













































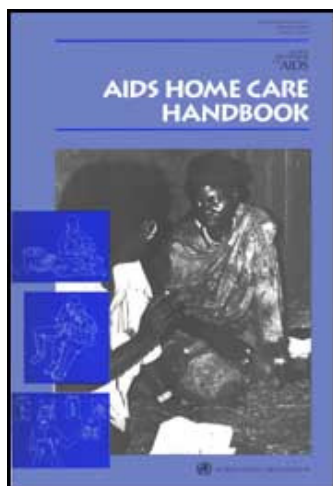
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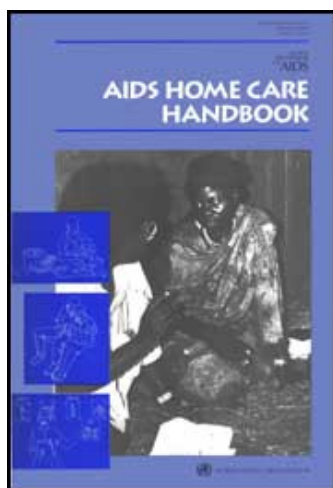
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Nsambya Hospital, Order of St Francis, Kampala, Uganda
Salvation Army Chikankata Mission Hospital, Mazabuka, Zambia**

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A booklet called *Living with AIDS in the Community* was the source of several ideas and drawings used in this handbook, including the faces revealing the variety of feelings about AIDS. WHO wishes to thank the organizations in Uganda (the National AIDS Programme, TASO and the country offices of UNICEF and WHO) for publishing this booklet and for sharing its contents. A revised WHO/UNICEF version of this booklet is now available - see the resource list at the back of this handbook.

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 **(introduction...)**

 **Acknowledgements**

  **Preface**

 **Introduction**

 **Part I: Teaching Guide**



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Preface

Every year, throughout the world, an increasing number of people are affected by the HIV/AIDS pandemic, either directly or through someone they care for. People with HIV infection can remain healthy for some years, but it is assumed at present that all HIV-infected people will develop AIDS in due course. AIDS is a chronic disease lasting months or years, and a person with AIDS may move several times from the home to hospital and back again. Much of the care of those with AIDS therefore occurs in the home.

Home care means different things to different people, but whatever form it takes, it relies on two strengths that exist everywhere in the world - the family and the community. It is with the hope of stimulating and utilizing the strengths of the family and the community that this handbook has been developed.

Care at home provided by family, friends or neighbours is not without problems. Very few of the people giving this care have ever had any training in looking after sick people. Many of them will be concerned about their lack of knowledge and skills. They may also be concerned about catching AIDS themselves. Therefore the aim of this handbook is to provide health care workers with the information they need to help families gain confidence about their own ability to give safe, compassionate and helpful care to people with AIDS in their homes.

In many families and communities, it is the most basic needs - food, clothing, and housing - and the money to pay for them that are the major problems. AIDS can create many additional demands on family and community resources. The handbook takes this into account. No expensive equipment or medicines are suggested. In fact, they are usually not needed - clean water and soap, essential medicines and other things commonly found in the home, combined with the caring hands of the family, are enough.

The readiness of families and communities to provide care for persons with AIDS at home is important. In early stages of the epidemic (when few people are noticeably sick) there is often a high level of stigma, fear and lack of acceptance of people with AIDS. People are frightened or ashamed to admit they have a person with AIDS in their homes. This can make it difficult for health workers to involve families in learning about or providing care at home.

As more people are personally affected, the tendency for hiding or denying the disease decreases. As peoples' knowledge and understanding of HIV increases, their attitudes toward caring for persons with AIDS are likely to become more positive.

Home care is often the best way to look after someone with AIDS. There are many reasons why:

- **Good basic care can be given successfully in the home.**
- **People who are very sick or dying would often rather stay at home, especially when they know they cannot be cured in hospital.**
- **Sick people are comforted by being in their own homes and communities, with family and friends around.**
- **Home care can mean that hospitals will be less crowded, so that doctors, nurses and other hospital staff can give better care to those who really need to be in hospital.**
- **It is usually less expensive for families to care for someone at home, for example they will not have to pay for hospital bills and transportation to and from hospital.**
- **If the sick person is at home, family members can meet their other responsibilities more easily. This can be difficult if they have to stay at the hospital, or have to travel frequently to help and to take food to the sick person.**
- **Sometimes hospital care is simply not possible.**

The aims of AIDS home care are the same as those for any home-based health care programme:

- **to prevent problems when possible,**
- **to take care of existing problems, and**
- **to know when it is time to get help.**

Since care of AIDS at home is similar to care for many other illnesses, the advice given in this handbook can be used to help anyone who has the same symptoms for other reasons, such as malaria or cancer. It can be used by health care workers who may also work in other areas such as maternal and child health, nutrition or immunization. It may also be useful to social workers, religious people, counsellors and others.

The information provided is based on accepted international guidelines and the extensive programme experience of many individuals and agencies working to combat the HIV/AIDS pandemic. However, it is rare that there is only one "right" way of dealing with a problem and it is impossible to give all the answers here. Nevertheless, it is hoped that the advice offered here will prove helpful and will stimulate readers to start thinking about new ways to solve problems.

This handbook can also be used by health care managers seeking to improve the home care of those with AIDS. It is hoped that they will adapt the handbook to suit the specific conditions in their own country or area, and use it as a resource book for training health care workers.

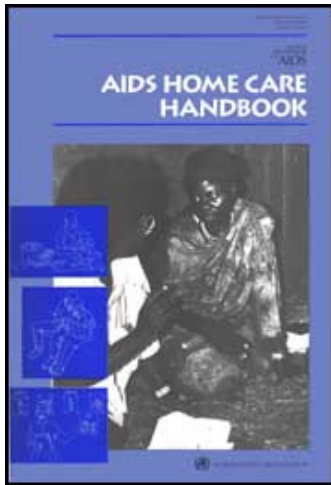
The handbook is therefore designed to be adapted and revised in order to suit the specific health needs of people with AIDS, and the customs, special ways of healing, and local language of the region in which it will be used. During the adaptation process, unsuitable sections can be deleted and new topics can be added. Attention will also have to be paid to the drawings. The people shown in the pictures need to look familiar to those who will use the handbook. However, large-scale changes might prove to be expensive, and might reduce the resources available for the translation and widespread distribution of the handbook. It is therefore important to plan and budget carefully at each stage.

It is perhaps fitting that this handbook was developed during 1992, the year in which the theme for World AIDS Day was "A Community Commitment". Every community must become involved

in the fight against AIDS and must be empowered to do so. It is only through an enormous commitment of resources - within and between communities at the international, national and local levels - that the world can hope to contain the HIV/AIDS pandemic and care for those who are ill.






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 **Aids Home Care Handbook (WHO, 1993, 178 p.)**

  **Introduction**

-  **Who can use this handbook?**
-  **What is home care?**
-  **How can you use this handbook?**

Aids Home Care Handbook (WHO, 1993, 178 p.)

Introduction

Who can use this handbook?

The handbook is designed to be used by health care workers.

In this handbook, the term health care workers includes staff in clinics or hospitals, and village or community health workers who are in direct contact with people with AIDS and their families. The handbook can also be used by social workers and those involved in HIV/AIDS counselling.

As a health care worker in any of these categories you can use this handbook when providing home care yourself or when teaching others to give such care.

What is home care?

In this handbook, home care means any form of care given to sick people in their own homes. It can mean the things people might do to take care of themselves or the care given to them by the family or health care worker. Care includes physical, psychosocial and spiritual activities.

The term family is used to refer to the person (or people) with the main responsibility for caring for a person with AIDS in the home. In fact, the person providing such care may be a blood relative, a relative by marriage (a spouse for example), a friend, a neighbour or some other person.

How can you use this handbook?

This handbook is divided into two parts:

Part I

Part I of this handbook is a teaching guide which is intended to help you to provide important information about HIV and AIDS to the community, to the sick person and their family, or to

anyone who is being trained to become a community health worker or a volunteer. Some sections in Part I may also be helpful as part of an in-service training programme. Much of the information in Part I is presented in the form of a story which uses words and pictures to describe how HIV and AIDS affected the lives of a woman called Yulia and the people around her. You should use this story to teach people about HIV and AIDS and you should show the pictures as you go along. To help you to do this all the pictures used in Part I have been printed in a larger size and are provided at the back of the handbook in the section entitled Pictures for Teaching. Part I can be divided as follows:

- **Chapter One explains the importance of teaching and illustrates some of the common difficulties which may be encountered by health care workers by using fictional examples.**
- **Chapters Two and Three provide important information about HIV and AIDS through a story about people who may be familiar to you.**
- **Chapter Four describes how to care for someone who is dying, again using the story.**

Part II

Part II of this handbook is a reference guide to help you, as a health care worker, to provide care for people with AIDS and their families. This part of the handbook will also help you to show people how to manage at home. Part II is composed of the following:

- **Chapter Five describes the common symptoms and problems of AIDS - for each symptom, the following information is given:**
 - **Problems and possible causes**
 - **What to do at home**
 - **When sick people and their families must seek help.**

This information will help guide sick people into the health care system. However, health

care workers will need to decide when and where to refer for additional care, depending on their training and the system in which they work. In addition, space is provided for you to make your own notes on each of the major symptoms and problems, as well as on resources for additional care and support.

- **Chapter Six explains what you should know and do about two special conditions: tuberculosis and pregnancy.**
- **Chapter Seven provides basic information to help you instruct people on how to take common medicines in the right way and how to deal with the problems that might occur when taking them. However, it does not tell you how to decide which is the right medicine to prescribe. Such information, for health care workers prescribing medicines, can be found in the World Health Organization's *Guidelines for the Clinical Management of HIV Infection in Adults* and *Guidelines for the Clinical Management of HIV Infection in Children* (see Resource List).**

Use Part II of the handbook with the standard treatment guidelines of your country.

Every health care worker who is providing medical treatment to a person with AIDS should have a copy of the national standard treatment guidelines which give the correct medicines and dosages for all diseases common in your country. If your country does not have general guidelines the government probably provides specific guidelines for certain diseases, such as tuberculosis, and diarrhoeal diseases.

The laws, regulations and practices that determine who can prescribe certain medicines and in what circumstances are different in each country. In some places almost any medicine can be bought from a store by anyone, while in others only doctors are allowed to prescribe certain medicines. Some medicines sold in pharmacies or village stores can be very useful. Others are of no value. Also, people sometimes use the best medicines in the wrong way, so that they do more harm than good. To be helpful, medicines must be used correctly.

Additional useful sections

- **The Resource List gives details of publications or documents, concerned with HIV and AIDS, that might be helpful.**
- **The Pictures for Teaching used in the story in Part I should be used when teaching others about HIV and AIDS. Some of these pictures have therefore been printed in a larger size, and are provided at the back of the handbook.**

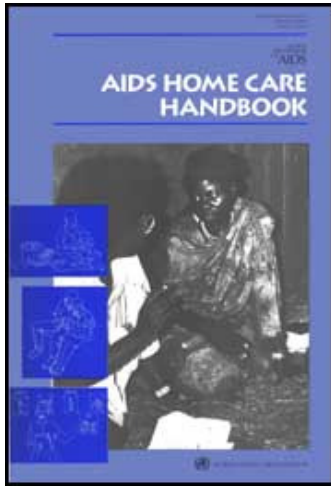
Remember, you can use the handbook:

- **to answer your own questions**
- **to answer the questions of people with AIDS, their families and communities**
- **to remind yourself of important points and procedures**
- **as a teaching aid to remind yourself of helpful and important teaching points or to show information to the people you are teaching. And remember to:**
 - **show pictures from the handbook while you are teaching; this can make the lesson clearer and more interesting**
 - **help the people you are teaching, if they can read and write, to copy out the instructions they need so they will remember what you have taught them to do**
- **as a place to write down additional information, ideas, solutions, or special notes, in the space provided.**

Keep learning!



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➔ **Part I: Teaching Guide**

Chapter One: Teaching people with AIDS and their families

 **(introduction...)**

 **Whom should you teach?**

 **Why is teaching important?**

 **Stories about teaching**

 **What is teaching?**

 **What are the benefits of teaching?**

 **What should you teach?**

 **How should you teach?**

 **More stories about teaching**

Chapter Two: From HIV to AIDS

 **(introduction...)**

 **A story: Yulia and Mukasa**

 **Teaching notes on HIV and AIDS**

 **What are HIV and AIDS?**

 **(introduction...)**

 **Box 1: Ways in which HIV is transmitted**

 **How can you avoid AIDS?**

 **(introduction...)**















 **Box 2: What is "safer sex"?**

 **How do you use condoms to prevent pregnancy and HIV transmission?**

 **(introduction...)**

 **Box 3: How to use a condom**

 **Box 4: HIV Testing**

-  **Box 5: Ways in which HIV is not transmitted**
- Chapter Three: Living positively with AIDS**
 -  **(introduction...)**
 -  **The next part of the story: Yulia and Yokaana**
 -  **Teaching notes about living positively with AIDS**
 -  **Responses to AIDS**
 -  **What is counselling?**
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 -  **Special issues concerning children with AIDS**
 -  **General rules on caring for a child with HIV infection or AIDS**
- Chapter Four: Care of the dying**
 -  **(introduction...)**
 -  **The last part of the story: Yulia's legacy**
 -  **Teaching notes care dying**

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Part I: Teaching Guide

Chapter One: Teaching people with AIDS and their families

◆ Which of the pictures below shows a health care worker at work?



Figure



Figure

The answer is that both pictures do.

Your main job as a health care worker and the most important skill you must learn is to teach.

Whom should you teach?

As a health care worker you are part of the group of people who work together to provide care for a sick person. List all the care providers out loud.

◆ **Did you remember to count the family members?...the person with AIDS?...and the members of the community?**

Look at the next two pictures below. The picture on the left shows a family together with a health care worker caring for a sick person in a hospital, clinic or possibly in their home. The picture on the right shows the same family, again giving care, but without the health care worker.



Figure



Figure

◆ **Remember, no family will have a health care worker with them all of the time. So, who is it who needs to know how to provide care when the health care worker is not there?**

It is the people in the second picture, the sick person and the family, who will be responsible for most of the care. They need, and will benefit from, your teaching.

Why is teaching important?

The following three stories are about health care workers. Read them and then think about the questions that follow each one.

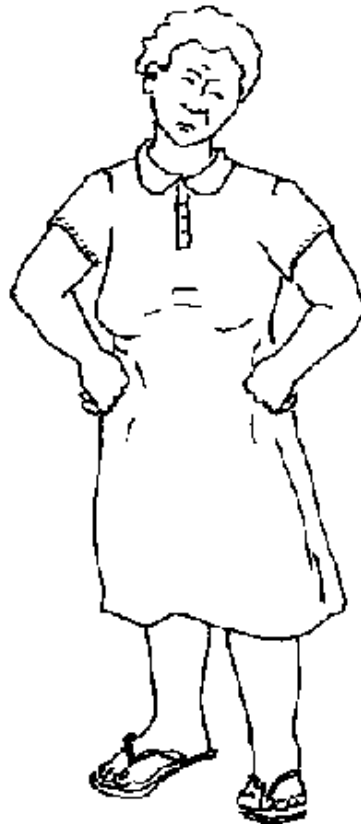
Stories about teaching

Story I

Mrs K, a health care worker, makes a visit to a sick person with AIDS and their family. She carries out all her tasks just the way she has been trained. She is very efficient. She tells the family she will come again next week and leaves.

Mrs K comes back the next week, as she promised, but the sick person is worse and the family is upset and feeling helpless.

Mrs K continues to work efficiently but after a while, she starts to dislike visiting this family because it seems they are always complaining.



Figure

◆ What has happened?

Mrs K is kind to the family but she doesn't try to teach them any of the things she knows. While the family will certainly benefit from her visits, her care will probably not help them become stronger in dealing with their problems. All of her useful knowledge goes away with her.

◆ What are the reasons for this?

Maybe...

- **Mrs K does not see the family as important members of the home care team**
- **she doesn't know or believe it's important to teach**
- **she doesn't believe families are able to take care of people with AIDS**
- **she doesn't feel confident about her own knowledge and skills**
- **she doesn't know how to teach.**

Do you have any other ideas?

Story 2

Mr Z, a health care worker, knows teaching is part of his job. When the family comes to the clinic he tells them many facts while he carries out his duties. He tells them what common problems to look for and the things they should do to take care of themselves.

When the sick person and family come back, Mr Z finds they are not doing things the way he told them. They can't even correctly remember much of the information he gave during their last visit Mr Z wonders why they don't listen better. He begins to feel this family is not very smart or that maybe they just don't really care



Figure

◆ **What has happened?**

Mr Z recognizes that families have a role in providing care. He thinks teaching is important, but he teaches the same way he was taught in school: he talks and they are supposed to listen. He gives them the advice and information he feels are important.

◆ **Why didn't this work?**

Maybe...

- **Mr Z didn't tell them the information in a way they could understand**
- **he didn't check to see if they understood what he had told them, or if they were able to carry out the directions he gave them**

- **he didn't give them information that they believed was useful or important, that is, information they felt they needed to help them solve their problems**
- **they already believed something completely different and had trouble believing what he said**
- **they didn't really have a chance to learn how to do what he taught; telling someone how to do something does not ensure that they will have the skills, or will remember the steps, needed to do it**
- **they didn't have the resources to do what he told them. Do you have any other ideas?**

Story 3

Mrs N, a health care worker, has taken care of Mr A in the hospital. Mr A is now getting ready to go home. His family has come to fetch him. Mr A and his family are a little afraid because at home there will be no medical care. Mrs N understands their situation. She talks with Mr A and his family about their problems. She asks them which are the most troublesome to them now. She listens to them carefully, discusses possible solutions, teaches them the necessary skills and watches while they practise these skills. She tells them what problems to watch for and how to tell if they need to seek more help. Then she does some additional tasks, explaining her activities as she does them. She helps them to think of other people in their community who might be able to give them assistance.

After one month, Mr A and his family come back to the hospital for a check-up. They ask to see Mrs N. The family tell her they are feeling more comfortable and a little more capable of dealing with problems. Mrs A says she has even been able to help a neighbour with a similar problem. They tell Mrs N what else they feel they need to learn.

◆ What has happened?

Mrs N sees Mr A and his family as part of the health care team: a very important part as they are

"on duty" 24 hours a day. She knows that once they learn, they can provide the necessary care and also provide similar help to others in their community. Mrs N also knows that a sick person and their family can become stronger if they know what is happening and what they can do about problems that arise.

She also knows that teaching hasn't been successful unless the family has learned.

◆ What did Mrs N do?

- **Mrs N spent some of the time before Mr A left hospital giving and explaining the new information to the family - sometimes talking about things they may not have known are important - and some of the time listening, and helping them with their own concerns.**
- **She taught them skills step by step and helped them practise while she watched.**
- **She asked them questions and listened carefully to their answers because she wanted to know what, and how much, they understood.**
- **She also asked questions and listened to make sure she correctly understood their concerns.**
- **She behaved in a way that showed the family that she cared about them.**

Do you have any other ideas?

What is teaching?

Teaching is:

- **Asking questions...**
- and listening**

- **Giving information...**

and discussing information

- **Checking to see whether information is understood and accepted...**

and asking questions

- **Listening...**

and answering questions

- **Showing people how to do a task correctly...**

and helping them practise doing the task correctly

- **Solving problems...**

and helping people discover their own solutions to problems



Figure

- **Listening...**

and asking questions

- **Listening...**

◆ **Why do you think "asking questions" and "listening" are repeated?**

Because these are the most important skills you can use to communicate effectively with others and to teach them.

What are the benefits of teaching?

- **People will learn the correct facts that they need to know.**
- **They will be less afraid.**
- **People will learn to do things which will help them to stay healthy.**
- **They will know how to identify and manage common AIDS-related health problems in their homes.**
- **People will learn to recognize danger signs, and learn when and how to seek more help.**
- **They will feel more confident and comfortable because they are more able to help themselves and their family members.**
- **As a result of all of the above, sick people will receive better care.**

What should you teach?

First, remember:

The sick person and the family have the main responsibility for giving care at home. They must be able to protect and promote their own and each other's health.

Ask yourself: "What do they need to know in order to do this?"

Focus on teaching the skills and knowledge that will be useful and valuable to them.

They need to know all of the following things:

- **what HIV and AIDS are**
- **how HIV is transmitted (and how it is not transmitted)**
- **what they can do to prevent the transmission of HIV**
- **what problems or symptoms are commonly associated with AIDS**

- **how to recognize and take care of the common physical and emotional problems caused by AIDS**
- **that caregivers themselves have emotional needs**
- **when it is important to seek additional help and where to go for this**
- **how to organize their own resources and those available to them in the community**
- **how to lead as normal and satisfying a life as possible.**

◆ **How can you help the people you know and work with to be sure they have the answers to all these points?**

Just after a person has learned that they have HIV infection or AIDS, they and their family will probably want to know exactly what AIDS is and how to prevent HIV transmission in the home. They will need help in dealing with the emotional shock of the diagnosis. They will also need to know that there is much they can all do to protect their own health.

As the disease progresses and people have had time to understand and accept the situation, they will probably become more interested in the specific physical and emotional symptoms that they experience.

Later, as the sick person moves into the chronic and finally the terminal stages of AIDS, they may become more interested in practical concerns such as making preparations for the care of children, or the settling of finances, as well as in the spiritual and emotional preparation for dying.

There is nothing in this handbook that, if carefully explained, should be of danger or too difficult for anyone to understand.

How should you teach?

◆ **Plan your teaching.**

☑ **Decide what you will teach. What you teach should depend upon what the sick person**

and family want and need to know at different times. Build on what they know already.

- **You may find that making and using a checklist of priority topics for teaching is helpful.**

✓ Make sure your information is correct. Preparing your information ahead of time will help you to make sure of this.

- **Use this handbook to prepare and check your information.**

✓ Be organized. Plan what you will say. Make sure you can remember all the steps of a procedure or treatment.

- **Refer to your handbook, or make a list of important points or steps.**

✓ Be ready to teach. If you have or need special materials for demonstration or practice, or pictures to help explain points, make sure they are ready.

✓ Be flexible. Before you start, find out if there is a more urgent problem. Take care of that first.

✓ Be patient. Fear in families can make it difficult for them to accept your help.

✓ Be tolerant. Show an accepting, caring attitude. This will help families and communities to become more accepting too.

✓ Be prepared. React quickly to your audience, and adapt your teaching if necessary as you go along.

◆ Help those you teach to feel comfortable.

✓ Talk politely to them. Use words they can understand.

☑ Encourage them to ask questions and talk, and remember:

- **listen to them carefully**
 - **show respect for what they say**
 - **show an accepting, caring attitude - this will help families and communities become more accepting too.**
- ◆ **Keep your teaching simple; too much information all at once is confusing.**
- ◆ **Make sure you find out what the family and the sick person know or believe.**

Ask questions:

- **to find out what they already know, believe, or plan to do about their problems**
- **to find out whether you understand correctly what their concerns are**
- **to make sure they understand correctly what you have told them**
- **to make sure they are satisfied with the answers they have received**
- **to find out what else they might need to know**
- **to learn from them.**

When you are asked something that you don't know, say... "I don't know but I will find out for you."

◆ **What is wrong with this answer?**

Nothing. If you aren't sure of something, the best thing to do is to say so. Tell the family you will find out the answer to their question. Make sure you do find out and tell them as soon as you can. In this way you have shown respect for their question and they will not lose confidence in or respect for you.

