support them when they are feeling sad and encourage them if they are feeling hopeless. In time these feelings will be easier for them to cope with.

Moses is 14 years old. He lost both his parents more than 5 years ago. He had to move to another village to stay with relatives he did not know well. They have been very kind to him. He still feels sad that his parents have died and sometimes cries at night. He hopes to go to secondary school. He wants to be a lawyer. He hopes that the future will be good.



## Problems related to grief

### Attitudes of adults

Hope is 9 years old. She lives with her uncle and aunt in Entebbe. Her mother died two years ago. Hope was not told that her mother had died. Her aunt has told her that she is in the village. Hope has heard from the other children in the family that her mother is dead. She does not know if they are right or if her aunt is telling the truth.

Adults may find it very difficult to tell children the truth about the death of their parents. They may either fail to say anything or lie to the children. Adults sometimes do this because they do not want to hurt the children. Adults who do this do not realize that by doing so, they may hurt the children more. Children often understand very well what is going on and honesty is the best way to help them. If they find out that someone has told them lies, they will not be able to trust that person in future.

### Depression

A few children may become ill with depression. They will lose their appetite for food and lose weight; they will be withdrawn and sad; they will not be able to sleep well, often finding it difficult to go to sleep or waking up earlier than usual; they may be very anxious. In severe cases the child may talk about wanting to die.

A child who is talking about dying should be watched closely. It may be possible to get help from the clinic.

### Problem behaviour

Some children may react in ways that are not acceptable in society. They may use alcohol or other drugs to take the pain away. They may be very angry and get into trouble because they are fighting. They may feel guilty about the death, blame themselves and thus prove they are bad by doing things that they know are wrong, such as stealing.

It is hard to feel sympathy when a child is being very difficult. Try to remain loving towards them. You can tell them that you do not approve of what they are doing but they are still special. A child who has a secure, loving family finds becoming better behaved easier than one who has been rejected by his family.

## 4.5 Caring for Orphans

Extended families have always cared for orphans. Children have been taken into other families and been raised as children of those families. Many children have happy lives in their new homes.

There are problems in some families where the aunts and uncles who could take over the care of the orphans have also been affected by HIV. It means that there are fewer people to take

care of the children. Elderly grandparents, who themselves have no one to take care of them as they become affected by age, are the only people who may be expected to care for the children.

Children do better if they have few changes in their life. It is hard for children if they lose their parents and have, at the same time, to move to a family they do not know in an unfamiliar place. If possible the child should stay at the same school and live in the same area for as long as possible after the death of their parents.

Moving from town to the village or the other way round can be very difficult for children who are grieving. If the move has to happen, try and prepare the child for the differences they will find. Talk about what life will be like and give them the chance to ask any questions they may have.

Orphans may have to leave school because there is no money for fees or uniform. For many orphans, school gives hope for the future. It may be possible to find help with fees from an NGO. Ask at the school if any organisation is helping orphans in the area.

"Other needs of the affected children that are too often unmet are adequate housing, clothing and bedding. Some orphans have trouble adapting when guardians who are not as well off as their parents take them up."

Teachers' discussion in Kisinga

Losing a parent to AIDS can bring stigma to the children. Children lose esteem for themselves because of this. This can lead to poor results in school, bad behaviour or depression. Share with the child good memories about their parent. Praise the child when they do well so that they know they are valued. The child may also have the stigma of being HIV-positive or being thought to be, because of their parent's illness. Other children can be very cruel to a child that they think is different. Show by example that rejecting the child is wrong and encourage them to play together.

Acceptance



Teach your children to accept orphaned children

Guardians often report that orphans are very quiet and sad. This is normal. It may take a long time for children to stop grieving for their parents. This does not mean that guardians are failing to look after them.

Some families take on orphans and mistreat them. The children may have to do all the heavy work and may be abused or neglected by members of the family. Stepmothers are often thought to mistreat children, giving preferential treatment to their own. No child should have to suffer in any home; child abuse and neglect is illegal and should be reported to the authorities.

#### 4.6 Caring for Children in School

Attending school is important for all children. It is particularly important for children who are having problems at home. They have a chance to be a child and to forget for a while what they suffer outside school.

#### Attending School



Children with HIV infection should attend school, and socialise with other children

#### Children with AIDS.

Children who are well enough should attend school. It is important for them to lead as normal a life as possible. Treatment for HIV/AIDS has improved and it is not possible to tell how long a child will live.