More stories about teaching

Here are some more stones about teaching:

Story 4

Mrs S was very worried her grandchildren would catch AIDS from their mother, who had recently become sick. It was all she could think about on Wednesday when she was talking with Mr T, the clinic health care worker. He sat down with her and began teaching her about the nutritional needs of people with AIDS. He gave her lots of good advice and information. Mrs S hardly heard a word he said, her mind was so full of her worries about her grandchildren.

Mr T gave her correct and useful information and spoke politely and clearly, but afterwards Mrs S couldn't remember what he had told her.

◆ Why didn't Mrs S learn?

Maybe...

Mr T gave the correct information, but at the wrong time. He didn't find out what things were worrying Mrs S most and address those things first. If he had, then Mrs S would have been reassured and could have concentrated on what he was telling her about nutrition.

Story 5

Mrs C was a new health care worker. She had come first in her training group and was proud of her training. She knew many medical words now, and how to use them correctly. But many of the families she dealt with were uneducated. She tried to teach them, but they didn't seem to learn. They didn't even ask questions.

◆ What do you think was happening?

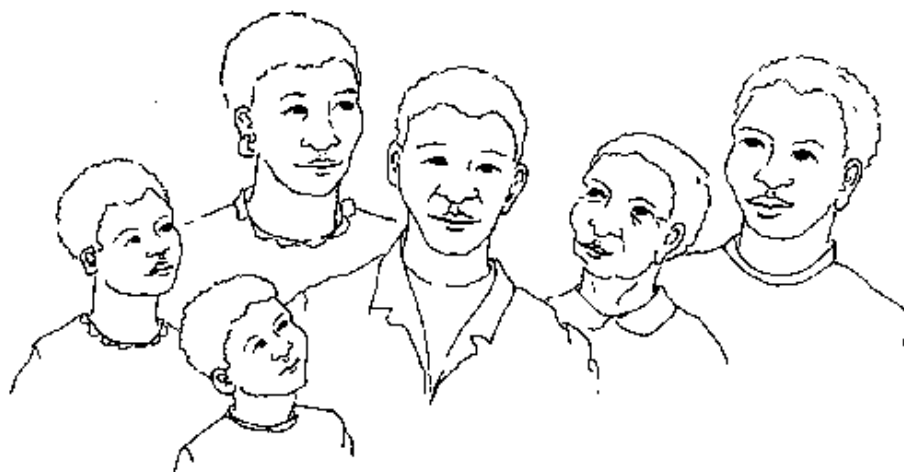
Maybe...

Mrs C forgot that talking at someone isn't the same as teaching them. Teaching means making sure the learner has understood and is able to use what has been taught. People need to feel comfortable in order to learn. Mrs C needed to use words that a sick person and their family could understand.

You can teach!

Teaching can take place anywhere. You can teach in the hospital, the outpatient clinic or in someone's home. You might be able to think of other places where informal teaching can take place. You have valuable information. Sharing it may save someone's life.

In order to make this handbook more useful to you, space has been provided at the end of each health problem section in Chapter Five for your own notes. As you learn about ways or methods that help the people you work with in your community, write them in. Often the best solutions to problems are the ones people discover for themselves.



Figure

Chapter Two: From HIV to AIDS

Most people find that information about HIV transmission and AIDS is very difficult to teach to others. The technical details are hard to grasp even for doctors, so it is no wonder that people

in the community have problems understanding the important points and acting on this information in ways that are helpful.

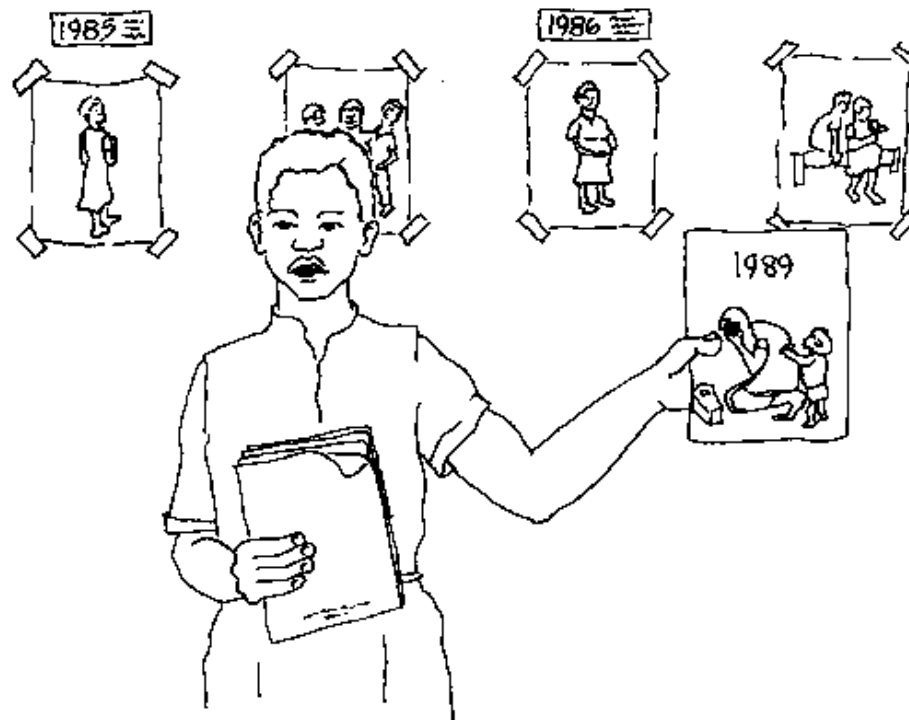
A story can be a very useful and effective way of explaining the key issues surrounding HIV and AIDS. This handbook tells a story about a family affected by HIV and AIDS that you can use to teach. It is a story similar to one told by a wonderful storyteller working with The AIDS Support Organisation (TASO) in Uganda. The first part of the story is told below. This is followed by teaching notes that look at the story in detail, explaining what has happened and providing more information about HIV and AIDS.

The story continues in Chapter Three and is completed in Chapter Four.

Here are some suggestions for using the story:

- **Tell the story (or your own variation of it) and then go through it again slowly, asking questions and providing information. You can tell the story in three parts, as suggested here, examining each part in detail before you go on, or you might prefer to tell the whole story right through first. You can keep coming back to the story in your teaching sessions, reminding your audience of what happened to the family - this will help you to explain the different issues involved.**
- **Full-page versions of some of the pictures used here are provided at the back of this book. You might find these larger pictures useful when telling the story.**
- **Be sure that you change the story to make it familiar to the people you are talking to. For example, change the names to ones that are common in your area. If you are telling the story in a rural setting you could say that the people are from the village where you are and then describe a journey to a city that is familiar to everyone in the village. You want the people hearing the story to think "Yes, I know these people".**
- **Review background information before telling the story so that you are clear on the facts and prepared to answer questions as they arise.**

- **Make the level of information and the words you use suitable for the people hearing the story and for what they already know. The questions given along the way in the story are a guide. However, encourage your listeners to ask their own questions too.**
- **Give your audience time to answer questions and tell you what is happening before explaining things clearly yourself.**
- **Tell this story with the pictures and make sure that the time at which the events occur is clear. To do this, you might first want to put the dates up on the wall, and as you tell the story and show the pictures you can then place the pictures on the wall under the date on which the events described happen. Please note that you should change the dates in the story to suit the date of the storytelling.**



Figure

A story: Yulia and Mukasa



Figure

This story is used to show how HIV comes into a family, and what happens over several years. The characters are shown in pictures to make it more interesting.

The original TASO story, from which this has been adapted, used symbols to help explain the processes of HIV infection, HIV transmission and development of AIDS-related conditions - using circles for HIV infection, squares for HIV antibodies and triangles for AIDS-related symptoms. If you feel this makes the story easier to explain to others, you can add these symbols to the pictures intended for use during teaching, which are presented at the back of the book. Other possibilities are to colour the clothing in some way or try to draw what is happening inside the body but cannot be seen on the outside.

Now let us start our story.

Early 1985

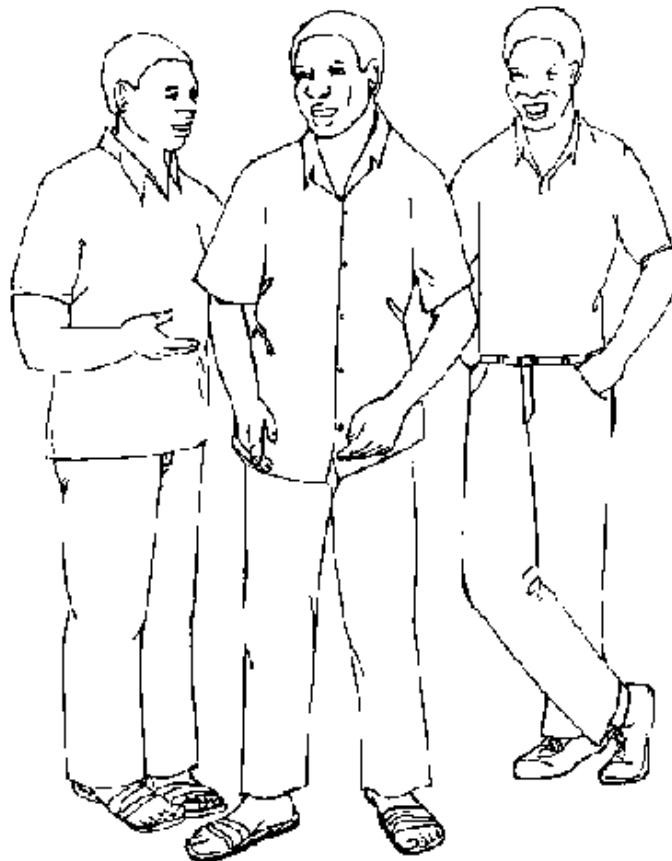


Figure

This is a girl, you know her, she lives just near, So beautiful as you see her. Her name is Yulia, and she is finishing school soon. Her parents are proud of her and know she will have a good life.

Soon she is to marry a man she cares for. This makes her very happy. And her family is pleased with her choice.

This good man is Mukasa.



Figure

He is doing well in his business - the shop down the road. You know him. He makes his friends laugh and is generous. Last year (1984) he went to the city for his business. It was a lonely time in the city, he stayed in a hotel and knew no one there. One night he drank some beers and he found a woman to ease his loneliness. He does not remember her name.

Now he is back here and will marry Yulia.

◆ Mukasa does not know it, but during his stay in the city he was infected with HIV.

Mid-1985

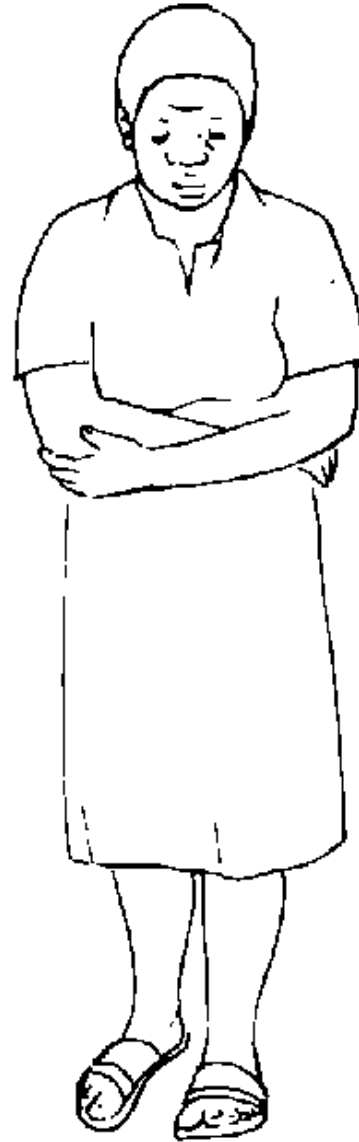
Yulia and Mukasa are married - there is a big celebration, everyone comes. Soon Yulia and Mukasa are living in their home and both help to run the business.



Figure

Late 1985

One day Yulia doesn't feel well-it isn't important, it feels like the flu and Mukasa makes her rest.



Figure

Late 1985 - shortly afterwards

Yulia has recovered from her illness and is back to work. She feels very well.



Figure

◆ **Although neither of them are aware of it, Mukasa has now passed HIV to Yulia.**

Early 1986



Figure

Yulia knows she will have a child. She and Mukasa are both very happy.

Late 1986



Figure

After some time the family is blessed with a child. A boy, named Yokaana, is born.

◆ Yokaana is not infected with HIV.

1988



Figure

Things have gone well for this family, they feel very lucky and the business is going fine. They have now been blessed with another baby.

◆ The new baby is infected with HIV.

1989

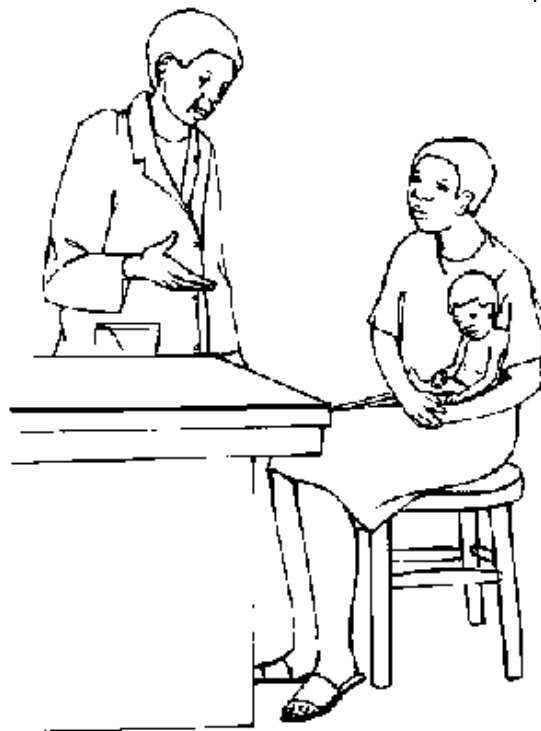
Yulia is worried about her new baby, he doesn't look well. He has fevers and diarrhoea, and doesn't seem to be able to gain weight



Figure

She buys many medicines for the baby but he doesn't seem to get better. Finally she becomes afraid - the child cannot eat without vomiting and he has diarrhoea again. She takes him to the doctor at the local clinic.

The doctor is very concerned.



Figure

He asks Yulia many questions about the baby, and he asks questions about her and her husband. He asks questions about their health and about their private life. She is embarrassed - no one has ever asked her questions about sexual things before. But this day is bad: the doctor tells Yulia he believes the baby could have AIDS. He says he cannot tell from a test until the baby is fifteen months old.

He tells her to have a blood test herself and talks with her about this. Yulia cannot believe what she hears and her mind refuses to accept what the doctor says. But, she agrees to the test so that the doctor will not be angry with her.

The doctor says her husband should also come to the clinic and be tested.

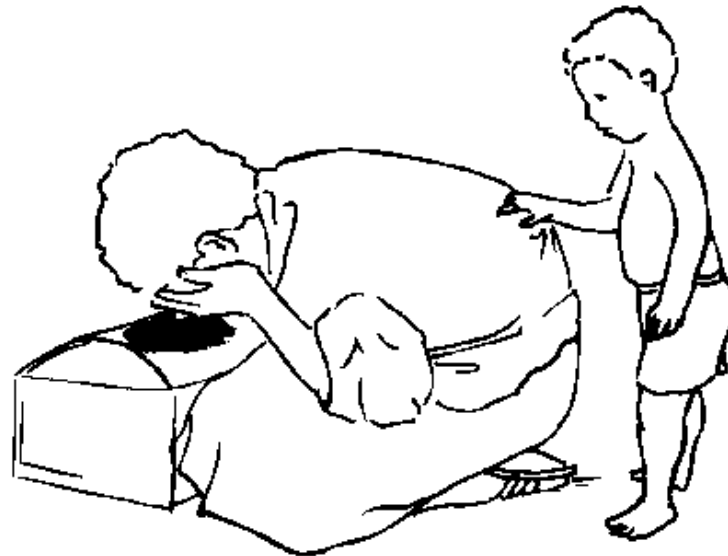
While she is having her blood taken in the clinic Yulia is worrying and does not know how she can talk to Mukasa about this or what to do.

The doctor gives Yulia medicine for the baby to help with the vomiting. He also tells her many things but she cannot remember much. She is told to return in two weeks for the result of the test

At home Yulia cannot tell her husband what the doctor said. She is sure that the doctor is wrong. She has known too many women and families destroyed by this disease and she tells Mukasa that the doctor gave her medicine for the baby to make him well. She does not go to find out the result of her test.

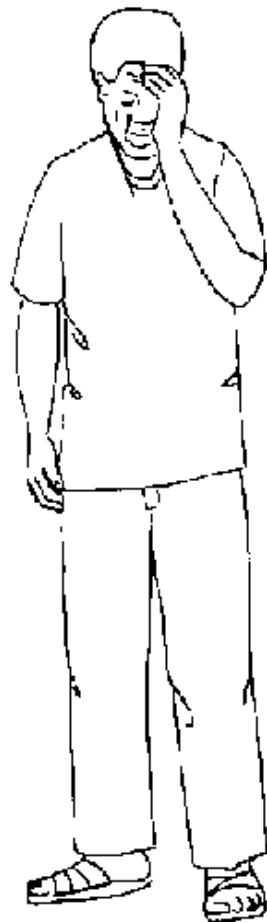
Late 1989

One night the baby dies, he got a fever and was suddenly gone. The family is very unhappy, but luckily Yokaana is healthy and tries to help his mother with her sorrow.



Figure

1990



Figure

Poor Mukasa. It seems like he is always coughing now and he says he feels tired all the time.

He goes to the doctor and is given medicines for tuberculosis and instructed in how to take them. Mukasa follows the instructions and after some time he feels better and even returns to work.

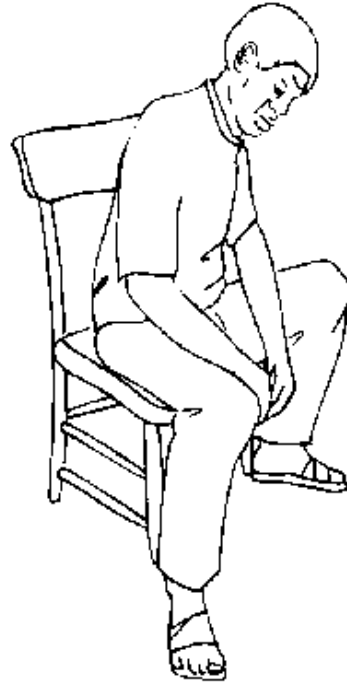
Here he is after treatment for his tuberculosis was started.



Figure

1991

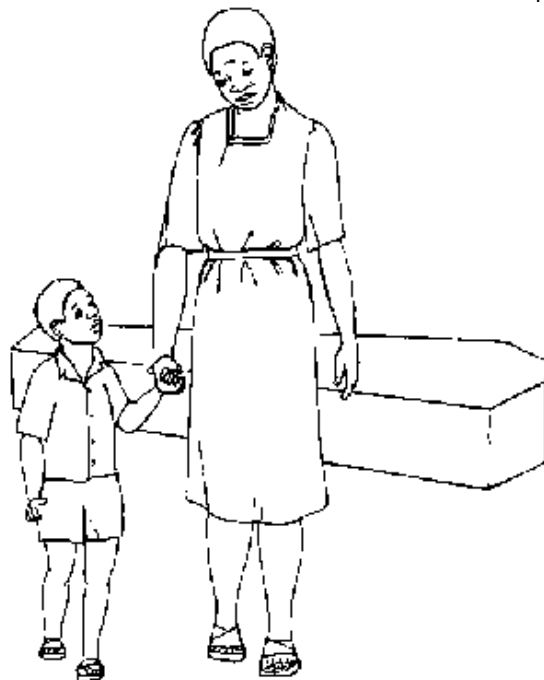
Yulia is having to do more and more at the shop. Mukasa is often ill and too tired to help with the work. He loses weight and keeps having diarrhoea. Yulia has so much to do looking after the shop and the home as well. Mukasa gets medicines from the doctors and they help for a time but it seems he soon falls ill again.



Figure

Later in 1991

Mukasa died this night and was buried just near here.



Figure

The six months before Mukasa died were so very hard for Yulia. Mukasa was very ill and often harsh and irritable. It was a lot of work caring for him and Yokaana. She is very scared and sad. She feels well but in her heart she now knows that her family has been found by this terrible disease that has taken so many of their friends and neighbours. She is afraid for herself but even more for her child - what will happen to him and how will they support themselves?

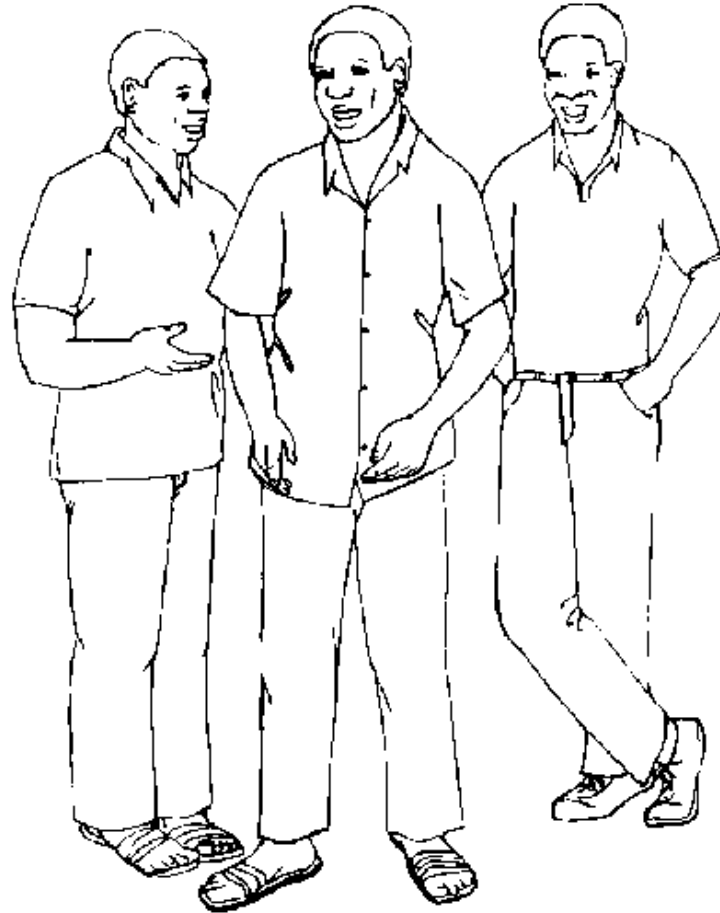
◆ **Let us leave our story here for now and think about what has happened.**

Teaching notes on HIV and AIDS

Take your audience back through the story, follow the course of the infection in this family and talk about what their story shows. An example of doing this is presented below in a way that you can use directly or adapt when teaching.

◆ **What has happened to the family?**

The story started when Mukasa had unprotected sex with someone who looked healthy but was infected with the human immunodeficiency virus (HIV). The virus was passed to him during sex. Look again at the picture of Mukasa after he came back from his trip to the city. By looking at him, you cannot tell that Mukasa is infected with HIV.



Figure

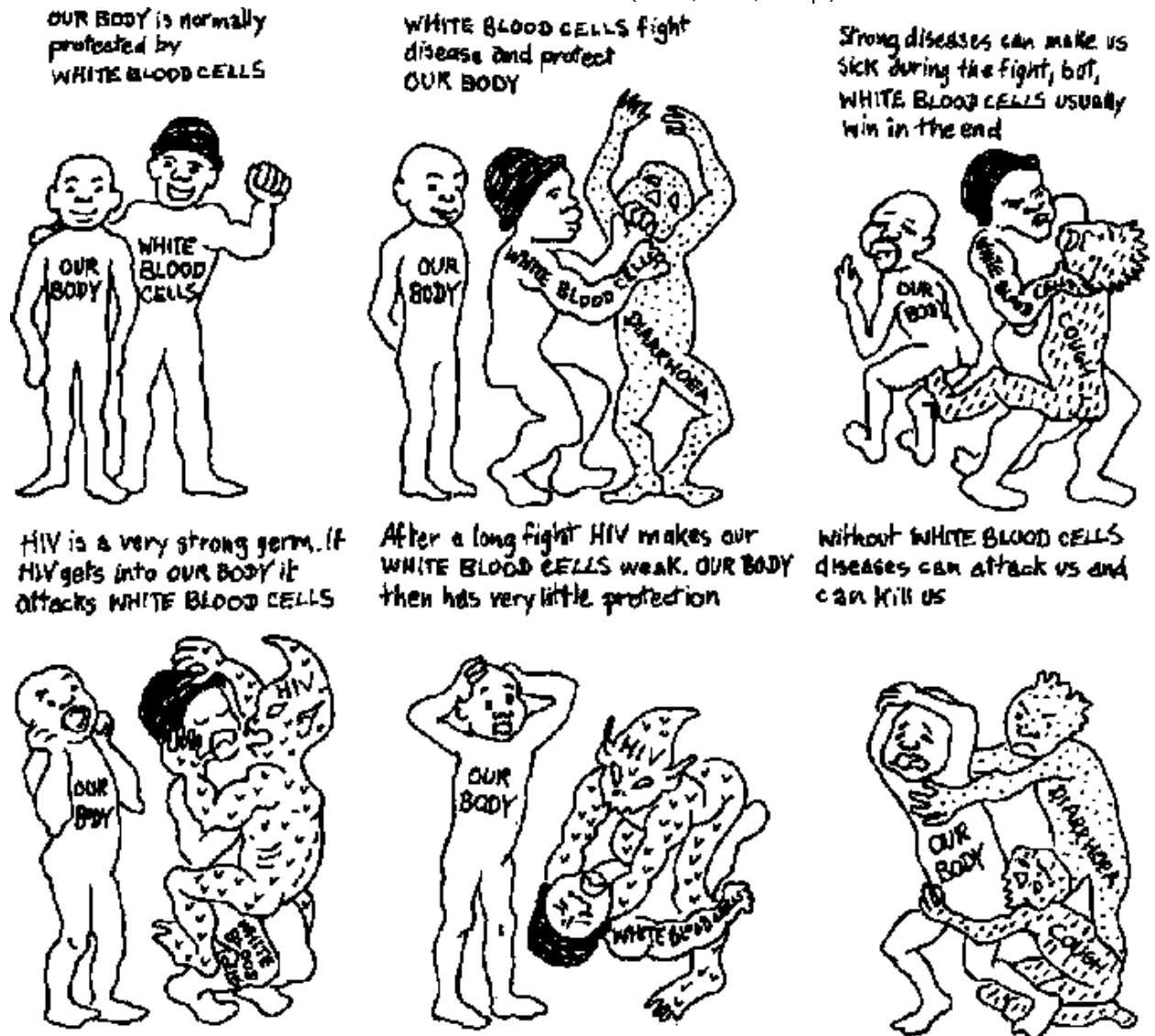
What are HIV and AIDS?

The disease AIDS - the acquired immunodeficiency syndrome - is caused by a virus, the human immunodeficiency virus (HIV). Viruses are very small living organisms that cause many

different diseases in humans, animals and even plants. Poliomyelitis (polio) is another example of a disease caused by a virus. Viruses are so small that even if thousands of them are put together they cannot be seen with the naked eye. In fact, viruses are among the smallest and simplest living things. They cannot reproduce on their own but depend on the animal or human they infect to act as a host. HIV reproduces in certain cells in human blood, called white blood cells (WBCs). These WBCs are a very important part of what is called the immune system. The immune system, with its WBCs, defends the body from infections - it recognizes things that are foreign or dangerous to the body and begins to attack them. It also starts to make specific substances called antibodies which are very active against the particular disease-causing organism that has infected the body.

When a person becomes infected with HIV, the virus begins to live and reproduce in the WBCs, multiplying until there are millions of viruses present. The WBCs begin to make antibodies to HIV which are found in the blood about six weeks after infection. Unfortunately, these antibodies cannot eliminate the virus completely from the body. The virus gradually damages the WBCs so that they can no longer do their job of protecting the body from infections, which healthy people can normally fight off without any problem. It is when these infections occur that a person is said to have AIDS. The bacteria, viruses and parasites present in the environment that cause these infections take the opportunity given by the weakened immune system to grow unhindered. This is why many of the illnesses that people with AIDS get are called opportunistic infections.

This process is described in a cartoon from Uganda shown below.



Figure

This may take many years. Remember how much time there was between Mukasa being infected to the time he began to develop the symptoms of AIDS. And also remember that Yulia still had no symptoms when Mukasa died.

For most of the time, people infected with HIV are healthy and usually unaware that there is

anything wrong with them. It is not unusual for the period of time between infection with HIV and becoming ill with AIDS to be eight or nine years, and sometimes as long as 15 years. The length of time between infection and the appearance of AIDS can vary widely in different people.

Mukasa did not know he was infected. He felt well and was happy to marry Yulia. Certainly, no one around him thought he was infected. "Not Mukasa", they would have said. So Mukasa became infected during his visit to the city and, without knowing it, was able to pass the virus to others.

HIV, the virus that causes AIDS, is passed (transmitted) between people by the ways shown in the box below.

HIV infection is most often passed by sexual intercourse. It can be passed from either a man or a woman. A person who is not infected with HIV can take steps to avoid infection just as a person who is infected with HIV can take steps to prevent passing the HIV infection to someone else.

◆ Mukasa passed the virus to Yulia during sex. What could he have done to prevent becoming infected himself or, if he had known he was infected, to protect Yulia from getting this infection?

Box 1: Ways in which HIV is transmitted

- through unprotected sexual intercourse with an infected person; that is, intercourse without a condom
- from an infected mother to her unborn or newly-born child
- through contact with infected blood, for example by:
 - the transfusion of infected blood

- the sharing of skin-piercing instruments, such as injection needles, that are not sterile

How can you avoid AIDS?

Abstinence (not having sexual relations at all) is the most sure way of preventing sexual transmission of HIV infection.

For many people, however, this may not be acceptable or realistic. The use of condoms and other safer sexual practices are the only ways of decreasing the risk of becoming infected with HIV or transmitting HIV infection to a sexual partner. Safer sexual practices are described in the box below.

The use of condoms could have protected this family. Certainly, if Mukasa had used a condom in his relations with the woman before his marriage (or avoided premarital sexual relations altogether) this story might have been very different. Mukasa could not have known whether the woman he had relations with in the city was infected, and for that reason he should have used a condom.

Condoms are best known as a means of preventing pregnancy. However, they are also the most effective means of protection against the organisms that cause sexually transmitted diseases, including HIV.

Box 2: What is "safer sex"?

Safer sex is any sexual practice that reduces the risk of passing (transmitting) HIV from one person to another.

The best protection is obtained by choosing sexual activities that do not allow semen, fluid from the vagina, or blood to enter the mouth, anus or vagina of the partner, or to touch the skin of the partner where there is an open cut or sore.

Safer **sex** practices include:

- staying in a mutually faithful relationship where both partners are uninfected
- masturbation, massage, rubbing, dry kissing, and hugging
- using a condom for all types of sexual intercourse (anal, vaginal and oral)
- avoiding certain practices that increase the possibility of HIV transmission, for example "dry" sex which may lead to breaks in the skin
- avoiding sex when either partner has open sores or any sexually transmitted disease (STD)
- oral sex - this may be an acceptable alternative for some people, but oral **sex** should be avoided if there are sores present in the mouth or on the genitals

Couples should talk about **sex** and learn to please each other. This can allow for the negotiation of safer **sex** and make the intercourse more pleasurable for both and less likely to cause discomfort or minor damage to the genitals.

How do you use condoms to prevent pregnancy and HIV transmission?

Condoms are effective if they are used properly every time you have sexual intercourse. Instructions on how to use condoms are given in the box below.

Drawings or teaching models can be very helpful in teaching people how to use condoms correctly. The types of instructions, drawings and models available for this purpose vary from country to country. You can use the written instructions provided in Box 3 to accompany any pictures or models you are using.

Unfortunately, because neither Mukasa nor Yulia knew what was going on, Yulia became infected during their sexual activities.



Figure

Now Yulia can pass HIV to others by the ways shown in Box 1. However, a test for HIV in the first 12 weeks after HIV entered the body could be negative because the test looks for antibodies to the virus, not the virus itself (see Box 4).

The mild illness that Yulia experienced at that time could have been caused by her initial

infection with HIV. Most people experience a mild flu-like illness a few weeks after they become infected.



Figure

Shortly after her initial infection with HIV Yulia's body responded to the virus by making antibodies against it.

Now her test for HIV would be positive because she has antibodies to the virus in her blood.

In this picture from the story Yulia is pregnant.



Figure

Like most couples, Yulia and Mukasa were very excited about the idea of having children. They did not realize they were infected or that there was any risk of passing this disease on to their children. Unfortunately, just as in the story of Yulia and Mukasa, people often learn they are infected with HIV only when one of their children becomes ill with AIDS.

Couples who know that one or both partners are infected with HIV will need information about pregnancy. You can be helpful in discussing the issues surrounding pregnancy and HIV infection, and can help them come to a decision that is right for them.

Look again at the picture of the family after the birth of Yokaana.



Figure

See how happy they are? As a baby Yokaana had antibodies against HIV which were passed to him from his mother's blood during the pregnancy. However, no HIV was passed to Yokaana during the pregnancy. His blood test would be positive at this time but it would not mean he had HIV infection. This is why doctors cannot easily diagnose HIV infection in children until they are 15 months of age, when all of the antibodies from the mother are gone from the baby's bloodstream

Look again at this picture of the happy family, now with a new baby.



Figure

What you and the family cannot see, is that this baby was infected during the pregnancy. Just as with Yokaana, the blood test of this baby would be positive because of antibodies he received from his mother, except that this time the baby really is HIV-infected.

You might wonder why this new baby became infected but not Yokaana.

Approximately one-third of babies born to women with HIV infection are infected with HIV themselves. Whether an infected woman passes HIV to a baby appears to be influenced by many factors, which scientists and doctors do not yet understand.

AIDS in children is very much like AIDS in adults. However, in children the disease is more

difficult to diagnose correctly, and the blood test cannot be done with certainty until the child is at least 15 months old. Small babies and children with AIDS often have fever, diarrhoea and coughing, and do not gain weight properly, but these are common symptoms that may also have other causes. This long period of uncertainty is very difficult for families. We shall talk more of this later.

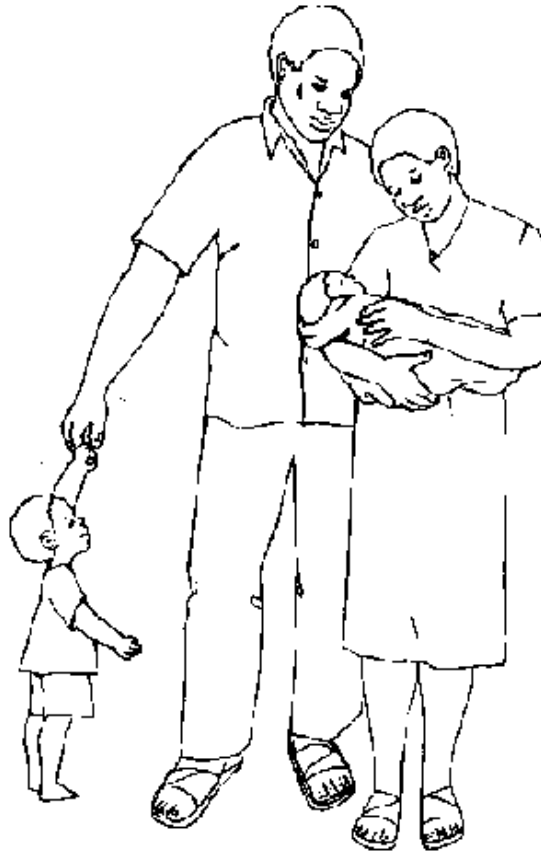
Later, the baby became ill with fevers and diarrhoea.



Figure

Babies develop the symptoms of AIDS after infection with HIV more quickly than adults do. This is because their immune systems are less developed and they cannot resist HIV or fight opportunistic infections as effectively.

Look at this picture of the whole family together. This picture is very important. It shows not only the infected child but also Yokaana, the first child. Yokaana remains uninfected even though he has been living with three other members of his family who are infected with HIV.



Figure

Think of all the things this child did with his family (all of whom were infected), yet he remains free of the virus.

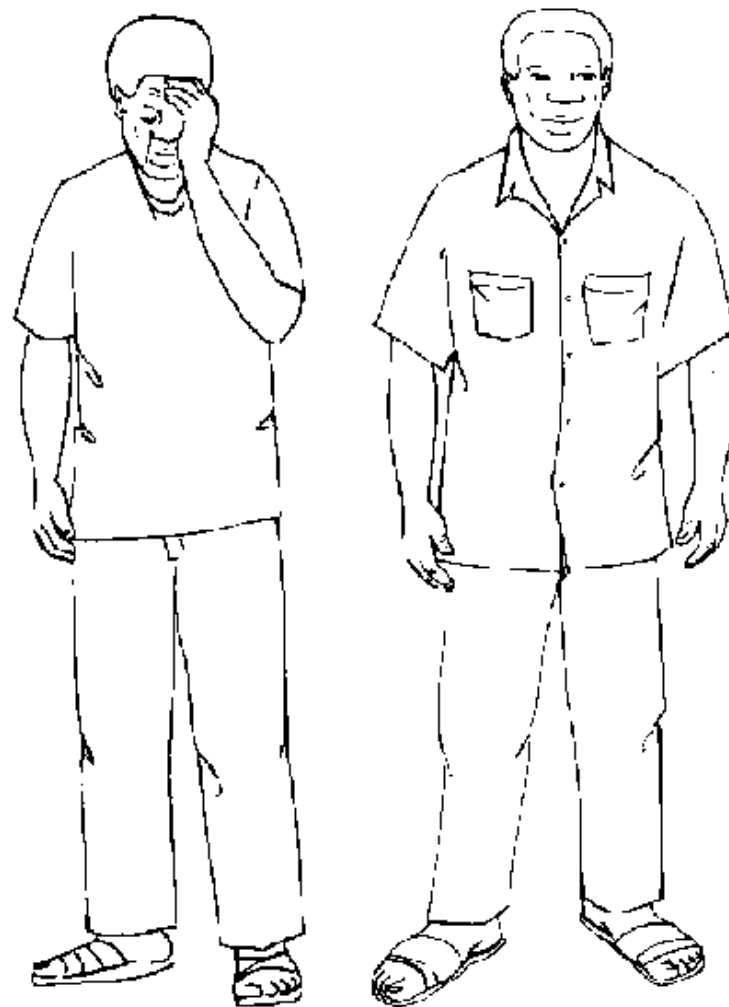
Clearly you can be very close to someone with AIDS and not catch the virus.

Yokaana's contacts with his own family, the community, and his environment included many of the things listed in Box 5, yet he did not get the virus. Yokaana helps us to see that it is not only

important for people to understand how it is spread. It is just as important to understand how it is not spread.

Otherwise, as people begin to see AIDS as a serious problem, they may panic and reject infected people. They may isolate them and their families. These reactions are deeply upsetting for people who are already facing the trauma of AIDS, and they are unhelpful in stopping the transmission of HIV. If people are not encouraged to share the problems they have, then they cannot receive help from their families and enjoy the time they have together.

Another point that came up in the story is told by the two pictures below. Mukasa was treated for his AIDS symptoms at the clinic and became well enough to work again. He had tuberculosis, one of the problems that is common with AIDS. Treatment of this and other HIV-related conditions can make a big difference to how long people with AIDS live and how well they feel. This will be discussed in greater detail later in the handbook.



Figure

Box 3: How to use a condom

- Be sure you have a condom before you need it
- Each time you have **sex** put a new and unused condom on the penis before it enters the vagina or rectum.

- Put the condom on only when the penis is erect
- If you are not circumcised, pull the foreskin of the penis back before putting on the condom.
- Do not pull the condom tightly against the tip of the penis but pinch the end when unrolling it - this leaves a small empty space, to hold the semen.
- Unroll the condom all the way to the base of the penis.
- If the condom tears during **sex**, withdraw the penis immediately and put on a new condom.
- After ejaculation, hold on to the bottom of the condom as you pull the penis out so that the condom does not slip off, then take off the condom carefully without spilling semen.
- Wrap the condom in paper (such as newspaper) until you can dispose of it in a toilet a pit latrine or a closed garbage bag, or by burying or burning it

The following tips will help to prevent condoms breaking or leaking:

- If lubricant is needed use a water-based one (like KY Jelly, or glycerine). Do not use a lubricant made with oil, like Vaseline, which can cause condoms to break more easily.
- Store condoms in a cool, dark, dry place, if possible. Heat light and humidity can damage condoms.
- If you have a choice, choose pre-lubricated condoms that come in square wrappers and are packaged so that light does not reach them.
- Open the wrapper carefully so that the condom does not tear.
- Do not use condoms that are sticky, brittle, discoloured or damaged in any way.

Box 4: HIV Testing

What is an HIV test?

Shortly after infection with HIV, the body starts to respond by making antibodies against the virus. This usually takes 8-12 weeks. An HIV test can find out if these specific antibodies are present in the blood - it does not detect the virus itself.

What do the results mean?

- *A positive test result in a person over 15 months old means that:*
 - The person has antibodies against HIV, and is thus HIV-infected and can transmit the virus to others (see Box I).

- *A positive test result in a child under 15 months old can mean either that:*
 - the child is infected with HIV, or
 - the child is not infected with HIV, but has received antibodies against HIV from its mother, in the same way as many other antibodies are transferred during pregnancy.

Because of these two possibilities, it is impossible to tell if a baby is HIV-infected until it is at least 15 months old, when the antibodies from the mother are usually no longer present.

- *A negative test result can mean either that:*

- the person is not infected with HIV, or
- the person is infected with HIV, but has not yet made antibodies against the virus. (This is sometimes called the "window" period.)

- *The HIV test:*

- does not provide any information about a person's present state of health
- does not determine if a person has HIV-related disease
- cannot tell when or how a person became infected with HIV
- does not provide any information about whether a person with HIV infection has transmitted the virus to anyone else.

Because the results of an HIV test can have dramatic effects on families, relationships, employment and the individual's own psychological well-being, it is important that people be tested only with their consent, that they be counselled before and after testing, and that the results be kept confidential, that is, shared only with the individual, or others designated by the individual.

Box 5: Ways in which HIV is not transmitted

Ordinary social contact:

- physically close

- in the same home
- breathing the same air; coughs and sneezes
- at work
- on the bus
- at the market
- at school
- playing together

- touching

- shaking hands
- hugging
- kissing on the cheeks, hands or forehead

Sharing:

- toilet seats
- towels
- washing water, bath water
- swimming pools
- eating and drinking utensils
- communion cups
- work tools

Being bitten by:

- mosquitos
- bed bugs
- other insects
- any other animal

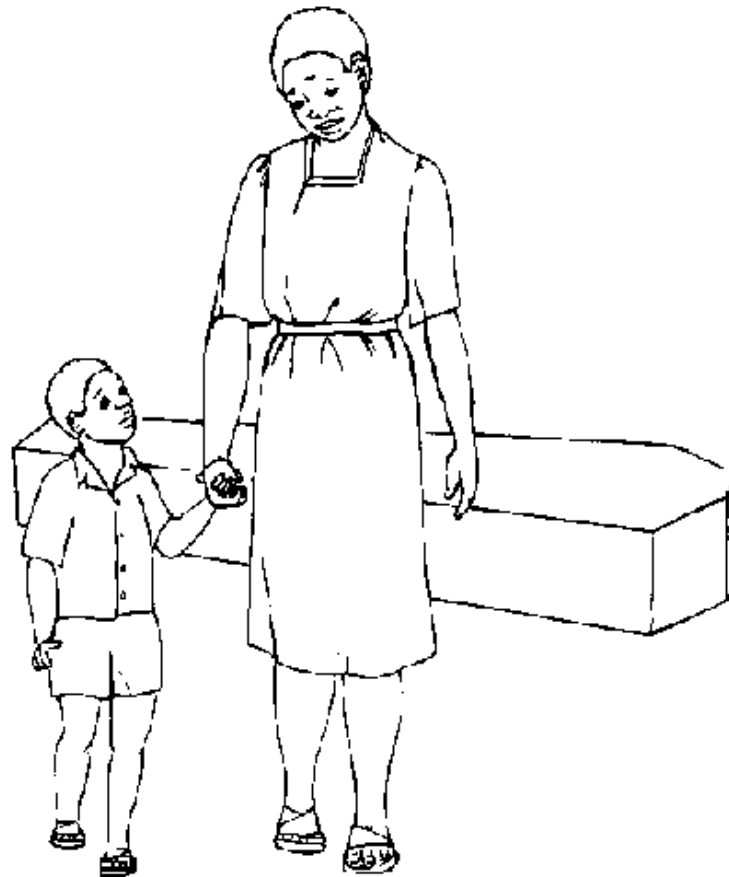
Chapter Three: Living positively with AIDS

This chapter tells the second part of the story about AIDS, which is again followed by teaching notes providing detailed information. The story continues below *from* where it left off in Chapter Two and again is presented in a way that you can use directly when teaching.

The next part of the story: Yulia and Yokaana

Now let us join Yulia and her family again, where we left off before, It is...

1991

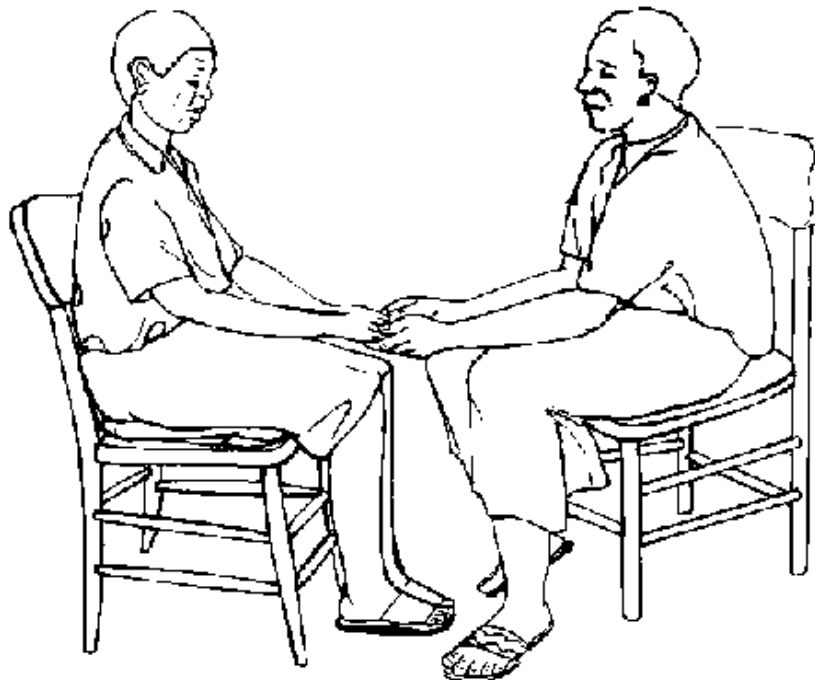


Figure

Her husband has just died and Yulia decides she must know what is happening to her family.