“Sometimes when he is sick he does not go to school but after improvement he can then go to school but then there is a general lack of concentration.”  
Parents with a sick child, Kasese Kizungu.

Other children and even adults may worry that they will catch AIDS from an infected child. The information in this handbook explains that normal social contact will not lead to HIV being passed from one person to another.

“The kids at school are not mature; they would laugh at the infected and this will cause them not to do well in class”.  
Bwera Kikwaso adults.

Children should be protected from bullying by other children. Teachers can set a good example by treating the children well. Children who are ill may need special treatment at school because they may need to rest or to have extra drinks.

Teachers need to know about clearing up blood safely if there is an accident so that there is no risk of passing the HIV virus. This is explained in earlier sections.

### **Children affected by AIDS.**

Children who are living in an AIDS-affected home may have a number of problems that will affect their school life. The family may have a lower income than they did before AIDS affected the home. This leads to difficulty in paying fees and buying uniform and books. Children may have to leave school or miss a

term while someone finds the money. This is additional stress for the child.

Children may have to take on jobs that would normally be done by adults in the family. This can make them tired and lower their attention in class. Some sick parents have only their children to care for them. The children have to nurse, bathe and feed them. This can mean that they will be late for school and that at school they may think about the sick parent instead of their schoolwork.

Children who are HIV-negative but come from homes with sick parents may bear the same stigma as the children who are known to be infected. Even though they are well, other children and adults may fear that they will pass on HIV. This may make the child feel that he cannot tell anyone about his problems. Teachers may not know that the child has problems because of this stigma. Teachers can have a positive role in teaching children about HIV and changing attitudes. Teachers who show understanding to children affected by AIDS assist them greatly.

### **4.7 Caring for the Carer**

Carers can be either people whose job it is to look after sick people, such as nurses, or people who look after family or neighbours. This section is about people who are not being paid to care. This guidance for such carers is necessary because people

sometimes forget that they have to look after themselves besides caring for the patient.

### **The carer's health**

Caring for someone can affect the carer's physical and emotional health. They may need to lift someone and can hurt their back with the action. They may not get enough rest themselves because they have to care for the patient night and day.

Try and make sure that the effort of lifting or moving the patient does not put any strain on your back.

The information in this book about a healthy diet, avoiding infection and having plenty of rest is good advice for adults too. Carers need to look after themselves so that they have the strength to look after the patient.

### **Worries about the patient's illness**

Carers may think that the patient will pass HIV to them. They may worry that they will not manage looking after the patient as their illness gets worse.

Besides the information about how to avoid catching HIV that is provided in this book, the staff at the clinic may be able to answer questions about treating the illness.

### **Worries about money**

Families have extra expenses when someone is ill and there may be less money than usual at this time. Carers can find that they have no money for school fees or other important items. They may have to choose between food and medicine.

### **Fears about the future**

Carers may have very real worries about the future. When they are nursing a patient, they may not be able to talk about what might happen when the person dies. Talking about the death might make them seem strange to others. The patient too may be worried about the future of their children and be unable to talk about this because of the same cultural attitudes.

Allowing carers to talk through their fears will enable them to feel less anxious. This may help them to be better carers for both the patient and any children they are responsible for.

### **Grief and depression**

Adults, like children, may begin to grieve even before someone has died. They feel sad, knowing that they will lose that person. This is normal.

People who have had to cope with a number of deaths of close family members are at greater risk of becoming depressed. As

### Caring for carers



Carers too need to be cared for.

with children, the signs of serious depression are loss of appetite, with noticeable weight loss; sleep disturbance; withdrawal from normal activities and, of greatest concern, talking about ending one's life. Someone should stay with them and comfort them through this difficult time and refer to local counsellor.

### Young carers

Children have had to take over adult duties when there is no one else. In some homes children have to nurse their parent. They may do this very well but bathing and providing other personal care for a parent can be difficult for a child. Children may want to do this because it is a way of showing their love for the parent.

Older children may have to take over the care of their younger brothers and sisters as well as the running of the home. Many manage to do this and go to school. Sometimes caring for the younger children has happened while they are nursing their sick parent. This gives them time to adjust to the responsibilities on them.