Shortly after Mukasa's death Yulia goes to a clinic and asks for a blood test for HIV. The people in the clinic talk with her a long time about her life and what the test means. Her blood is taken and she is told to return to the clinic in two weeks.

Yulia returns to the clinic and meets a woman who tells her that the test is positive, that she is infected with the virus.



Figure

They talk for a long time. The woman is very kind and tells Yulia she must fight this virus and live as long as she can for Yokaana's sake. The woman says there are many things she can do, and that there are many people who will help her.

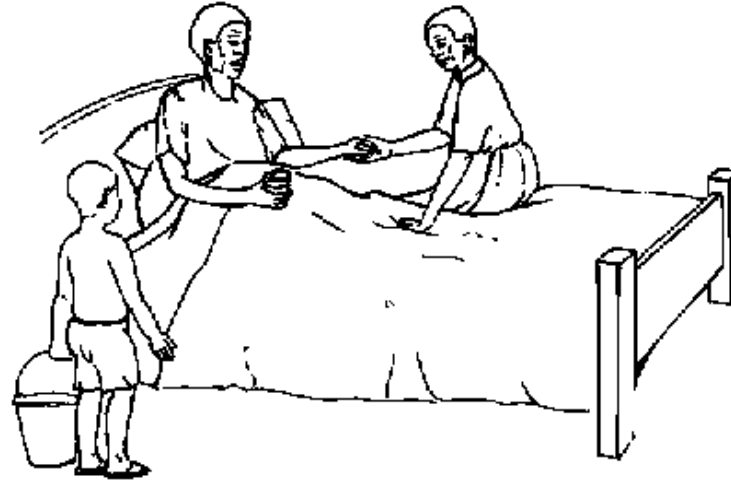
1992

Sometimes Yulia does not feel well and she goes to the clinic for treatment

She has been able to keep working in the shop. Recently she took a training course offered by an AIDS organization from the capital city and now she has been trained to provide help to people who are sick - especially those with AIDS. She learned about coping with the problems of AIDS and how to help people with AIDS and their families manage.

NOW

This is Yulia, she still lives near here. Yulia visits people in their homes. She takes her son with her and he helps with simple chores for these other families. She talks in the community about AIDS and about health. She gives both her knowledge and her hope. She says she can live with AIDS and that when she dies the virus in her will die too.



Figure

Teaching notes about living positively with AIDS

Again, take your audience back through the story and look in detail at how Yulia coped after the death of Mukasa. As in Chapter Two, the information is presented below in a way you can use directly when teaching.

◆ What has happened to the family?

1. The reaction Yulia had to learning that her child had AIDS was normal. When somebody experiences a shock or a loss they have emotions or feelings called "loss reactions". These are feelings which come any time new and serious problems like HIV and AIDS are confronted. It is normal to have strong feelings about them. Most people are frightened of HIV and AIDS.

2. People who find out that they have HIV infection or AIDS, or learn that someone important to them has HIV or AIDS, may experience many different feelings, such as anger, fear and sadness. Sometimes people may deny having the disease at all. Remember Yulia's first visit to the doctor when she refused to believe that AIDS was the cause of her child's problems? This is denial. Feelings like these can cause family communication to break down. Whether because of denial or fear of his reaction, Yulia did not tell Mukasa what the doctor told her, and she did not go back to find out the result of her first blood test.

3. Yulia's denial was, unfortunately, very common. It was only after the death of Mukasa that something in Yulia would no longer allow her to push this information away or deny it, and this is when she began to take positive action.

◆ What might cause Yulia's denial?

Yulia was probably afraid that her family and friends would no longer love and accept her.

Other concerns that come with AIDS are about what will happen to the children in a family. There will also be worries about jobs, like "Will I be allowed to work?" or "Will I be able to work and support my family?" and also about housing.

Think about ways to increase support and acceptance in your own community.

◆ How did Yulia feel when she understood that she had HIV infection and possibly AIDS?

Think about how you would feel if you were infected.

Shown on the next pages are some of the feelings people might experience when they find out they have HIV or AIDS.

Responses to AIDS

Each of these feelings or reactions is part of a normal response to a situation of great stress. A

person might move from one response to the next in a progression leading finally to acceptance of their situation, or more commonly their feelings will keep changing. One day they might feel rejected and lonely - the next day hopeful and energetic. One day depressed, another day angry. Let us look at each of these reactions separately and think about how these make someone feel, and how a person feeling like this might be helped.

SHOCK



Figure

No matter how much someone prepares, it is a shock to learn that one has HIV infection or AIDS. A person might feel confused and not know what to do. It is good for people to be with someone they trust at this time.

DENIAL



Figure

At first they might not be able to believe that they really have HIV or AIDS. They might think, just as Yulia did, "The doctor must be wrong" or "It can't be true - I feel so strong".

Not wanting to believe is a strong force that people may use subconsciously to protect themselves from the threat posed by AIDS. If you are trying to help such people, don't be angry or impatient with them if it seems that they are not facing facts. Try to remember that as a health care worker you can help them to understand what having HIV or AIDS means and that this is the best way to help overcome denial.

ANGER



Figure

People might become very angry when they learn that they have HIV or AIDS. This is a common feeling and can come when they blame themselves or the person they think gave them HIV. Some may even blame God.

Anger is normal but it may not be helpful since it can focus on blaming others (being angry with them) or themselves (feeling guilty), rather than taking positive actions. Talking to someone can help a person overcome feelings of anger and help them accept their situation.

If you are trying to help someone with HIV or AIDS, anger is a difficult reaction to cope with, especially when it is directed at you. It is important for you to try to understand and not take the anger personally. It is difficult, of course, to receive anger without responding.

BARGAINING



Figure

A person with AIDS might try to bargain, thinking, "God will cure me if I stop having sex" or "The ancestors will make me better if I slaughter a goat" or "I will be good and it (AIDS) will go away". People with HIV or AIDS need to be helped to get through the feeling of bargaining.

FEAR



Figure

People with HIV or AIDS fear many things, for example:

- **pain**
- **losing their job**
- **other people knowing that they are infected**
- **rejection**
- **leaving their children**
- **death.**

These fears become less when they talk to someone who understands. Someone with AIDS might also find that they are worried about things that they do not need to fear. For example, they may find that when other people learn they have HIV, they show great love and kindness rather than the feared rejection.

LONELINESS



Figure

A person with AIDS might often feel lonely. This feeling may come and go for a long time and depends on the support given by family and friends. Anyone who has AIDS must be helped to remember that they are not alone; that they are surrounded by family, friends and a community that cares about them. Many other people have HIV or AIDS.

Help families and communities to understand that people with HIV and AIDS need companionship. Infected people can often find others with HIV and AIDS and provide companionship and support for one another.

SELF-CONSCIOUSNESS



Figure

When a person has HIV or AIDS they might think everyone is looking at them or talking about them. This may make them want to hide. Sometimes a person with AIDS may feel unworthy of friendship.

You can help them not to hide or feel discouraged by encouraging them to stay active in the community. This can increase the acceptance of people with HIV/AIDS by showing the world that people with HIV and AIDS are valuable members of society, just like everyone else.

Help them to think well of themselves and to be proud. They are still important.

DEPRESSION



Figure

If a person finds out that they have HIV or AIDS they may feel there is no good reason for living. They may feel useless, and want to stay at home, not eat, and not talk to anyone.

Depression can make someone weak both in mind and body. It is important to try and help them overcome this depression and not give up. Encourage them to put on nice clothes, visit friends, keep busy with things that matter, do something that helps others, and to think about their children and friends who still need them.

ACCEPTANCE



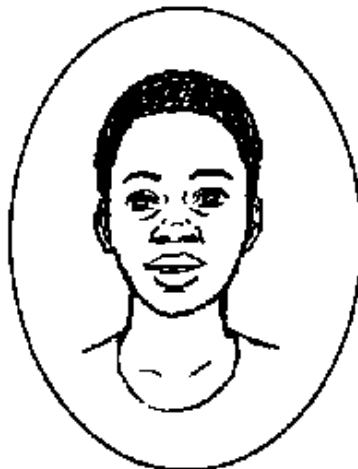
Figure

After some time, a person with HIV or AIDS will usually begin to accept their situation. This will help the person to feel better. Such a person will feel more peaceful in their mind, and will begin to think about the best ways to live.

They might think:

- **"What can I do to make the best of the rest of my life?"**
- **"What foods should I eat to help me stay healthy?"**
- **"What plans should I make so that my children are provided for in the future?"**
- **"Let me be grateful for every single day. Let me appreciate my family and friends and show them how much I care for them."**

HOPE



Figure

You can help someone with HIV or AIDS have hope about many things. For example:

- **hope that they will live a long time**
- **hope that their baby will be healthy**
- **hope that each sickness will be treated as it comes**
- **hope because they are loved and accepted for who they are**
- **hope that scientists will find a cure**
- **hope because of belief in a life after death.**

It is important to have hope. Hope lifts spirits and gives strength to face each situation. Hope can help each person to fight HIV and AIDS - to live positively and to live longer.

Remember, even if a person has hope today, it is possible to feel angry or depressed tomorrow. This is normal. Even people without HIV or AIDS go up and down emotionally every day. The important thing is to try to instill the feelings of hope again and again.

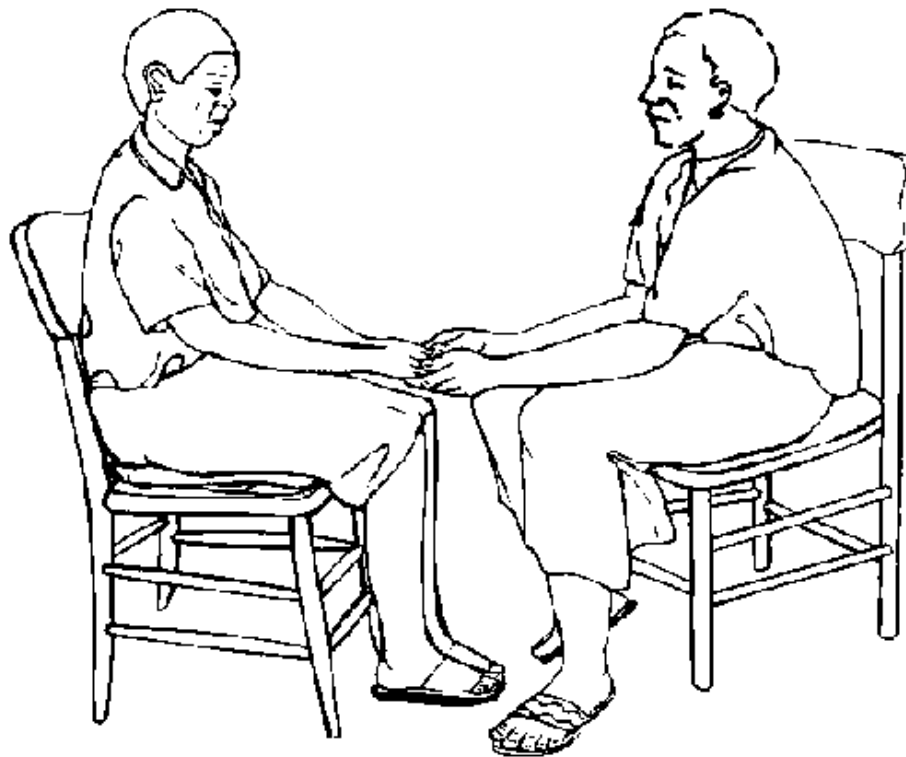
People who have AIDS, or people who are in contact with someone with AIDS, are often afraid that the negative feelings described above will become too strong. **These feelings cannot, and should not, be avoided. They are normal reactions to a crisis.** Family, friends, neighbours/health care workers-

anyone who cares - can help another person cope with these feelings by listening, and talking to the person about their feelings.

What is counselling?

Counsellors are people who are trained to help others to understand their problems, identify and develop solutions, and make their own decisions about what to do. Counselling involves being with them, listening to them talk about their problems and fears, helping them to increase their own self-esteem, and when necessary giving correct and useful information based on what they need to know at that point in time.

When Yulia went back to the clinic she was counselled.



Figure

Many of the skills needed for counselling are similar to those needed for teaching (see Chapter One), because they are skills of effective communication.

In the last section you saw the reactions people might have on learning they have HIV/AIDS. Go back and look at all the faces showing those reactions. No matter how much you care for people you cannot change their feelings. Only they can do that. But by offering your time and just listening, you are telling them that you care and that their feelings are normal and accepted. By allowing them to talk about their feelings, you give them the opportunity to understand and overcome their negative feelings. This helps them begin to make choices and act on decisions. A feeling of empowerment or hope, of having a choice and being able to act, is strong therapy for someone who is feeling helpless and unworthy.

Counselling is a skill that requires effective training to develop. There may be times, if you are working with people with AIDS and their families, when you believe more skilled counselling is needed to deal with serious psychological issues. At these times you may want to refer the sick person for help elsewhere, from people who are experienced in providing such support, perhaps in government or voluntary services or in religious or spiritual organizations.

However, there are skills used by counsellors which all of us can use to help each other during the times we are talking together. Many health care workers and people like Yulia are being trained to improve their communication skills, particularly in relation to AIDS. Those who are in contact with someone with AIDS, or with anyone who is experiencing emotional pain, can do a lot to help them and make them feel better by using simple counselling techniques.

◆ Think of a time when you felt badly about something and how, after talking with someone else - a friend, a family member, a health care worker, a pastor - you felt better. What did that other person do that "helped" you?

Often the answer is:

"Nothing, he just listened and sat with me while I told him everything".

Or maybe:

"She was just kind and didn't judge anything I said. She helped me to understand what was really bothering me and what I could do".

These answers tell us what some of these effective communication skills are:

- **listening actively**
- **trying to understand what the person is feeling**
- **asking good questions**
- **respecting people and their feelings, and not telling them to change**
- **being non-judgemental**
- **providing correct information.**

All of these things tell a person, "You are not alone - I am with you". This is so important to someone who is afraid of being rejected and who might feel like a failure.

The most common mistake you can make when trying to "help" people who are experiencing emotional pain is to try to change their feelings. You don't want them to be hurt and perhaps the issues they are confronting scare you too.

To distance yourself from this pain you may:

- **deny their emotions, for example by saying, "You shouldn't feel that way"**
- **give advice, such as "All you need to do is... and things will be better".**

These types of messages are a "mistake" because they tell people:

- **that they are not respected or capable - that they cannot manage their own problems**
- **that you are not interested**
- **that you are uncomfortable with the pain they are experiencing.**

Because you want people to feel better or to be "cured" of the difficult feelings they are

experiencing, you may try to convince them to feel differently. But by doing this you are telling them that what they are feeling is unacceptable and that they are failing you somehow unless they change. This only adds to their feelings of self-rejection and isolation.

Listening is one of the most important parts of good communication. This means you have to be silent sometimes. Let the conversation move at the other person's speed rather than at yours.

Asking good questions comes from good listening and is part of helping someone see another point of view. The questions you ask should always come from your listening. When you listen you are not just hearing words, you are hearing the feelings behind the words and the person's own view of their situation. The questions you ask can help both of you gain a better understanding of the situation.

Another important way you can help is by being able to give consistent and accurate information. The ability to say you do not know an answer but will try to find one is always better than making an answer up (see Chapter One). Telling the truth establishes the trust and the respect needed to build a helpful relationship.

The trust you earn means you must guard the privacy of the information shared. Never gossip or break this trust. Breaking trust tells a person:

- **they are not worthy of respect**
- **it was a mistake to seek help or share their feelings.**

Because of this, they may not seek the help they need in the future.

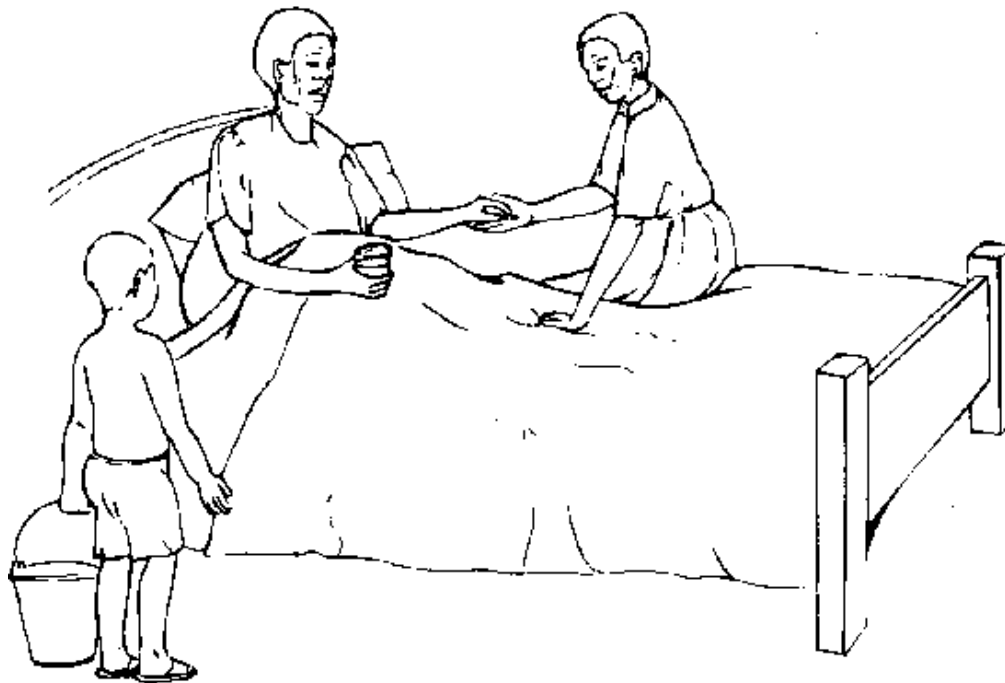
There are no easy answers to the difficult questions that are asked by those with AIDS. You cannot always have the "right" answer. Using truth and your ability to care are the only things you can be certain are "right". Your own discomfort and fears will be part of your attempts to help. Sometimes you will need to pay attention to these feelings and get help for yourself. Perhaps this comment from a woman who described the counselling she received says it all equally well:

"He looked me in the eye and said 'I don't know what I would do in your situation, except I would be scared'. I felt, suddenly, so much better. I was scared but I wasn't alone somehow."

When you are caring for someone you must watch your own reactions to the person you are trying to help. If you find yourself becoming impatient or angry these are signs that you are having trouble dealing with your own emotions and are less likely to be helpful to the person. You may be thinking, "He just doesn't seem to be able to face facts" or "She won't do anything to help herself". Your needs as a care-provider cannot be ignored but they should not be a burden to the person who is experiencing the grief of his or her own condition. You may need some special time to address your own concerns in private with counsellors, pastors or other health care workers. You may need help in understanding the sick person's needs and fears.

As AIDS worsens and a person becomes more and more ill, very often worries about physical health are outweighed by practical and emotional worries about money, housing, disability, change in lifestyle, family and other relationships, and the approach of death. You can help by offering practical help in planning for the future and by giving spiritual support, for example by helping someone strengthen or re-establish their religious affiliation (see Chapter Seven).

Yulia and her child going into the homes of other people with AIDS gave a very important message in the community.



Figure

Often the help needed in caring for someone with AIDS and for those who love them is very simple. Offering to help with chores, bringing favourite foods, watching over children and playing with them, telling stories, singing songs, sharing prayers - these are simple acts with strong messages of hope and belonging.

Everyone needs the love and help of those around them. Isolation from other people is frightening and it hurts very deeply when it seems the love of others has gone and you are rejected. A clear understanding between those with AIDS and everyone around them can do a great deal to help people face this disease compassionately and rationally.



Figure

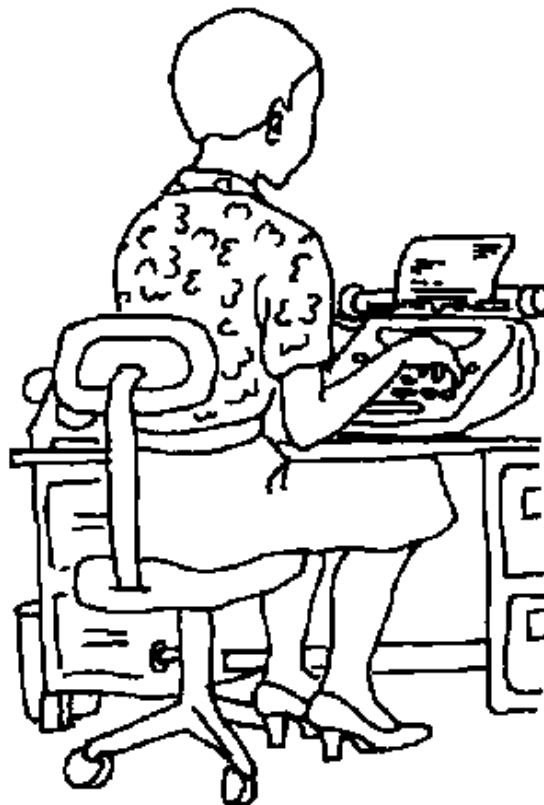
◆ **What did Yulia learn in her training to help her care for herself and for others with AIDS?**

First she was told that it is currently believed that all people with HIV infection will go on to develop AIDS. Modern medicine and traditional healers do not yet have a cure for AIDS. But many of the infections that come with AIDS can be treated and many symptoms can be dealt with using simple medicines and proper care. Most importantly, Yulia was taught about how to live positively with AIDS.

She learned that if you have HIV or AIDS, you should try to keep strong. This means you should:

- **eat a good diet whenever possible, including food that is rich in proteins, vitamins and carbohydrates**

- **stay as active as possible; exercise helps prevent depression and anxiety**
- **rest when you are tired and get enough sleep**
- **continue to work, if possible**
- **stay occupied with meaningful or at least distracting activities**
- **give both physical and emotional affection**
- **meet as often as you can with your friends and family**
- **talk to someone about the diagnosis and the illness**
- **seek medical attention for health problems and follow the advice you are given - this includes taking steps to prevent other infections.**



Figure

If you are caring for children or infants with HIV/AIDS you should make sure they receive immunizations for other diseases.

And you should avoid:

- other infections - including further exposures to HIV; each infection you get weakens the immune system further making you susceptible to subsequent infections, which makes your immune system weaker still, and so on**
- using unprescribed medicines - certain medicines can have side-effects that may be particularly harmful if you have AIDS**

- **isolation - your friends can do a lot to help you keep active and feeling positive; do not shut them out of your life.**



Figure

Yulia was taught about caring for people with AIDS at home.

She learned that there are two issues that are of great concern to people with AIDS and their families. The first is how to prevent HIV transmission from the person with AIDS to anyone else in the home or the community. The second is how to maintain a safe environment that does not expose the person with AIDS to unnecessary infections.

Preventing HIV transmission in the home

As you learned from the first part of the story, HIV can be transmitted from one person to another. However, unlike some other infectious organisms, HIV is not easily transmitted except by unprotected sexual intercourse or close blood-to-blood contact. The virus dies quickly outside the human body.

There is no risk of acquiring HIV from people infected with HIV (or people with AIDS) in the

home care situation provided you follow certain simple rules.

Because AIDS is known to be fatal, people are concerned about whether it is safe to care for an infected person. Those providing home care should be taught to follow these rules:

- **Wash your hands with soap and water after changing soiled bed sheets and clothing, and after having contact with body fluids.**
- **Keep wounds covered. Both caregivers and people with AIDS should cover any open wounds they may have on their hands or other places likely to have contact with other people, their bedding or clothing. Cover open wounds with a bandage or cloth. Use a piece of plastic or paper, gloves or a big leaf to handle soiled items.**
- **Keep bedding and clothing clean. This will help keep sick people comfortable and prevent skin problems. If you follow the first two rules the risk of transmission through contact with soiled clothing or linens is extremely low. To clean clothing or sheets stained with blood, diarrhoea or other body fluids:**

- 1. keep separate from other household laundry**
- 2. holding an unstained part, rinse off any blood or diarrhoea with water - be particularly careful if there are large amounts of blood, such as after childbirth**
- 3. wash in soapy water, hang to dry and fold or iron as you would normally.**

Any action you want to take beyond this, such as the use of bleach or boiling water, will also be effective but is not necessary.



Figure

- **Don't share sharp skin-piercing instruments. Don't share toothbrushes, razors, needles, or anything else that can cut or come into contact with blood. If it is necessary to share these types of objects, boil them in water prior to use.**

It is important to emphasize that HIV is not spread during normal social contact. People should not worry about getting other sexually transmitted diseases (STDs), like syphilis or gonorrhoea, from this type of contact with people, and they should have no greater worry regarding HIV/AIDS. However, it is important to avoid other common infections that are spread by normal social contact, such as diarrhoea and respiratory infections.

Avoiding other infections

Yulia also told people other things that are simply good health practices.

Yulia learned that if you have AIDS you have a weak immune system and can get infections

more easily. Each infection you get weakens your immune system further. But there is a lot you can do to ensure that you are protected from infections of all types. Good hygiene (cleanliness) in the home is an important part of protecting against diseases such as diarrhoea and respiratory infections. But many organisms that cause opportunistic infections already live in your body, and will cause disease if your immune system becomes too weak to stop them. Therefore, avoiding contact with healthy people is not necessary.

The following is what Yulia taught other people to do in their homes so that everyone in the family (including the person with AIDS) was safe from common infections.

The best way to prevent these common infections from spreading from person to person is to wash your hands frequently with soap and water and then dry them well.



Figure

Good Hygiene

Always wash your hands before:

- cooking
- eating
- feeding another person
- giving medicine.

Always wash your hands after:

- using a toilet or changing nappies.

Other practices that ensure good hygiene:

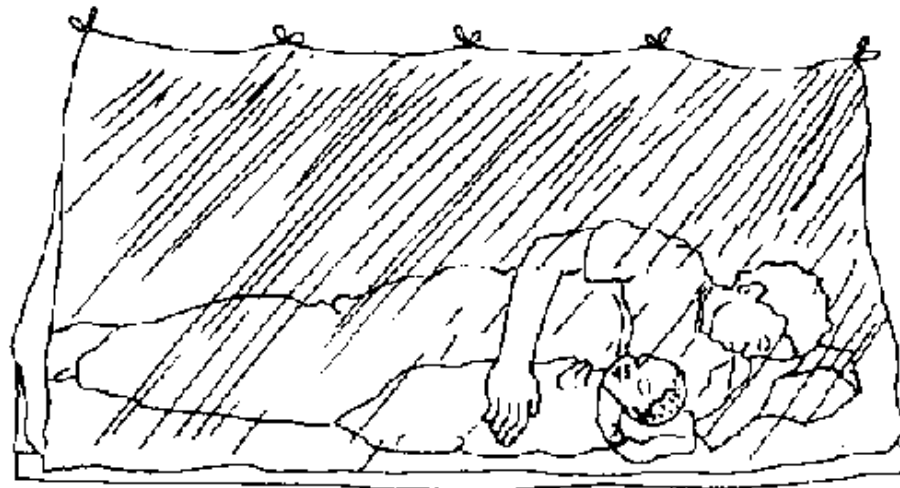
- Use clean water whenever possible and boil drinking water, especially for young children.
- Wash bed linen, towels and clothes with soap and water.
- Store food properly to prevent it from spoiling and causing infection.
- When someone in the family is sick, wash drinking cups before you share them.
- Cover your mouth when sneezing or coughing.
- Avoid spitting or always spit into a container, not on the ground.
- Kiss babies on the top of their heads rather than on the lips.
- Wash eating utensils, including items for babies, with soap and water.
- Carefully wash all raw fruits and vegetables with clean water.

- Wash objects that a child or infant frequently puts in its mouth with soap and clean water.
 - Dispose of waste properly.
 - Put dirty things like nappies, used tissues, handkerchiefs, and other soiled objects out of the reach of children until they can be removed from the home. Put them in a container that is hard to open until you can clean or dispose of them properly.
- Proper waste disposal may include using a pit latrine, or burning or burying objects.

Avoiding malaria

In many parts of the world malaria is a very common illness caused by an infection passed by the bite of a mosquito. There are many things you can do to prevent this infection and therefore prevent the further weakening of the body, including the following:

- **Use bed nets (mosquito nets preferably treated with insecticide) or a sheet to protect the family when they sleep - cover the baby's cradle or bed with a mosquito net or thin cloth.**



Figure

- **Use insecticide sprays and repellents to protect your home or body from any mosquitos in the area.**
- **Drain any standing water which may be a mosquito breeding ground in your community.**

Special issues concerning children with AIDS

There is another issue that Yulia knew was a great worry to the people in her community - the children. The fact that a mother cannot know for sure, even with a test, whether her baby is infected with HIV is very distressing. Remember, both of Yulia's children would have tested positive at birth for HIV antibodies. Yulia knew many mothers whose feelings were mixed - if a child has HIV and might die soon then perhaps it is best not to get too attached, yet if the child is not infected it will need every help to grow and thrive.



Figure

There is no easy answer to this problem. Even if a child is infected there can be years of life and things that can be done to make those years as healthy and full as possible.

Mothers and fathers need information to help them understand the facts and then they need support to help them cope during this time of uncertainty by focusing on their child's life and health rather than on the fear of illness.

General rules on caring for a child with HIV infection or AIDS

Yulia learned the following rules.

1. Feed the child well



Figure

For a child less than four to six months old the best food is breast milk. Breast milk is important because it gives an infant protection against many types of infections. Also, since breast milk is clean, the infant is not at risk of getting diarrhoea as with milk of other types.

However, the fact that HIV can be passed through breast milk makes it more difficult to decide what is best for the child. In many areas of the world the risk of transmission of HIV by breast-feeding is low compared with the risk of the infant dying of other infectious diseases if not breast-fed.

As the health care worker, you will have to help the HIV-infected mother weigh the possible risks to the infant of breast-feeding versus not breast-feeding, taking into account such things as:

- whether many of the children in the area are at risk of, or die from, infections and poor nutrition**
- whether there is a good alternative to breast-feeding available that is clean, safe,**

nutritious and affordable.

It is recommended that if the HIV-infected mother lives in a place where many children die at a young age from infectious diseases (like respiratory infections or diarrhoea), or if the child is likely to be malnourished, she should breast-feed her infant, even if she is infected with HIV or has AIDS.

However, if she has the possibility of giving a clean, safe and nutritious substitute for breast milk that is affordable for the entire period it is required, it would be a good choice. If she decides to feed her baby using breast-milk substitutes rather than breast milk, she must use clean water, which has been boiled and then cooled, and clean equipment (teats and bottles, cups and spoons). Remind her to follow the directions carefully and not to add more water in an effort to save money - this can lead to malnutrition in her child. If she cannot follow all of the above requirements all of the time, advise her to breast-feed her baby.

An infant who is breast-fed should receive only breast milk until it is four to six months old. Once a child is four to six months old it should be given some solid foods along with the breast milk. Healthy foods that are warm and either soft or mashed can be given with a spoon or your fingers. (Don't forget hands must be washed first!) Milk alone is not enough for a child after six months, but it is very important that breast-feeding or a nutritious substitute be continued along with other foods.

As the child grows give more and larger quantities of adult foods. The section on nutrition problems in Chapter Five gives information on healthy foods.

2. Have the child immunized



Figure

You may be asked whether an infant with HIV/AIDS should be given vaccines against the common childhood illnesses. All infants, including those with HIV infection and AIDS, should be given the standard vaccines against diphtheria, pertussis (whooping cough) and tetanus (DPT vaccine), and against poliomyelitis (polio) and measles. This should be done as early as possible in accordance with the immunization schedules of your country. In many countries, the BCG vaccine is given to all infants at birth to prevent tuberculosis. The only exception is that if an infant has clinical symptoms of AIDS, such as failure to thrive and frequent infections, it should not receive BCG, but should receive all other vaccines mentioned above.

3. Make sure the child gets early treatment for infections

The advice given earlier in this chapter on avoiding common infections is important. As children become older they will need to learn these things for themselves, for example about washing their hands after going to the toilet or latrine, and about the importance of washing their hands before eating. Protecting children with AIDS from other infections is more difficult than protecting adults because children tend to put things in their mouths and they are exposed to more illnesses that are new to them.

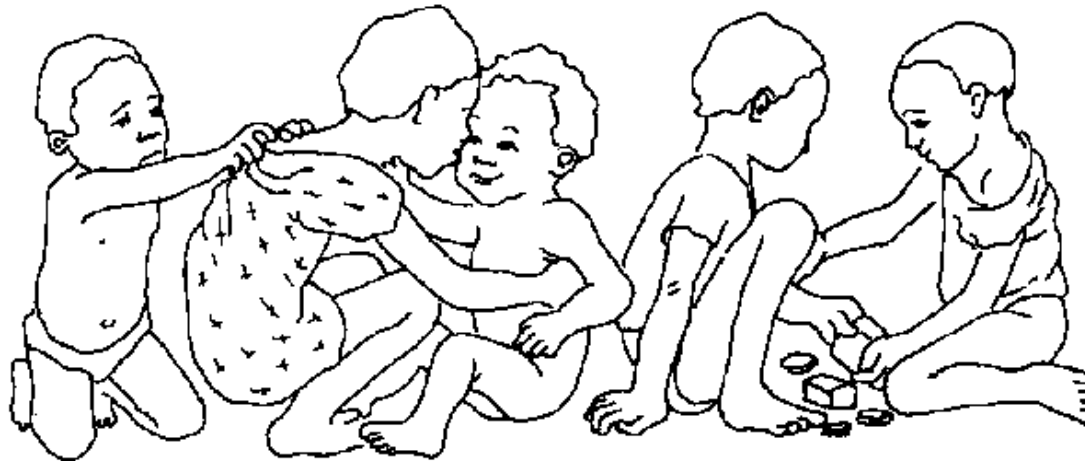
It is much better for a family to go to the same health care setting where the child's health history is known rather than keep changing or "shopping around".

Note: Chapter Five of this handbook describes the common symptoms of AIDS and how to treat them. Many of the symptoms children show are the same as those experienced by adults and the advice for their care is also very similar in most cases. Where the treatment of children is different, this is explained.

4. Treat the child as normal

Many of the infants who are infected with HIV will have months or years of life without symptoms. Every effort should be made to help them lead as normal a life as possible. This includes letting them spend time playing with other children.

A child with HIV infection should go to school as usual, except when there is an outbreak of an infection in the school which could make the child ill.



Figure

Chapter Four: Care of the dying

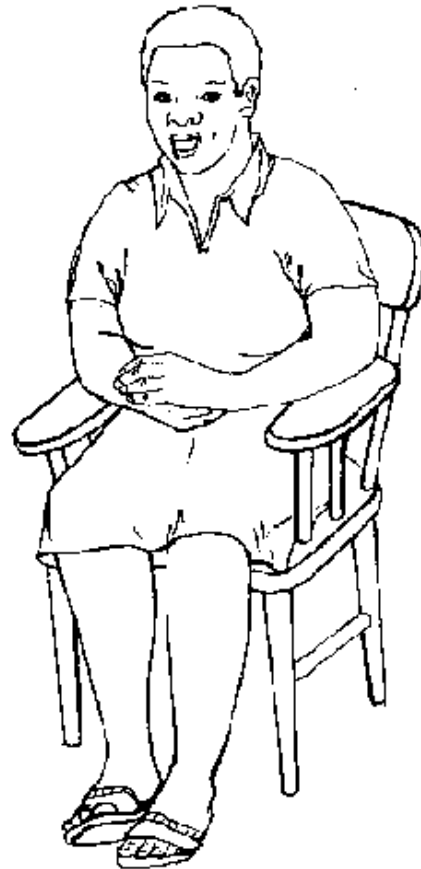
This chapter begins with the final part of the story about the family you first met in Chapter

Two. Yulia is dead now and her sister Anna tells how she died and how her community reacted.

The rest of the chapter provides information you need to give to family members who are caring for someone who is dying from AIDS. The information is presented in a way that you can use when speaking directly to the family.

The last part of the story: Yulia's legacy

Yulia died last night. I am Anna and she was my sister. I will miss her.



Figure

Our family and community have lost another. But we all must die in our time and it was her

time. She went as one should, proud and in peace. She taught us in her death much about our fives. Let me tell you of her dying - it was good and perhaps we shall ail live and die so well.

She was carrying this infection, who knows how long.



Figure

It seems to come from nowhere, or maybe everywhere. But it is in so many of us and takes us one by one until I think there are thousands who are gone.

She lost her husband three years back and a child before that Then she faced it, told us it was called AIDS and learned that there was just a bit more time before she too would go. So, she began to fight, for herself and for her little one who was left - Yokaana is his name. She was so

proud of him and so sure that it was up to us to teach and keep our little ones free of this illness until they could learn to keep themselves free.

Long before her death Yulia said it was important to plan to die. We began to sit together, many of us. At first it was just the women - women who were sick or widowed, had lost their children or were worried. In her work Yulia came across many women whose lives were so similar to hers - they too had lost their husbands but for them everything seemed lost We began, slowly, to meet together and talk of these things.



Figure

We had seen people die alone, people die with all their wishes for those they loved ignored, people die rejected, people die without names or a family to remember them. We had seen families divide and become warring parties. It was too much sorrow for all the world to bear. "Not us, not me", we each said.

For most of us the only place we have learnt or thought of death has been in our religion. We don't talk of it anywhere else in our lives. Making money, raising children, carrying water, chopping wood, building the future are what we know best How strange death seems when we look it in the face - bow little related to our "lives" and how difficult to talk about Yulia had great courage to speak of this.

Yulia said that each person needed to make a plan for "living and dying proud" as she called it so that even when death seemed very far away we could be sure we would be ready when it was our time to die. We talked about what each of us wanted at the end that would make death not so bitter. We decided that if a person can do things to have a "good life" then they can also do things to have a "good death". These are the things we decided we must be sure of in order to meet and accept death:

- that, if possible, we should know what it is that is killing us***
- that there is nothing more that can be done by doctors and healers and that it is our time to die***
- that those we care about will be taken care of and will try to accept our leaving them***
- that we are not alone in our fear and are loved here and now***
- that we accept what we have done to others and what others have done to us***
- that our wishes will be respected, so that as far as possible we shall be given full choice over our lives and what will happen to us until the end***
- that we should not be forgotten, or perhaps that our life has a meaning larger than we can know.***

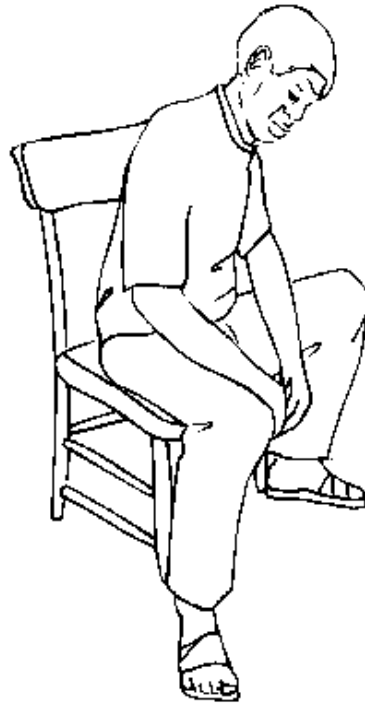
We began by looking at each of these things and thinking about what it would take to make them possible. Some of these are things that can happen only if all of us encourage and help each other.

We began, together, to decide what things we could do and what help we needed from outside to strengthen our ability to face up to this disease and fight it Our actions really began by asking some questions:

- ***What do I need to do to keep myself and my family safe?***
- ***What could we do to make our community stronger to face the challenge of this disease?***
- ***What help can we get from outside our community (from the Government or other agencies) to protect and support our people?***

Within each of us the first thing we had to find was acceptance. It is in acceptance that caring can grow.

Yulia always said she was sorry that when her husband died they had not known that it was because of AIDS. She is sure that he would have accepted death more easily had he known that and had a chance to prepare.



Figure

He was caught by surprise in some ways and never understood what it was that got him. She was sorry because she knows she kept this knowledge from him by her denial, and she did not tell him what the doctor had said when she took the baby to the clinic. May be things would have been different if she had listened to the doctor then and told Mukasa. And, she knows he never meant to pass this illness to her. But, she said through not blaming anybody - not blaming herself for perhaps taking from Mukasa the chance to live longer and to die in knowledge, and not blaming him for bringing this illness into their little family, because of which she lost her second child - comes acceptance.

From this acceptance, she said, her heart could look outwards to give more and to ask more of the community.

We talked together of our own sorrows and anger. Soon our little group of women was joined by some of the men and after a while we asked the village elder, the headman, to join us and

hear our ideas.

We were not sure how to plan. Yulia said that the people who had given her training would be willing to come to us if we asked. In some communities there is help for people with AIDS; practical and spiritual help. Help with ways to make money, keep jobs, find food and medicines, make wills and ensure that last wishes are respected. Yulia told us of a community near the capital which was being helped in these ways.

So, Yulia and some of the men went and told these people about us and they agreed to come.

And it was then, together with these people, that we made a community plan.



Figure

Together some of us women started to collect money, small amounts left, over from what we had, and to set it aside for our children. Over time and with the help of those people from the AIDS organization, we found ways to raise some money for those too sick to work or care for their families. The AIDS organization also gave us materials or loans to help. Some people

raised chickens to sell the meat and eggs and others worked with their hands making pieces to sell on the road. The money we earn is first for the children, second to help with the costs of transporting people to health centres and back to the village, and last for funerals and burials.

The face of our community changed. It became a friendlier place in which to live and die. This Yulia offered to us all and to herself.

Last night was her time and she died as she lived - an example for us all. Let me tell you what she did in those last days.

Yokaana is seven years old now. Yulia had him tested at the clinic to show us and herself that caring for each other, staying together and being a family, carried no risk - Yokaana has no HIV. She turned the illness into the enemy, not those with the illness. Maybe now we know this enemy a little better and how to keep it away. She turned her anger at the illness into a force in all our lives.

But one day, it seemed, she knew that death was near and that it could no longer be kept away. She changed. She became quieter. I argued with her then saying "Fight, fight more, it doesn't have to win now". But she said "Yes, sister, the time is short just as we have a time to fight and to live, so we have a time to die and mine is near - be with me". Over these two weeks we came to be with her as she had done for so many others.

She made it clear how Yokaana was to be brought from a child to a man and with whom he would live. The money and possessions that they had were taken into account and agreements were made on how they should be passed to others, and within her family. We did this as a community to be sure that all would honour her wishes and protect her son. She had seen too many others lose even this last peace.



Figure

She asked to be part of our lives even to the end. We put her bed outside with us. My sisters and I took turns cooking, telling stories, remembering the past, praying and doing what needs to be done.

She had pain - it made her feel better to have her skin rubbed with Vaseline. She said it eased the aching. And the doctor had given some medicine for her pain which she would ask for sometimes, but she would also say, "Sister, tell me a story or sing me a song".



Figure

She would move about a bit with our help, sometimes to a bench in the shade and sometimes to lie in the breeze near the door. She kept saying how beautiful it was - this life, this earth. It was something that shone from her - what can I call it? Yokaana would tell her of his day and they would talk together quietly sometimes. It is hard for a boy so young who loved his mother.

I did what she had done for so many others - reminded people of the good things they had done and helped them forget their sorrow or pain. I'd ask her, "What did you do here on this earth that made one person smile and feel better? Tell me a story of one of those times".

In these last years her trust in God was more and more a part of her life, and in these last weeks she seemed to belong as much with God as with us. It was a great comfort to her when friends visited to share the spirit with her.

I have lost much but I know she died in grace knowing she was loved. I hope to die so well.



Figure

Teaching notes care dying

At some point in the disease process of AIDS, there is nothing more that can be done to treat the opportunistic infections, or the symptoms that they cause. The infections or illnesses have progressed beyond what medicines can cure. At this point, the goal of all care (medical, nursing, pastoral and psychological) is to keep the person as comfortable as possible and to maintain their dignity. In some places this is called palliative care.

◆ When does this begin?

It is often difficult to decide when the focus on medical treatment should stop and care for the dying should begin. The change in care may begin, for example:

- **when medical treatment is not available or is no longer effective**
- **when the person says he or she is ready to die and really does appear to be very sick - this is clearly different from someone who is depressed for a time and who must be encouraged not to give up**
- **when the body's vital organs begin to fail.**

◆ **Where can you provide care for someone who is dying?**

Care for the dying can be provided in a hospital or in the home. Most people prefer, or are forced by circumstances, to remain at home. However, some people may not want to actually die in the home. They may want to stay at home until the last moment but either because of their own or the family's wishes they may want to go to the hospital to die. If this is the case, a plan for transporting them will need to be thought out.

◆ **What are the goals of caring for someone who is dying?**

- **keeping them comfortable and protecting them from problems that can make them feel worse**
- **helping them to be as independent as possible**
- **assisting them in grieving for, and coping with, the continuing losses they experience**
- **helping them and their families prepare for death - this may include making a will, tending to relationships in the family or the community, and arranging for the transfer of responsibilities**
- **keeping them within the community and family groups for as long as possible - family members can bring them into this part of their lives even when it seems they are too ill to enjoy or understand what is going on.**

◆ What can you do to meet these goals? Give comfort

- **If the person is in constant pain, make sure that the pain medication is available in regular doses. It should not be taken just when the pain is really bad.**
- **Use relaxation techniques such as encouraging deep breathing, or giving back rubs or body massages.**
- **Continue basic physical care to keep the person clean and dry and to prevent skin problems, and stiffness or locking of joints.**
- **Encourage communication within the family and community. People with AIDS and those they love need to feel that they are not outside the love and life of their community. Help them use this time as a chance to heal old wounds and to make peace with each other. This will help to increase the comfort and acceptance of the whole family.**
- **Provide physical contact by touching, holding hands and hugging.**
- **Provide or arrange for counselling if desired, for example from religious representatives. They can be very helpful for spiritual counselling.**

Allow the sick person independence

- **Accept the person's own decisions such as a refusal to eat or get up, or even a demand to get up when you think that resting would be better for them.**
- **Respect requests, for example regarding visitors.**
- **Ask them what they are feeling. Listen and allow the person to talk about how they feel.**
- **Accept the person's feelings of anger, fear, grief and other emotions.**

Prepare for death

- **Talk about death if the person wishes to. Many people feel that it is not good to talk about the fact that someone is going to die, as if mentioning death is a wish for death. But by discussing death openly, those around are helping the dying person to feel that their concerns are heard, that their wishes will be followed and that they are not alone. To avoid talking about death is a form of denial.**

- **One of the most common worries is for the future of the children in a family. People may fear that their children will be hungry or lack money for school fees after they have died. Begin planning with relatives, friends or orphan programmes for the future of the children. It will ease such worries if the person knows that suitable arrangements have already been made.**

- **The person may be worried about being in pain as they near death. The fear can be lessened by knowing what it will be like. If the person asks, describe what might happen, such as difficulty in breathing, or passing in and out of consciousness. If pain medications are available, reassure the person that they will be used in order to prevent unnecessary pain.**

- **The person may be worried about what will happen after they die. The anxiety can be lessened by helping them to write a will, by planning details such as funeral arrangements and discussing spiritual beliefs, perhaps with a representative of the person's religion.**

◆ What precautions do you or the family need to take with the body of someone who has died of AIDS?