These children need support from adults that recognises their important caring role. Adults can try to take over the role from the child and this can make the child angry. Talk to the child and ask how they want to be helped and discuss what can be done by the adults around them.



**Abstinence** Refraining from penetrative sex .

**Adolescents** Boys and girls in their teens.This usually lasts from 12 to 20 years

**Anaemia** A condition under which one does not have the required amount of blood in the body. Anaemia is common among children suffering from malaria or who are malnourished.

**Antenatal care** Regular medical examination and care given to pregnant women in health facilities. The care includes physical examination, health education, testing for syphilis, tetanus vaccination and counselling.

**Antibodies** Substances produced internally by the human body to fight a disease - causing germs that attack it.

**ARV** Anti retro-viral drugs are modern medicines that are taken by people with HIV to control the multiplication of HIV in their bodies. ARVs are known to prolong and maintain the health of people living with HIV/AIDS

**AZT** An anti retroviral drug given to people with AIDS known as Zidovidine

**Being faithful** Deciding to have sexual intercourse with only one partner; permanent person

**Blood to blood transmission** Acquiring HIV infection through being exposed to blood products like blood itself

**Body building foods** Food types that support body growth growth and development. Examples include beans, groundnuts, eggs, meat and fish, among others.



<b>Body protecting foods</b>	Food types that strengthen our resistance to diseases. Common examples include vegetables and fruits.	<b>Counsellor</b>	A person trained to provide emotional support and guidance to those who are worried about HIV and its associated problems. Counsellors are available at health centres or at organisations like TASO and AIC.
<b>Candida</b>	An organism (fungal) that is one of the causes of thrush in patients with lowered immunity	<b>Disclosure</b>	To open up to someone about one's personal problem (s) eg. HIV infection
<b>Casual contact</b>	Contact with a person that does not involve exchange of body fluids and does not transmit HIV	<b>ELISA test</b>	Enzyme linked immunosorbent assay. A complex HIV testing procedure conducted in laboratories. It takes 3-8 days in most places at least two weeks for one to obtain the results
<b>Condom</b>	A piece of rubber, worn by a male on his penis during sexual intercourse in order to prevent HIV, STD and pregnancy. Also female condoms exist	<b>Emotional care</b>	Providing comfort and reassurance to a child with problems such as worries and fears
<b>Complementary foods</b>	Foods that add value to an existing one	<b>Energy rich foods</b>	Food types that supply our bodies with energy. Examples include cassava, maize, sugar, millet and bread, commonly categorised as carbohydrates
<b>Confidentiality</b>	Ensuring that information about a person's HIV status is not revealed to others unnecessarily	<b>Exclusive breast feeding</b>	Feeding the baby on breast milk only, without giving any other foods.

<b>Family Planning</b>	Medical options used to prevent conception or aid child spacing	<b>HIV testing</b>	A procedure carried out in health units to find out whether one has HIV antibodies or not
<b>Femidom</b>	It is a female condom.	<b>Home care</b>	A practice of nursing people suffering from HIV/AIDS in their homes
<b>Health centre</b>	A facility in our communities where people go for medical treatment and other health care services	<b>Immunisation</b>	Giving vaccines to children (who are usually below 5 years) for protection against diseases like measles, polio, diphtheria, whooping cough, tetanus, hepatitis B
<b>Health worker</b>	A person who is trained to provide health care services.	<b>Incising</b>	The act of cutting the skin either to administer herbs portions or for beautification or to drain pus
<b>Herpes Zoster</b>	A skin reaction that follows a dermatome	<b>Infant formula</b>	Natural milk or artificial milk that is fed to babies. This includes Lactogen, Nan and others.
<b>HIV antibodies</b>	Chemical substances produced by white blood cells to fight HIV infections. These could be referred to as soldiers produced by our bodies to fight HIV.	<b>In-Patient</b>	A medical term that refers to patients who are admitted into hospital wards for some time
<b>HIV-negative</b>	An HIV test result that indicates absence of HIV antibodies	<b>Memory Book</b>	A book written by parents or guardians to help their children preserve family history and childhood memories.
<b>HIV-positive</b>	An HIV test that indicates the presence of HIV antibodies		