Immediately after death, you need to follow the same rules in dealing with the body as you did when helping the person through their illness. Hands should be protected when cleaning and laying out the body, particularly if there are body fluids such as diarrhoea or blood, and then washed with soap and water afterwards. Wounds on hands or arms should be covered with a

plaster or bandage.

Shortly after the person has died the virus will also die. HIV can only live and reproduce inside a living person. Therefore you do not need to worry about special precautions during the funeral itself.

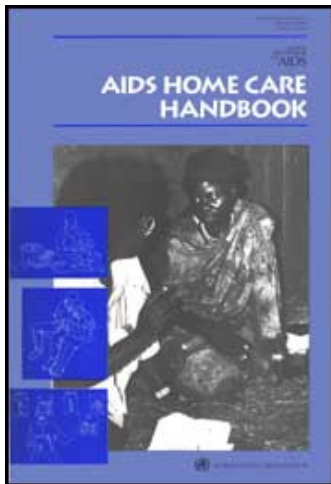
◆ How can you help the family after the death?

Immediately after a person has died, the family may need help to grieve or to arrange practical matters. You can offer this by listening to them. You can also assist them with the funeral arrangements in accordance with the customs and regulations of the area in which you live.

The death may continue to cause practical difficulties for the family. This is particularly true if planning for the death was not done properly. Also, the family and loved ones will continue to grieve for many months. Any care or practical help you can give during this time can be useful. Setting aside time to visit and asking how they are doing will help them to think of life beyond this painful time.



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Aids Home Care Handbook (WHO, 1993, 178 p.)

Part II: Reference Guide

Chapter Five: Management of the common symptoms of AIDS in the home















 *(introduction...)*

 **Fever**

 **Diarrhoea**

 **Skin Problems**

 **Mouth and throat problems**

-  **Coughing and difficulty in breathing**
-  **Genital problems**
-  **Nutrition problems**
-  **Nausea and vomiting**
-  **Anxiety and depression**
-  **Pain**
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- Chapter Six: Conditions that need special attention in people with HIV infection**
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 -  ***(introduction...)***
 -  **Teaching notes on the use of medicines**
 -  **Medicines commonly used to treat symptoms in people with AIDS**

Aids Home Care Handbook (WHO, 1993, 178 p.)

Part II: Reference Guide

Chapter Five: Management of the common symptoms of AIDS in the home

This chapter covers the management of the most common symptoms that people with AIDS are likely to develop. It provides the information which you as a health care worker need to give to people with AIDS and their families so that they can prevent and treat these symptoms at home and know when they should seek help.

Each group of health problems or symptoms is discussed under the following headings:

■ **Problems and possible causes**

This section gives a brief description of the health problem or symptom, and how it relates to someone with AIDS. In addition, some possible reasons for the symptoms are given in order to help people think how to prevent or reduce them.

■ **What to do at home**

This section describes what people can do in the home to prevent and treat the symptoms.

Only the most simple, inexpensive, and readily available medicines that may be used safely in the home are described in detail. Chapter Seven covers the use of such medicines in more detail. If available, the national standards of your country for treating specific problems should be followed; the information provided here is merely a guide.

For medicines or treatments not described here, it is the responsibility of the health care worker prescribing or distributing them to give full instructions on how and when they should be used.

■ **When sick people and their families must seek help**

This section describes the symptoms and changes that should warn the person with AIDS or the family to seek help from a health care worker. You, the health care worker, must explain to sick people and their families that the appearance of the symptoms and signs described in this section means that they need to seek the advice and help of a health care worker, preferably the health care worker they usually see, who may be working in the community, at a clinic, health centre or hospital. It is much better for people to go to the same place and work with the same health care worker repeatedly during the process of treating AIDS symptoms than it is to keep changing or shopping around. Meeting more health care workers does not mean increasing the chances of having good health.

■ Notes

This section is for any notes you may have on the topic, based on your experience of treatments, on your knowledge of local conditions or on further training you may receive.

Fever

■ Problems and possible causes

When a person's body temperature is too high, they have a fever. Fever is not a disease in itself but a sign that something is wrong in the body. Fever may indicate one of many different illnesses.

High fever can be dangerous, especially in small children. Fever as a symptom can make anyone feel very uncomfortable.

In people with AIDS fevers often come and go. It is difficult to know whether the fever is a symptom of a treatable infection or whether it is due to the HIV infection itself. The causes of fever include:

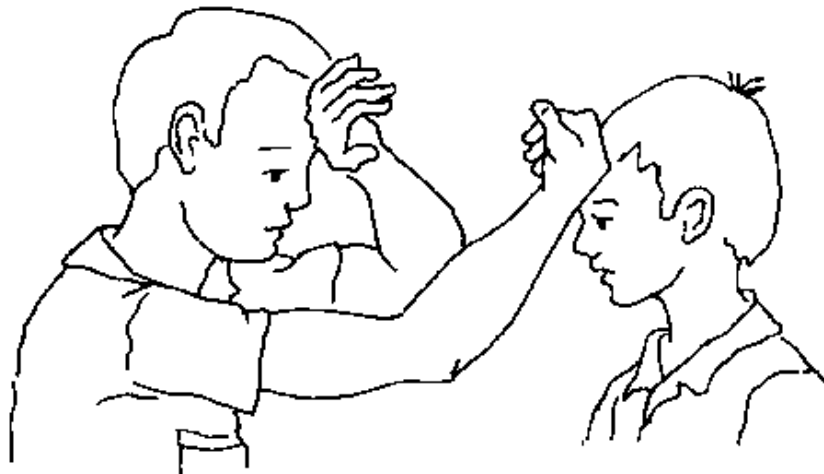
- **AIDS-related opportunistic infections, such as tuberculosis**
- **endemic diseases, such as malaria**
- **HIV infection itself.**

It is important to identify tuberculosis as early as possible because it can be easily spread to others in the home, especially to children. See Chapter Six for more information about tuberculosis.

■ What to do at home

The best way to check whether someone has a fever is to use a thermometer and measure their temperature. If you do not have a thermometer you can still get an idea of whether someone has a fever by putting the back of your hand on their forehead and the back of your other hand

on your forehead. If they have a fever, you should be able to feel the difference.



Figure

How to lower a fever

- **Remove any unnecessary clothing and blankets; fresh air (for example from a breeze) is not harmful and helps to lower the fever.**
- **Cool the skin by taking baths or pouring water on it, putting cloths soaked in water on the chest and forehead and fanning the cloths, or just wiping the skin with wet cloths and letting the water evaporate.**



Figure

- **Provide plenty of water, weak tea, broth or juice. When someone has a fever they lose more fluids than usual and this can make them feel worse, and can cause them to become dehydrated.**
- **Use medicines that reduce fever (antipyretics): for example, aspirin or paracetamol, two tablets every eight hours. For children the dose is lower and depends on size (weight) or age. See Chapter Seven for specific information about these medicines.**

How to manage the discomfort of fever

- **In between bathing and cooling the skin to lower the fever, keep the skin clean and dry.**
- **Use lotions or powders to prevent skin problems such as rashes, sores, sore areas or broken areas.**

Diarrhoea

■ Problems and possible causes

Diarrhoea is very common in people with AIDS. The diarrhoea is usually clear and watery and is sometimes accompanied by abdominal cramps and vomiting.

What is diarrhoea?

The number of stools normally passed in a day varies with diet and age. In diarrhoea, the stools contain more water than normal - they are called loose or watery stools. They may also contain blood, in which case the diarrhoea is called dysentery. Frequent passing of normal stools is not diarrhoea.

People usually know when they have diarrhoea - the stools smell strongly or pass noisily, as well as being loose and watery. Someone has diarrhoea if they have three or more loose or watery stools in a day.

Diarrhoea is more common in people who have AIDS than in those who do not.

There are two types of diarrhoea, acute diarrhoea and persistent diarrhoea.

- Acute diarrhoea lasts for less than two weeks.**
- Persistent diarrhoea is when someone has more than three liquid stools a day every day for more than two weeks.**

The most common causes of diarrhoea in people with HIV infection are:

- **intestinal infections from food or water that is not clean and fresh.**
- **opportunistic infections related to AIDS**
- **side-effects of some medicines.**

□ Why is diarrhoea dangerous?

The two main dangers of diarrhoea are dehydration and malnutrition. Dehydration is the loss of a large amount of water and salt from the body, which if not treated can cause death.

How does diarrhoea cause dehydration?

The body regulates the amount of water and salts it needs by a two-way process. It takes in water and salts from the food and drink consumed. It also gets rid of excess water and salts through the stools, urine and sweat. In a healthy person there is a balance between intake and output. When someone has diarrhoea, however, the intestines do not work normally and this balance breaks down. Increased amounts of water and salts are passed into the intestines and the output of water and salts becomes greater than the intake. This results in dehydration. The greater the frequency of diarrhoea the more water and salts are lost. Dehydration can also be caused by vomiting, which often accompanies diarrhoea.

Dehydration occurs faster in infants and young children, in hot climates, and in people who have fever.

How does diarrhoea cause malnutrition?

Diarrhoea (either acute or persistent) can cause malnutrition or make it worse because:

- **nutrients are lost from the body in the stools**
- **people with diarrhoea often do not feel hungry**
- **some think *wrongly* that they should not eat when they have diarrhoea, or even for some days after the diarrhoea lessens.**

■ What to do at home

□ How to prevent diarrhoea

- **Drink clean water. Boil water that is to be used in making food or drinks. The water need only boil for a few seconds. Drinking water from a dirty well, or water kept in a dirty container, can cause diarrhoea.**
- **Eat clean, safe food. Eat freshly prepared foods. Make sure that raw foods are washed and that cooked food, especially meat, has been cooked properly. Badly washed food, or food not protected against dirt, flies and animals can be unsafe to eat because it can become contaminated with disease-causing organisms. If previously cooked foods are to be eaten, make sure they have been stored safely and reheated thoroughly at a high temperature.**
- **Clean your hands. This is particularly important. People should always wash their hands:**
 - **after using the latrine**
 - **after helping somebody else use the latrine**
 - **after cleaning soiled children or sick people**
 - **before preparing food or drink for them-selves or other people.**

□ Three rules for treating diarrhoea in the home

The treatment recommended here is suitable for anyone with diarrhoea, with or without AIDS.

I. Drink more fluids than usual

Dehydration can usually be prevented in the home by drinking more fluids as soon as the diarrhoea starts.

What fluids?

People should be advised by health care workers on the type of fluids to drink (see the section on how to treat dehydration below). Fluids such as unsweetened juices and weak tea or food-based fluids such as gruel, soup or rice water are all effective in combating dehydration.

In the case of breast-fed infants with diarrhoea, the mother should continue to breast-feed and try to do so more often than normal (at least every three hours).



Figure

How much?

Drink as much as possible.

If someone does not feel thirsty they may have to force themselves to drink. It may help people to keep a glass of water nearby and sip some of it every five to ten minutes.

It is particularly important to encourage children with diarrhoea to drink. Give children under

two years old about a quarter to a half of a large cupful of fluid (50-100 millilitres) after each loose stool. Give older children one half to one large cupful (100-200 millilitres) after each loose stool.

2. Continue to eat



Figure

If people try to stop eating when they have diarrhoea this can cause malnutrition or make existing malnutrition worse, and will not decrease the diarrhoea. The fluids taken in do not replace the need for food. It is very important for people to take the nutrients needed to stay strong and prevent weight loss - a strong person will resist illness better.

Even if someone does not feel hungry they should eat small amounts of nutritious and easily digestible food frequently. After the diarrhoea has stopped, an extra meal each day for two

weeks will help to regain any weight lost during the illness.

It is particularly important to encourage young children with diarrhoea to eat. Some children will continue to need extra food after the diarrhoea has gone for some time to make sure they regain any weight lost.

What foods?

Advise people to eat foods with the largest amounts of nutrients and calories relative to bulk. These should be mixes of cereal and locally available beans, or mixes of cereal and meat or fish. Oil can be added to these foods to make them more energy-rich. Dairy products, eggs and bananas are also suitable. Very dilute soups are recommended as fluids, but are not sufficient as foods because they fill you up without providing sufficient nutrients.

Advise people to avoid:

- **high-fibre or bulky foods, such as fruit and vegetable peels, and whole grain cereals; these are hard to digest**
- **foods or drinks containing a lot of sugar, such as commercial soft drinks, as these can worsen diarrhoea.**

Prepare foods by cooking well, mashing or grinding to make them easier to digest.

The section in this chapter on nutrition problems gives more detailed information about healthy foods.

How much food?

People should eat as much as they want. They should take some food every three or four hours (six times each day) - food should be given more often to young children with diarrhoea. A person may prefer small, frequent meals and these are best because they are more easily digested.

3. Recognize and treat dehydration early

People should watch for signs of dehydration (feeling very thirsty, feeling irritable or lethargic, and the skin going back slowly when pinched). If someone notices these signs, they should take oral rehydration solution used by health care workers to treat people with dehydration, and it can also be used in the home. It is made by dissolving a packet of oral rehydration salts (ORS) in cooled water that has previously been boiled.

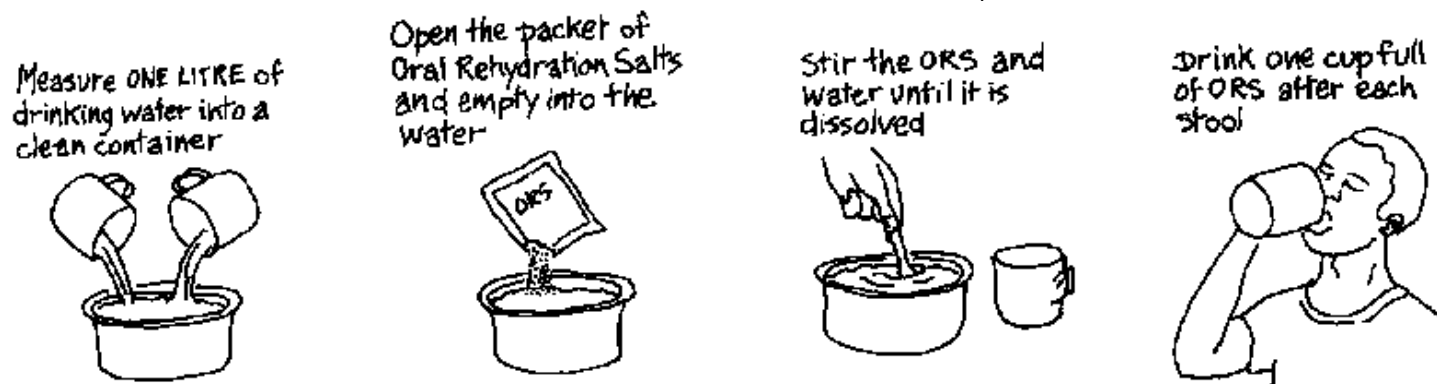
ORS packets are available in most parts of the world. Dissolve the contents of the packet in the amount of water indicated on the packet. Not all packets are the same size so people will have to read the instructions to be sure how much water to add. If they use too little water, the drink could make the diarrhoea worse. If they use too much water, the drink will be less effective. The mixture should be stirred well and then drunk the same day it is prepared.

If ORS packages are not widely available you should advise people that they can still make a suitable solution at home. You should advise on the recipe for the solution used in your country.

Other treatments for diarrhoea

Discourage the use of medicines at home to control diarrhoea. Further details about when to use such medicines are given in the section on medicines for diarrhoea in Chapter Seven.

For severe stomach cramps that sometimes accompany diarrhoea, paracetamol may be helpful. Recommendations on the dose to take are given in the section on medicines for pain in Chapter Seven.



Figure

□ Other problems that may come with diarrhoea

Skin irritation in the rectal area

To prevent or treat sore or broken skin you should advise the sick person to:

- dean the rectal area gently with water after each bowel movement and pat dry
- apply a lotion to help relieve the discomfort and protect the skin
- sitin warm water containing a little pinch of salt three or four times a day; this may also relieve the discomfort.

Haemorrhoids

Haemorrhoids can develop after the diarrhoea has been present for some time. They are caused by a weakening of the walls and blood vessels of the rectum. The tissues around the anus become very sore and itchy. The blood vessels may become very tender and may bleed - small amounts of blood may be noticed in stools or during cleaning of the rectal area.

Trying to relax during bowel movements and not straining or pushing too hard to pass the stools can prevent haemorrhoids. Sitting in a bath may help to ease the discomfort and

paracetamol can be taken to relieve the pain.

To help someone with diarrhoea who cannot get out of bed

Use a bedpan or other suitable plastic or metal container. Be sure it is not too high and can be used by slipping it under the person in bed. Empty the contents frequently. Do not use this container for any other purpose once it has been used as a bedpan. Change wet or soiled bedding immediately to prevent damage to the skin.

■ When sick people and their families must seek help

People are at risk of dehydration and should seek help if they have diarrhoea and:

- **are very thirsty**
- **have a fever**
- **cannot eat or drink properly**
- **do not seem to be getting better**
- **pass many watery stools**
- **see blood in the stools**
- **are vomiting and cannot keep down fluids.**

Help should be sought quickly if signs of dehydration have already developed, such as:

- **the person is extremely thirsty**
- **the person is in an irritable or lethargic state**
- **the skin returns slowly after pinching.**

The information contained in this section has been modified from the WHO programme for Diarrhoeal Disease Control modular course "Supervisory Skills: Treatment of Diarrhoea"; see the "Resource List" which follows Chapter Seven in this handbook.

Notes on diarrhoea

- **yeast infections (thrush, candidiasis)**
- **other fungal infections (e.g. ringworm)**
- **bacterial infections**
- **shingles (herpes zoster)**
- **poor hygiene**
- **allergic reactions to medicines or skin irritants**
- **bed sores (caused by lying in one position in bed)**
- **eczema**
- **Kaposi sarcoma.**

■ **What to do at home**

As a general rule, cleaning the skin frequently with soap and water and keeping it dry between washing will prevent the most common problems.

Almost all skin problems involve the sensation of itching. Scratching the itching skin with fingernails can make things worse, either by breaking the skin or by introducing or spreading infection. This can be avoided by keeping nails short. Try to encourage people not to scratch any type of skin lesion or sore. However, rubbing with the flat of the fingers or gentle slapping can give some relief.

Itching can be reduced in a number of ways, including the following:

- **cooling the skin with water or fanning it**
- **applying lotions such as calamine that are soothing and prevent the skin from becoming too dry**
- **not letting the skin get hot and not applying warmth to itching areas**
- **using effective traditional remedies that are available locally from a herbalist.**

If people have trouble with very dry skin, they may have to avoid soaps and detergents and use bath oils and skin creams as much as possible. Vaseline, glycerine, and vegetable or plant oils can be as effective as the more expensive oils and creams sold in the shops.

To prevent babies, or someone who is confused, from scratching themselves, cut their fingernails very short or put gloves or socks over their hands.

For children in nappies who have diarrhoea or yeast infections, the buttocks area will need special care. For example people should:

- **leave the baby's bottom exposed to air as much as possible**
- **soak the baby's bottom with warm water between nappy changes**
- **not let the child remain in wet nappies or cloths but remove or change them as soon as they become soiled**
- **avoid wiping the buttocks area; instead squeeze water from a wash cloth or pour water over the area and then pat dry**
- **use simple lotions provided by a health care worker or pharmacist - this may help cure rashes in the nappy area, particularly if they are treated early**
- **not forget to wash their hands afterwards!**

Treatment of wounds

Wounds (including open sores and ulcers) which are not infected:

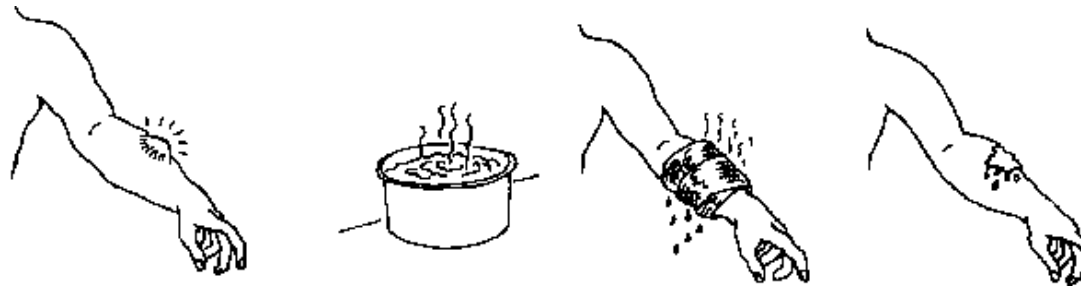
- **Wash the affected areas with clean water - preferably water which has been boiled and cooled - mixed with a little salt (one tea-spoonful of salt to one litre of clean water) or gentian violet solution (one teaspoonful of gentian violet crystals in half a litre of clean water).**
- **Protect by covering with clean gauze bandages or cloth, wrapped loosely.**
- **Put warm compresses of weak saltwater on the area four times a day (one teaspoonful**

of salt to one litre of clean water).

- **If the wound is on the legs or feet, raise the affected area as high and as often as possible. During sleep it should be on pillows. During the day, try to raise the foot for 5 minutes in every 30 minutes. Walking helps the circulation, but standing in one place or sitting with the feet down for long periods is harmful.**

Closed wounds (including abscesses and boils) which are infected:

Boils - and some abscesses - are red, raised painful lumps on the skin. They are most common on the groin, buttocks, armpits, back and upper legs. They may start as single lumps under the skin or in groups. They quickly become more painful as they increase in size. Once someone notices a red lump under the skin they should start using warm compresses over the area for 20 minutes four times a day. The warmth of the compresses will help the boil or abscess "mature" or to form and harden and drain its contents. If they are having a great deal of pain and the boil or abscess continues to get bigger without draining (i.e. opening out onto the skin) they should seek help. The wound may require drainage and treatment with antibiotics.



Figure

Open wounds (including abscesses that are actively draining) which are infected:

If wounds are not cared for properly they can become infected. A wound is infected if:

- **it becomes red, swollen, hot, and painful**
- **it has pus either draining from it or visible under the skin**

- it begins to smell bad.

The infection is spreading to other parts of the body if:

- it causes fever
- there is a red line above the wound
- the lymph nodes under the skin in the neck, armpits or groin become swollen and tender.

People should attend to infected wounds with one of the following:

- a salt wash (one teaspoonful of salt in one cupful of clean water)
- hot compresses over the wound for 20 minutes, four times a day.

If there is pus or dead tissue, you should show the person how to dean it away.



Figure

Advise people to treat infected wounds as follows:

- Use a gentian violet solution on the wound before applying dressings.

- **If the wound is on a hand or foot, soak it in a bucket of hot water with soap or potassium permanganate (one teaspoonful of potassium permanganate to a bucketful (4-5 litres) of clean or boiled water - do not exceed the recommended amount; if the solution is too concentrated it can burn or irritate the skin). Be sure that any compress or water applied to the wound is not too hot, since damaged skin can easily burn.**
- **When it is not being soaked, keep the infected part at rest and elevated (raised above the level of the heart).**
- **If there is dead tissue, hydrogen peroxide can be used to rinse the wound.**

Advice on washing or cleaning an infected wound and applying dressings

- **Use gloves, plastic bags, or a big leaf when handling cleansing cloths or dressings to avoid touching blood from the wound, and wash your hands afterwards with soap and water.**
- **Wash around the edge of the wound first, then wash from the centre out to the edges using separate little pieces of clean cloth for each wipe if possible.**
- **Cover the area with a clean piece of cloth and bandage if the wound has pus or blood. If the wound is dry it can be left exposed to the air - it will heal quicker this way.**

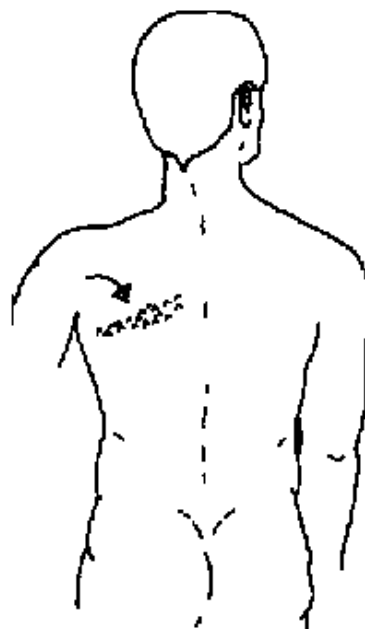
Dressings are used to cover wounds to prevent them from becoming infected, to protect other people from infection, to keep medicines in place or to avoid painful contact with the environment.

- **Never apply a dressing tightly.**
- **Make sure dressings are clean.**
- **Change the dressing at least once a day. Be sure to look for signs of infection.**

- **After changing the dressing, rinse the soiled cloth and bandages in water and soap and put them in the sun to dry or put them in boiling water for a short period and hang them to dry. If the dressings are not to be reused, always dispose of them properly by burning them or putting them in a pit latrine.**

If soil or dirt gets into the wound it can become infected with the bacteria that cause a serious disease called tetanus (lockjaw). You should therefore ensure that people are fully immunized against tetanus. Even if they have been immunized for tetanus before, they may still need further immunization. Advise people who are not immunized against tetanus to seek medical help immediately if they are wounded or develop open sores.

Shingles



Figure

Shingles (herpes zoster) is a viral infection which used to be seen only in older people or in those with weakened immunity for various reasons. Now shingles is very common in people with AIDS and it may be one of the first symptoms they have of HIV infection or AIDS.

Shingles begins as a painful rash with blisters, usually on the face, limbs or trunk. Shingles on the face may affect the eyes, causing pain and blurred vision. The blisters often combine, resulting in a large eroded or broken area, and there may be an intense burning feeling in the affected area. Healing takes place over several weeks and leaves discoloured areas on the skin.

The following measures may be helpful:

- **Applying calamine lotion twice daily to relieve pain and itching and promote healing.**
- **Keeping the sores dry and not letting clothes rub on them if possible.**
- **Wearing clean, loose-fitting, cotton clothing.**
- **Relieving pain with aspirin or paracetamol, but sometimes the pain maybe so severe as to require stronger prescribed medicines, including pain killers and sedatives at night. For additional measures to control pain, see the section on pain in Chapter Seven.**
- **Preventing infection by bathing the sores with warm salt water three or four times a day or applying gentian violet solution once a day, or antibiotic skin creams or ointments if available.**
- **Watching for signs of infection of the shingles sores such as redness or pus. If infection occurs treat as indicated for infected wounds above.**

The pain usually diminishes after three or four days. Unfortunately some people develop a persistent pain and scarring over the affected area. Rubbing creams on the scars or painful areas may help; medicines for pain such as aspirin or paracetamol may also be needed.

Allergic reactions

Allergic reactions to medicines are more common in people with AIDS. These often appear suddenly and start as skin rashes, redness, and itchy skin. If people think they may be having a reaction to a medicine they should immediately go to see the health care worker who

prescribed it. Medicines that commonly cause reactions in people with AIDS include:

- **anti-tuberculosis medicines**
- **antibiotics**
- **anti-cancer medicines.**

See Chapter Seven for further details of possible reactions to anti-tuberculosis medicines.

Kaposi sarcoma

Kaposi sarcoma is a cancer of the cells in the blood vessels or lymph system. The cancer may begin as:

- **discoloured (brown or purple) areas on the skin or in the mouth**
- **enlarged lymph glands which are not painful.**

Both of these are a type of external cancer (affecting the outside of the body) and are mostly a problem for cosmetic reasons, but the cancer may go on to affect internal parts of the body causing the enlargement of internal organs or bleeding from the lungs or digestive tract. How Kaposi sarcoma will appear in a specific person and what its course will be are very difficult to predict. Some people have only mild complaints arising from the appearance of the lesions; others may become very ill as a result of the cancer.

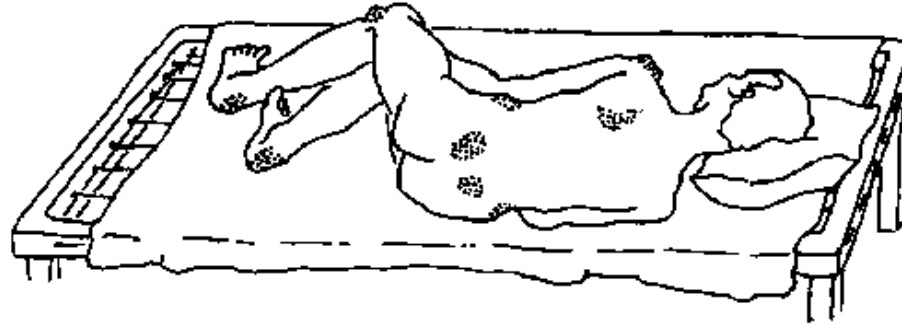
Because of the variety of ways in which Kaposi sarcoma may appear and because of the numerous parts of the body that may be affected, this disease can be mistaken for many others. Once the diagnosis of Kaposi sarcoma is made, it indicates that the person has AIDS.

The specific care needed for the problems caused by Kaposi sarcoma will depend on where the cancer is situated and on what type of problems it is causing.

Bed sores

It is very important to prevent infections resulting from sores of any type that do not heal

adequately. Included in this category are "bed sores" or sores caused by breakdown of the skin due to pressure. These chronic open sores appear in people who are so ill that they cannot roll over in bed, especially those who are very thin and weak. The sores form over bony parts of the body where the skin is pressed against the bedding. They are most often seen on the buttocks, back, hips, elbows and feet.



Figure

To prevent bed sores in sick people you should advise them to:

- **get out of bed as much as possible**
- **change position, when lying down, every two hours from one side onto the back, from the back onto the other side, and so on in order to prevent prolonged lack of circulation to any one area of the body; this is particularly important if an area of skin is already affected - the person may need help with this in the home if they are very weak**
- **use soft bed sheets and padding, which should be hung to air daily and changed each time the bedding is soiled with urine, stools, vomit or sweat. Straighten the bedding often as lying on wrinkled bedding can hurt the skin**
- **put cushions under the body in such a way that the bony parts rub less (see illustration below)**



Figure

- **eat as well as possible; extra vitamins may help.**

A bedridden child who has a severe chronic illness should be held often on someone's lap.

■ **When sick people and their families must seek help**

- **If pus, redness or fever (indicating infection) accompany the skin problem.**
- **If the wound has a bad smell, if brown or grey liquid oozes out, or if the skin around it turns black and forms air bubbles or blisters - this might be gangrene, a very dangerous condition. Medical help must be sought very quickly.**
- **If there is severe pain from a skin problem, like shingles, and the sick person is unable to sleep or function during the day.**
- **If shingles affects the eyes.**
- **If there is an allergic skin reaction to a medicine.**
- **If the sick person is wounded or develops an open sore and they are not fully immunized against tetanus.**

■ **Notes on skin problems**

- **oral herpes simplex (blisters and sores on the lips)**
- **malnutrition (cracks and sores on the mouth)**
- **Kaposi sarcoma of the mouth or throat**
- **dental problems**
- **hairy leukoplakia.**

■ **What to do at home**

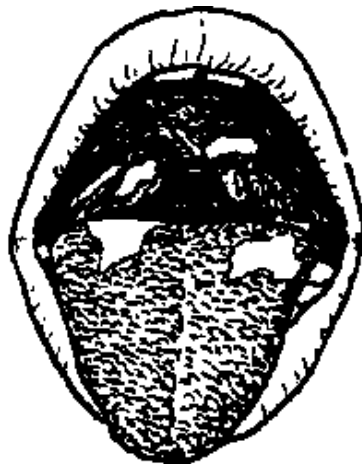
Poor nutrition can cause problems in the mouth and can make existing problems worse. Encourage people to eat a healthy diet or take vitamin supplements. For additional information refer to the section on nutrition in this chapter and the section on medicines for nutrition problems in Chapter Seven.

To help prevent problems in the mouth and throat, the mouth can be rinsed with warm salt water (half a teaspoonful of salt in a cupful of water), or with a mouthwash solution after eating and between meals. The wash should be swished gently in the mouth then spat out (not swallowed or it may upset the stomach and cause nausea).

General hints for dealing with a sore mouth:

- **Eat soft foods rather than hard or crunchy foods.**
- **Eat bland not spicy foods.**
- **Use a straw for liquids and soups. This may help when taking in the food needed while preventing it from touching the sore areas.**
- **Cold foods, drinks or ice, if available, may help numb the mouth and relieve discomfort.**

☐ Thrush



Figure

Thrush is a fungal infection that causes small white patches on the inside of the mouth and tongue. The infection looks like milk curds stuck to raw meat. If the white plaques scrape off with a brush or a fingernail it is probably thrush. If it does not it may be another condition called hairy leukoplakia (described below).

You should advise someone with thrush to:

- gently scrub the tongue and gums with a soft toothbrush at least three or four times per day, then rinse the mouth with dilute mouthwash, or a salt water or lemon water rinse**
- suck a lemon if it is not too painful - the acid of the lemon slows down the growth of the fungus**
- apply gentian violet solution three or four times a day - gentian violet solution is prepared by dissolving 1 teaspoonful of gentian violet crystals in half a litre of dean water.**

If necessary, you may prescribe antifungal oral suspensions or lozenges given three or four times a day. In some people, thrush affects not only the mouth but the entire esophagus causing pain on swallowing and a burning sensation in the chest. See the section on medicines for fungal infections in Chapter Seven for information on the use of these medicines.

Hairy leukoplakia

Hairy leukoplakia may look like thrush. However, it does not cause pain, it will not scrub off the tongue or gums, and it commonly makes vertical ridges on the edges of the tongue. It is mentioned here only so that you know that it can be confused with thrush. There is no need for a specific treatment for this condition. It will not interfere with the ability to eat or with a person's general comfort. The main point is to not use too many medicines for thrush if in fact the problem is hairy leukoplakia.

Herpes simplex sores

These are painful blisters on the lips, which may appear after a fever. In people with AIDS these sores may appear even without a fever and may last a long time. Gentian violet solution (made as described in the previous section on thrush) can be applied to the herpes sores on the lips and mouth. Although the strong purple colour may bother some people, the solution can help in preventing the sores from becoming infected.

Dental problems

Thorough cleaning of the teeth and gums is important. Many people with AIDS suffer from inflammation of the gums, tooth abscesses and infection. For this reason, people should be encouraged to make regular visits to a dentist when possible, and to be particularly careful about oral hygiene, being sure to brush the teeth and clean between the teeth (using dental floss or toothpicks) to remove food particles.

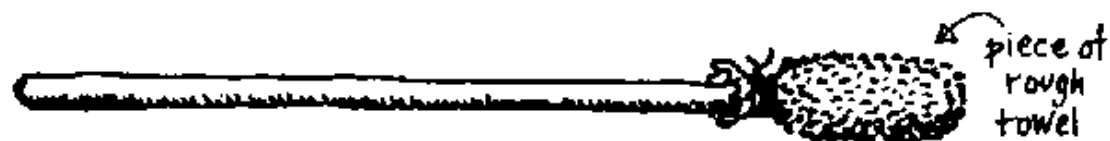
If someone does not have a toothbrush, they can use a tooth-cleaning stick.

Use the twig of a tree, like this:



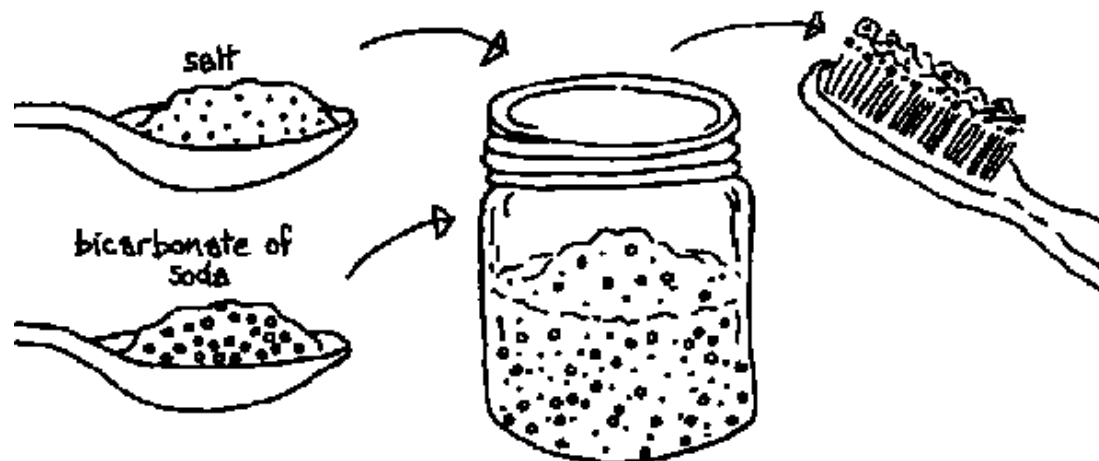
Figure

Or, they can tie a piece of towel around the end of a stick, and use it as a toothbrush.



Figure

If toothpaste is not available, a tooth-cleaning powder can be made by mixing salt and bicarbonate of soda (or ashes) in equal amounts. To make it stick, the brush should be wetted before being put in the powder. This mixture works just as well as commercially available toothpaste for cleaning teeth.



Respiratory problems, particularly lung infections, are common in people with AIDS and can be quite serious. The most common symptoms are chronic cough, shortness of breath, chest pains, and increased production of mucus (also called sputum).

The most common causes of respiratory problems include:

- **colds and flu**
- **bronchitis**
- **pneumonia**
- **tuberculosis (see Chapter Six)**
- **heart problems.**

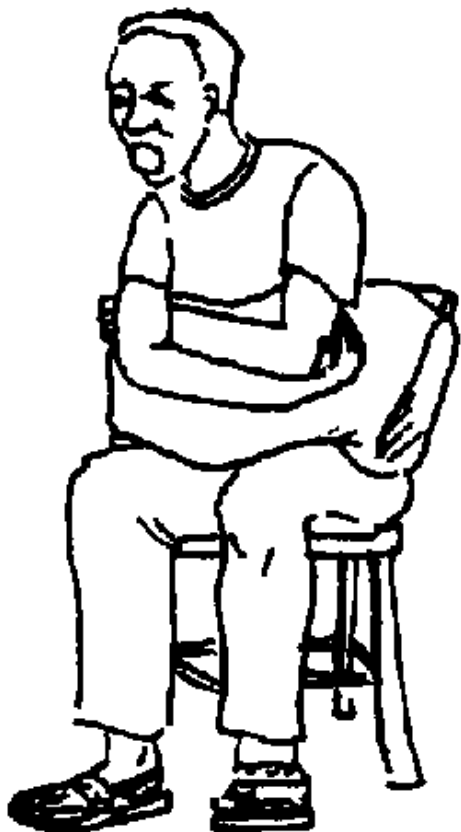
■ **What to do at home**

People should be made aware of the signs and symptoms that are of concern, including:

- **the onset of a fever or a change in the regular fever pattern of the sick person**
- **blood in the sputum**
- **a sudden or rapid worsening in their ability to breathe or catch their breath after normal activity**
- **a change in the colour of their sputum from clear to grey, yellow or green.**

The following advice may help to decrease respiratory problems.

- **Keeping active by walking about, turning in bed and sitting up. This encourages the lungs to drain.**
- **Other measures which encourage drainage of the lungs include massage or gentle patting on the back of the chest over the lungs. Someone in the home can do this, especially for younger children.**
- **If pain is felt in the chest or ribs during coughing, a pillow or hand should be held tightly over the area that hurts when coughing. This helps make the cough less painful.**



Figure

- **During the day it may be beneficial to cough and clear the lungs at least four times a day. Even though coughing may cause discomfort, it is an important way to clean the lungs of the accumulated mucus and disease-causing bacteria.**

Thus, anyone with lung problems should be encouraged to cough. Several points are worth mentioning:

- **The bacteria or infectious agents in the sick person's sputum can be passed to other people through the air, especially when coughing. When anyone is coughing, they should always cover their mouth with their hand or with a cloth which can be cleaned or**

disposed of.

- **All homes and other places where people meet should be ventilated - make sure there is a way in and a way out for fresh air.**
- **An irritating cough can sometimes be relieved with safe cough remedies, for example:**
 - **Soothe the throat by drinking tea with sugar or honey.**
 - **Use a safe, home-made cough syrup. Throughout the world families and herbalists have suggestions for things that soothe coughs.**
 - **Commercial remedies may also be useful although they are often expensive and usually work no better than home remedies.**
- **A constant cough can be very tiring and interfere with a person's rest. If coughing keeps someone from being able to sleep at night a cough suppressant can be prescribed. It is important to cough, so do not encourage the use of cough suppressants during the day. They should only be used at night to allow someone to rest.**

Pain in the chest without signs of infection, and difficulty in breathing, are common problems in people with AIDS. Very often the cause is not known. Warm compresses to the area where the discomfort seems to be centred may be helpful. Additional hints are provided in this chapter under the section on pain. Medicines like aspirin or paracetamol may be useful at times. Paracetamol is safer for children. The dosages are described in the section on medicines for pain in Chapter Seven. It is important that the things done to help relieve the pain will also help someone in their efforts to keep active, moving and coughing.

When someone is experiencing difficulty in breathing the following advice might help:

- **Lie with pillows under the head, or with the head of the bed raised on blocks.**
- **Sit leaning forward with the elbows on the knees or on a low table.**

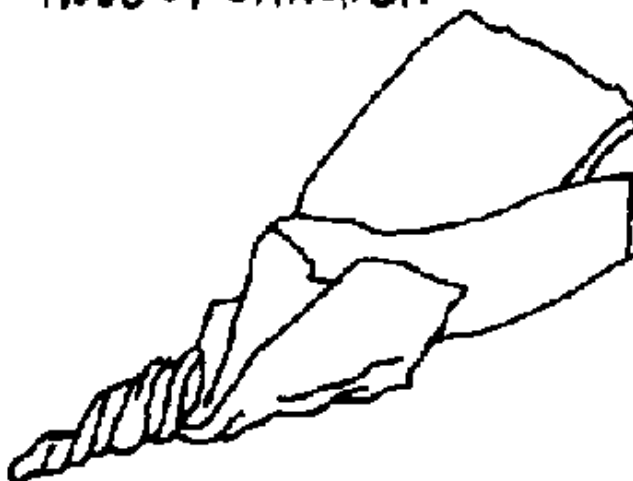


Figure

- **Have someone else there. Difficulty in breathing can be very frightening.**

In children with respiratory problems it is important to clear the nose if it is congested, and especially if the congestion interferes with the ability to eat or to be breast-fed. Dry or thick sticky mucus can be softened and removed with a wick moistened in salt water (a quarter of a teaspoonful in a cup of water).

WICK TO help clean the
nose of children



Figure

If a lung infection with cough is present, it is important that plenty of fluids are drunk: first, to replace the extra fluids lost through the lungs by rapid breathing, and second to help keep the mucus in the lungs from becoming too dry and sticky and more difficult to cough out. Remind parents that fast or difficult breathing in children may be dangerous and needs medical treatment quickly.

Encourage children with respiratory problems to take more fluids by increasing the frequency of breast-feeding or by giving additional fluids by spoon or cup.

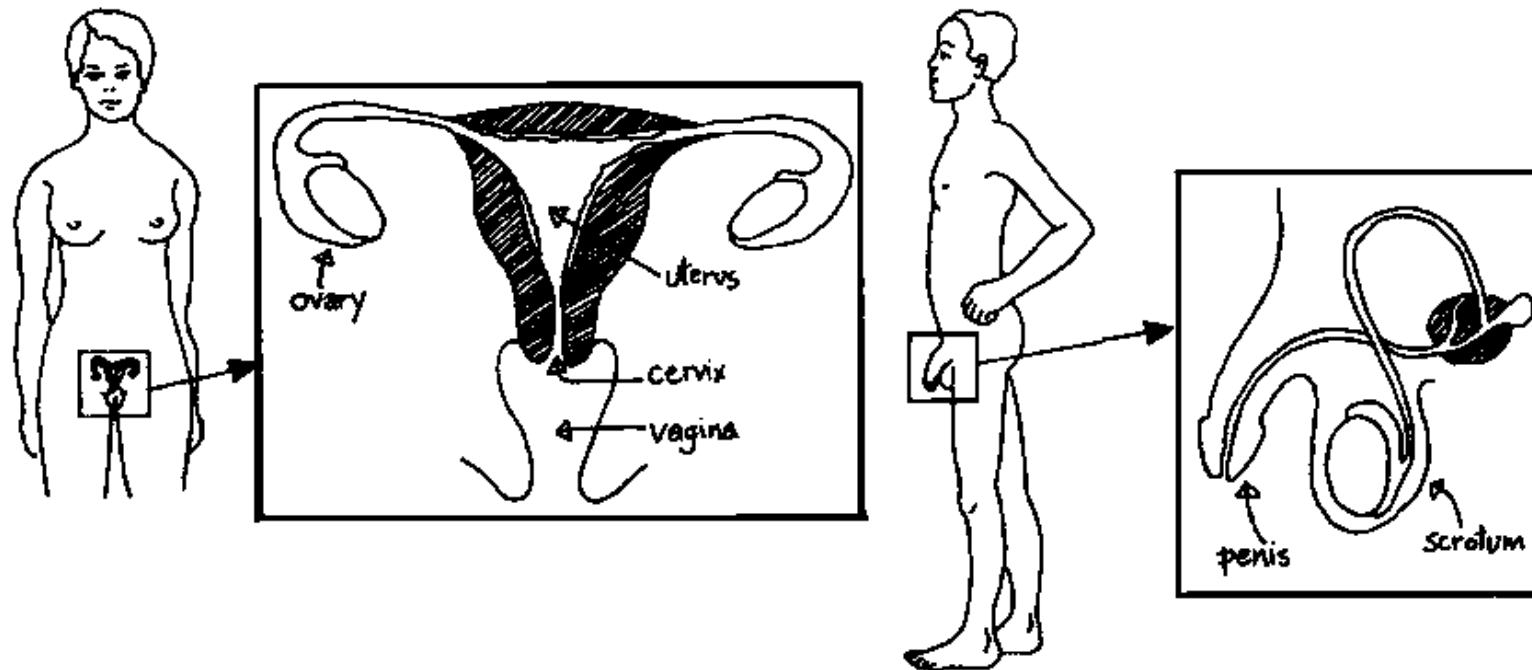
If the problems experienced with coughing, chest pain, or other respiratory symptoms are chronic (lasting more than three weeks) and do not respond to antibiotic treatment, tuberculosis may be the cause and should always be considered (see Chapter Six).