<b>Microscope</b>	An instrument used to magnify objects to see details of small living organisms	<b>Poliomyelitis</b>	Is a disease caused by the polio virus
<b>Myths</b>	Beliefs that are untrue though upheld by society	<b>Polygamy</b>	A marriage relationship that involves more than one wife
<b>Non -penetrative sex</b>	Showing sexual affection without inserting the penis into the vagina or anus	<b>Positive living</b>	A term used among people living with HIV/ AIDS that refers to adopting practices that promote health, a good self image and behaviour that prevents further spread of HIV
<b>Nevirapine</b>	An anti retroviral drug used during labour to prevent mother to child HIV transmission.	<b>Pre-test counselling</b>	An informative session one holds with a counsellor, in private, to understand more about HIV/ AIDS and to decide whether to take an HIV test or not
<b>Opportunistic infections</b>	Illnesses one gets due to weakened immunity as a result of HIV infection	<b>Prophylaxis</b>	Medicine taken to prevent occurrence or manifestation of certain diseases
<b>ORS</b>	Oral Rehydration Salts that are mixed with water and given to children who have diarrhoea or are vomiting. Sachets of these are obtained from health units, clinics or local drug shops.	<b>Psychosocial</b>	ones mind and society-how one relates to society mentally
<b>Out-patient</b>	A medical term used to refer to patients who come in to attend the hospital clinics and go back to their homes	<b>Rapid test</b>	A simpler HIV testing procedure than the ELISA, by which one gets to know the results in 15 minutes
<b>Paracetamol</b>	Panadol, a drug taken to reduce pain		
<b>Penis</b>	The male reproductive organ		

**Safer sex** Sex that does not involve exchange of sexual fluids

**Semen** Sexual fluids from the man's body

**Sexual intercourse** The act of having penetrative sex

**Spouse** One's wife or husband

**TB** Tuberculosis

**Tepid sponging** The process of normalising the body temperature of a child or adult having high fever by using a soft cloth soaked in lukewarm water

**Thrush** white sores in the mouth due to Candida infection

**Vagina** A female reproductive organ

**Virus** A very small germ that cannot be seen by an ordinary microscope

**Vitamin A** One of the nutrients essential for the proper development of the eyes that is given to children during immunisation but is also found in dark leafed vegetables

**Voluntary Counselling and Testing** The initial process one is taken through at an HIV testing centre to help him or her decide whether to take an HIV test or not and how to cope with the test results

**Weaning food** Food other than milk or breast milk given to a child who is about to stop breast feeding

**Window period** A term given to the period between contracting HIV and the development of adequate antibodies against HIV in the human body



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## Individuals who contributed to the development of this handbook

- |                            |  |                         |                              |
|----------------------------|--|-------------------------|------------------------------|
| 1. Ida Kigonya             | Ministry of Gender Labour and Social Development | 18. Rena Geibel         | Save the Children UK         |
| 2. Sophie Odongo Okino     | Ministry of Health                               | 19. Elaine Ireland      | Save the Children UK         |
| 3. Jane Nabalonzi          | Ministry of Health                               | 20. Douglas Webb        | Save the Children UK         |
| 4. Linda Kavuma            | Ministry of Health                               | 21. Christine Musisi    | Save the Children UK         |
| 5. Dr. Elizabeth Namagala  | Ministry of Health                               | 22. David Maweje        | Save the Children UK         |
| 6. Dr. Israel Kalyesubula  | Mulago Hospital                                  | 23. Dorothy Oulanyah    | Save the Children UK         |
| 7. Dr. Nakaketo-Kijjambu   | Mulago Hospital                                  | 24. Dr. Christine Ondua | Paediatrician, Arua Hospital |
| 8. Y.K.Nsubuga             | Ministry of Education                            | 25. Dr. Gamba Osiga     | Save the Children UK         |
| 9. Mary K. Lukubo          | The AIDS Support Organisation                    |                         |                              |
| 10. Resty Bwangu           | AIDS Information Centre                          |                         |                              |
| 11. Edith Asiimwe          | Mildmay Uganda                                   |                         |                              |
| 12. Simon Banga            | Freelance illustrator                            |                         |                              |
| 13. Edward Namasenda       | Graphic Designer/Typesetter                      |                         |                              |
| 14. Dr. Jonathan Mermin    | CDC  |                         |                              |
| 15. Dr. Donna Kabatesi     | CDC  |                         |                              |
| 16. Dr. Sheila M. Coutinho | CDC  |                         |                              |
| 17. Patience Alidri        | Save the Children UK                             |                         |                              |