■ When sick people and their families must seek help

You should advise people to seek help if the sick person has a cough or difficulty in breathing and:

■ Problems and possible causes

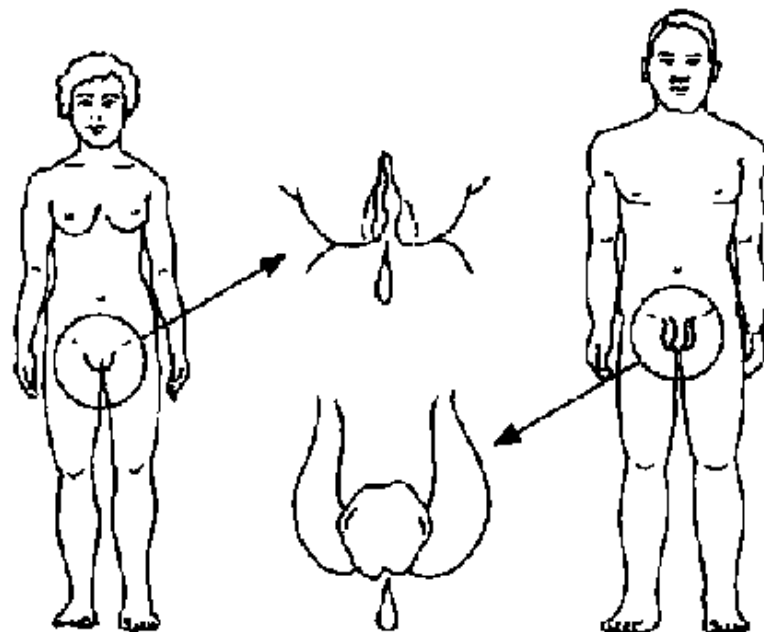
Opportunistic infections of the genital area, including certain sexually transmitted diseases (STDs), are common in both men and women with AIDS. They often cause pain and discomfort.



Figure

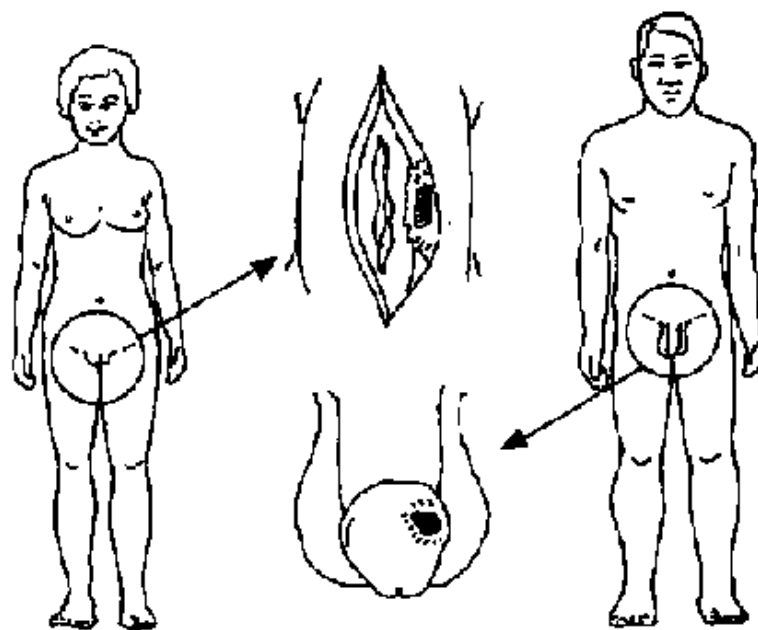
There are six common ways that such genital problems appear in men and women:

- **an unusual discharge (a mucus or pus-like substance) from the vagina**
- **an unusual discharge from the urethral opening of the penis**
- **open sores or ulcers in the genital, groin or rectal areas, which sometimes start as blisters**
- **a rash in or around the genital area**
- **warts in the genital area or around the anus**
- **swollen glands in the groin.**



1. Vaginal discharge

2. Discharge from penis



3. Genital sore (ulcer) in

4. Genital sore in

a woman

a man

Figure

If a person feels they may have a sexually transmitted disease (STD), their first action should be to seek treatment from a health care worker where available, BEFORE attempting any form of home treatment.

■ What to do at home

Firstly and very importantly, always advise people to use a condom each and every time they have any sexual contact. It is dangerous for someone who is already infected with HIV' to be exposed to other sexually transmitted diseases. The use of condoms offers protection from all STDs, and also provides protection to the partners of those with such conditions. (See Chapter Two for further information on safer sex.)

□ Vaginal discharge

All women normally have a small amount of vaginal discharge which is clear, milky-white or slightly yellow and varies in amount and appearance over the course of the monthly menstrual cycle. Any change in this normal discharge, particularly if it is accompanied by an unpleasant smell, itching, soreness and sometimes fever, is probably caused by a sexually transmitted infection such as gonorrhoea, chlamydia or trichomonas.

Vaginal infections are important because:

- **They may be passed on to others through sexual intercourse.**
- **Sexually transmitted infections (e.g. gonorrhoea, chlamydia) are particularly likely to spread from the genital area to the upper reproductive tract causing pelvic inflammatory disease. This may even lead to abscesses with severe cramps and pains in the abdomen, with the result that such infections become difficult to treat, even with strong medicine, and can be life-threatening.**

- **They increase the risk of acquiring, or passing on, HIV infection during sex.**
- **They may be transmitted to an unborn child during pregnancy.**

People should be given the following advice on ways to avoid vaginal problems:

- **Always use condoms when having any sexual contact (see Chapter Two).**
- **Keep the vulva and anal area clean by washing with water (but avoid soaps that damage this delicate skin).**
- **After going to the latrine, wipe the anus in a direction away from the vagina so that faeces doesn't get into the vulva, vaginal region.**
- **Avoid washing out the vagina or putting anything (e.g. leaves, herbs) inside unless advised by a health care worker.**

Anyone with vaginal discharge should be examined by a health care worker.

Urethral discharge in men

Pus or mucus discharge from the opening of the urethra, often accompanied by burning when passing urine, is usually a sign of an STD. Anyone with these symptoms should be examined by a health care worker.

Genital sores

Open sores or lesions on the genitals may be caused by an STD. As with any open wound (see the section on skin problems in this chapter) an additional infection may occur. People with open sores should be advised to:

- **always use condoms when having any sexual contact (see Chapter Two)**

- **keep the affected area dean with soap and water**
- **between washings keep the wound dry**
- **watch for signs of infection, and seek help if redness, pus or swelling are seen, or if the sores become painful.**

Genital warts

Genital warts are very common, are infectious, and can be caught by sexual contact then passed on to other people in the same way. They are often larger, spread more quickly and are more difficult to treat in people with AIDS. In women, they appear as skin-coloured lumps or swellings on the outside and inside of the vagina, and the area around the anus, while in men they appear particularly under the foreskin and around the anus. If they get rubbed by clothing or damaged they may become sore (inflamed), infected and may even bleed.

Encourage people to seek early treatment from a health care worker for this condition. Local treatment of the warts provided by a health care worker can be effective if it is applied before the warts are too big. If someone waits too long and the warts become quite big it may be necessary to have them cut out, a surgical procedure which has risks associated with it. Warts that are damaged may become infected. If this occurs they should be treated like any open wound in the genital area.

Herpes

Herpes is a viral infection that many people get around their mouths or genital area. It tends to remain latent (hidden away), under the control of the body's defences. It occasionally appears as blisters which break down to give painful ulcers which heal slowly by themselves. In people with AIDS, the blisters appear more frequently, spread over a wider area and sometimes do not heal at all. They can be very difficult to treat.

If herpes is diagnosed, advise the person to bathe the affected area with salt solution

consisting of a teaspoonful of ordinary cooking salt in half a litre of clean water. They should do this often, every two or three hours if possible. Between times the affected area should be kept dry. Calamine, talcum or starch powder may also be applied to the sore.

☐ Candidiasis

Candidal infections - caused by several of the fungi belonging to the genus *Candida* - are common but they are particularly frequent and more difficult to cure in people with AIDS. In women, they produce a curdy discharge and cause redness and soreness of the vulva that is accompanied by severe itching. The skin may break down and bleed, particularly if scratched. Candidiasis is also found in men, especially among those who are uncircumcised, and occurs often and severely in men with AIDS. The foreskin and the area underneath it become very sore and red. There may be a yellow discharge under the foreskin. The skin of the penis, scrotum, and around the anus sometimes becomes red, sore and itchy.

Candidiasis is not sexually transmitted but is often brought on by the use of antibiotics for the treatment of other conditions, or simply because the person with AIDS has lowered resistance to the fungi that cause it. The organisms are always present in the genital area but are not normally a problem because the body's defences keep them from growing out of control.

If someone is experiencing candidiasis repeatedly, the following approach may help to alleviate discomfort, to prevent the onset of a new infection (which can occur, for example, as a result of taking antibiotics given for another problem) and possibly to decrease the intensity of an existing infection:

- **Apply gentian violet to the vulva and vaginal area or the affected male genital area. To prepare a gentian violet solution dissolve one or two teaspoonfuls of gentian violet crystals in one litre of clean water. Apply once daily for three days. Gentian violet solution should be applied internally or externally to the affected area using a soaked piece of clean cotton wool, cloth or gauze. This should be done for at least three days or until the symptoms improve - if this does not happen then the person must see a health care worker. People should be advised that gentian violet stains clothing and sheets a**

purple colour.

A rash on the penis or under the foreskin will often respond to soaking in a dilute salt and water solution. Dissolve a teaspoonful of salt in a glass or jam jar of water. Pull back the foreskin, put the penis in the water and soak for 5 minutes. Repeat 2 or 3 times a day.

If this does not work carry out the same procedure using a gentian violet solution (1/2 teaspoonfuls gentian violet in 1 litre of clean water). If the rash does not clear up in 3-4 days the person should ask advice from a health care worker.

Someone who experiences candidiasis repeatedly should learn to recognize the signs of an infection and begin the treatment at home while it is still in the early stages.

□ Loss of Menstruation

Loss of menstruation and irregular bleeding occur in many illnesses including AIDS. If a woman loses a lot of weight her periods may stop altogether or become infrequent. Loss of menstrual bleeding can have many causes (including pregnancy) and is often seen in women with AIDS. This should be assessed in order to plan for the future care of the woman (see Chapter Six). If a woman misses one or two periods, she should be encouraged to go to the health centre to be examined. If pregnancy is not the cause then the reason for the loss of menstruation should, where possible, be determined.

Always remember that a woman may feel that loss of menstruation represents a loss of capacity to bear children or a loss of femininity and may feel sad or even depressed. You can help a person to fight off this loss of self-esteem by reassuring her that loss of menstruation is experienced by many women for a wide variety of reasons. Women should be encouraged to be with friends, to involve themselves in the people and activities around them, and to remember that they are still worth while and have a great deal to give.

■ When sick people and their families must seek help

- **If a STD is suspected.**
- **If difficulty or pain in passing urine is experienced.**
- **If genital warts are present.**
- **If genital ulcers are present.**
- **If there is an unusual vaginal discharge that is foul-smelling, itchy, very plentiful, or green, yellow or grey in colour.**
- **If a pain develops in a woman's lower abdomen, particularly if it is accompanied by a fever.**
- **If a woman's periods stop or become irregular or erratic.**
- **If there is a discharge from the penis.**
- **If there is swelling and/or pain in the scrotum.**

■ Notes on genital problems

Nutrition problems

■ Problems and possible causes

AIDS almost always causes severe weight loss, even in people who eat good food. There are many reasons for this including:

- **not enough nutritious foods available**
- **painful or difficult swallowing because of:**
 - **oral or esophageal thrush**
 - **mouth sores such as the blisters caused by herpes simplex**
 - **Kaposi sarcoma lesions (purple lesions which can occur on gums or palate)**
 - **inflammation of the gums or infections of the gums and teeth (redness, pus or swelling of the gums); these can be caused by a lack of vitamin C (found primarily in citrus fruits and in dark green leafy vegetables).**
- **nausea and vomiting**
- **chronic diarrhoea**
- **tuberculosis (see Chapter Six)**
- **depression or anxiety**
- **fever from any cause.**

■ **What to do at home**

A sick person has an even greater need for food than a healthy person. People should be encouraged to think about the foods that will help make them healthy, rather than worry about foods that are not considered to be good for them.

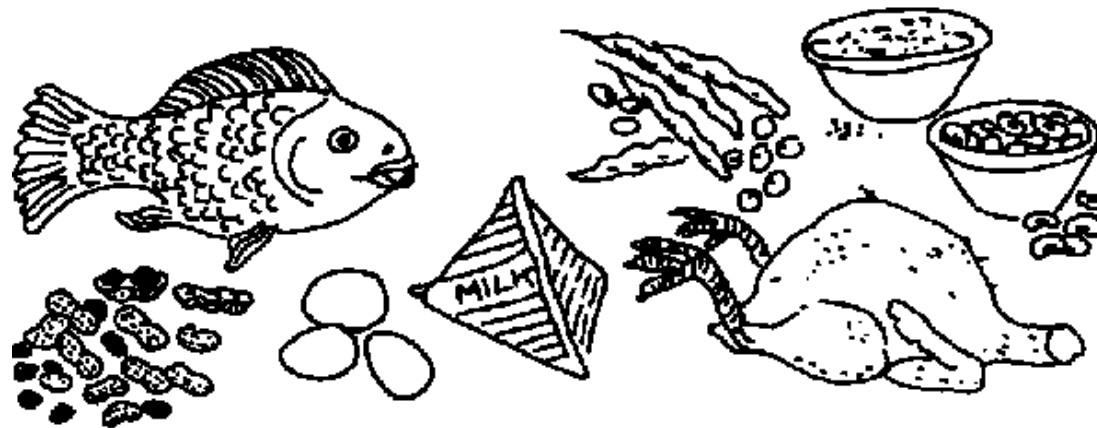
The same foods that are good for you when you are healthy are good for you when you are sick.

All of the foods you are familiar with will fall into one of the following three groups. Everyone

should try to eat food from each of these groups at every meal.

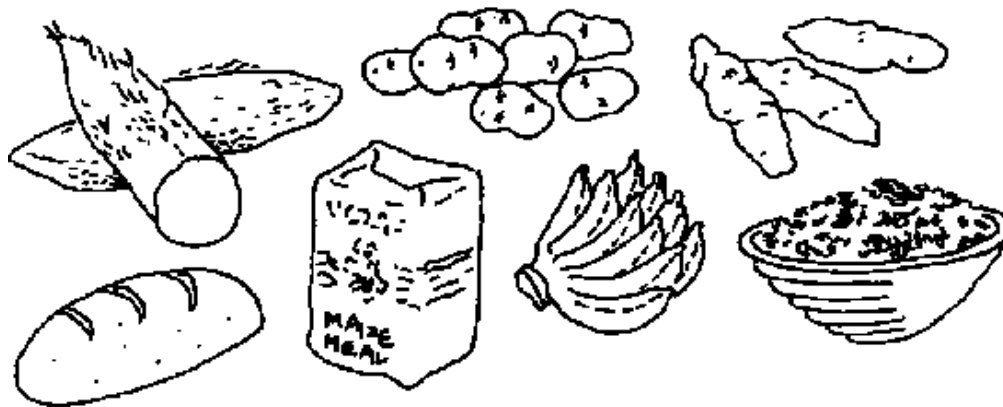
1. Body-building foods: These include peas or beans, soya, groundnuts, nuts, eggs, meat, fish and milk.

These foods are rich in protein and contain iron and calcium.



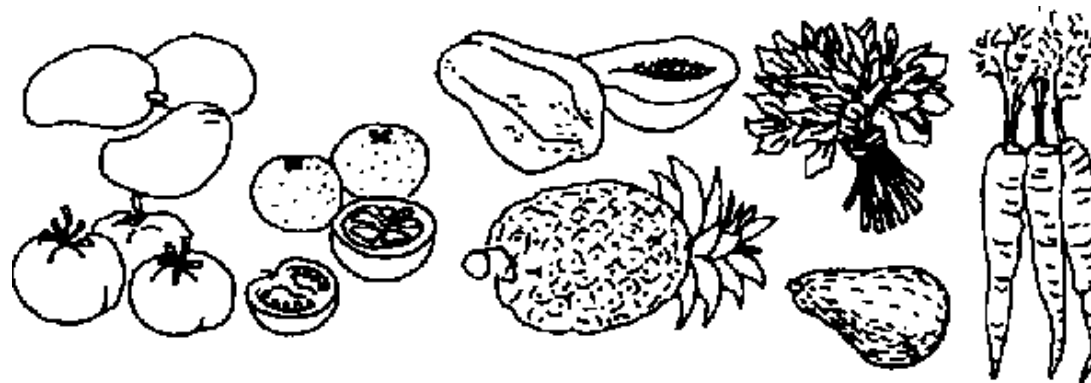
Figure

2. Energy-giving foods: These include potatoes, yams, cassava, taro, plantains, sugar, wheat, rice, millet, maize, animal fats and vegetable oils.



Figure

3. Foods that protect the body from infection (vitamin-rich foods): These include all fruits and vegetables. Dark green leafy vegetables are the most nutritious, then orange-coloured vegetables and fruits. Cooking for too long destroys vitamins so these foods should be cooked or steamed lightly, and the cooking water used as a soup or sauce.



Figure

As mentioned in the section on diarrhoea in this chapter, correct preparation and storage of foods should ensure that they are clean and safe and do not cause disease. This is especially important for infants.

General hints for people who are having trouble eating or maintaining their weight and strength

- **Eat small amounts often. Foods that can be eaten with the fingers are easier to manage, particularly if the person is weak.**
- **To supplement a regular diet of nutritious foods, vegetable oil or groundnut paste can be added to food.**
- **Raw vegetables are not very digestible and can easily be contaminated, so they are not advisable.**
- **If someone is experiencing nausea or vomiting, preparing the foods in liquid or semi-**

liquid form may help.

- **If persistent diarrhoea is present, use soft or mashed foods and avoid irritating foods, for example pepper and raw vegetables.**
- **Drink plenty of fluids and watch for dehydration (see the section on diarrhoea in this chapter).**
- **Taking vitamin tablets may be helpful although eating good foods is always better (see the section on medicines for nutrition problems in Chapter Six).**
- **Certain problems that decrease the appetite or the ability to eat, such as thrush or dental problems, can be treated and action should be taken before the problem gets very bad. Refer back to the section on sore mouth and throat in this chapter for more information about this.**
- **If a person is interested or has more questions, they could try to find reading materials in their own language that give further information. Many health centres have books and pamphlets on nutrition.**

Loss of appetite or difficulty in eating can be very distressing for the sick person and their family and might make them feel helpless and ineffective. It may help if they can discuss this with a health care worker. A nutritionist may also be available at the health centre to provide further information.

■ When sick people and their families must seek help

People should be encouraged to seek help if a sick person:

- **becomes dehydrated or very malnourished**
- **is suddenly unable to eat**
- **starts to have severe abdominal pain with or without vomiting.**

■ Notes on nutrition problems

Nausea and vomiting

■ Problems and possible causes

Nausea and vomiting can be an important problem for people with AIDS. These symptoms may be caused by:

- **medicines**
- **infections**
- **a problem with the stomach or intestines**
- **Kaposi sarcoma in the intestines**
- **HIV infection itself.**

In some people with AIDS, nausea and vomiting are very short-lived, and go away by themselves or after treatment of the cause. In others, they are chronic or long-lasting and become a part of daily life.

■ What to do at home

If a person is having trouble with nausea and vomiting advise them to:

- **avoid cooking smells if possible**
- **watch out for dehydration (see the section on diarrhoea in this chapter)**
- **talk to a health care worker, who may prescribe medicine to control the symptoms if they are very severe, in order to allow the person to eat. See the section on medicines for nausea and vomiting in Chapter Seven for further details.**

If someone is vomiting severely they should:

- **not eat any food or drink any fluids for one or two hours**
- **then gradually start drinking room-temperature water, oral rehydration solution, weak tea, or other clear liquids (about two tablespoonfuls an hour for two to three hours), or suck ice in small amounts**
- **then increase the amount of fluids to four to six tablespoonfuls an hour for two to three hours; the amount can be increased as desired but people should force themselves to keep taking fluids to make up for what they have lost.**

As the nausea decreases, people should increase the amount and types of foods they eat. It may be best to start with small quantities of dry, plain foods such as bread, rice or cassava.

Frequent care of the mouth will remove the foul taste and freshen it. This can include rinsing the mouth with water, or gently scrubbing the tongue and gums with a soft toothbrush or cloth at least three or four times a day, then rinsing with dilute mouthwash or lemon water rinse.

Ventilating or freshening a room may make a person feel better and less nauseated.

It is also a good idea for people to identify and reduce the things that seem to make them feel nauseated, such as specific odours, medicines, or foods (high-fat foods, for example).

A cool compress applied to the forehead, or other things which help someone to relax, may be

useful.

■ When sick people and their families must seek help

- **If vomiting occurs repeatedly and fluids cannot be kept down - in such cases the sick person is at risk of becoming severely dehydrated.**
- **If regular vomiting lasts more than 24 hours, particularly if it is accompanied by pain in the abdomen.**
- **If the person has a fever in addition to the vomiting.**
- **If the sick person is vomiting violently, especially if the vomit is dark green, brown, or smells like faeces.**
- **If the vomit contains blood.**

■ Notes on nausea and vomiting

Anxiety and depression

■ Problems and possible causes

The diagnosis of HIV infection or AIDS is a crisis for the infected person, their family and their

friends. When people receive the news of AIDS they begin to experience the psychological reactions described in Chapter Three, starting with shock. They may feel confused and that their mind is in constant turmoil. How someone reacts and behaves after this initial shock depends on many things, for example how they have dealt with stresses in their life before and what types of support they can get for emotional and social problems. Resources that are available within a culture should be used to deal with anxiety and depression.

Anxiety (a feeling of nervousness, fear and dread) and depression (a feeling of sadness and hopelessness) are normal if someone has been told that they have HIV infection or AIDS, and is trying to cope with it. It is when these feelings are very intense or last a long time, so that normal daily activities are interrupted, that they are considered abnormal.

The physical symptoms experienced with either anxiety or depression can be dramatic and may lead people to think that they are physically ill. Learning to recognize their own symptoms allows people to distinguish between those which are caused by anxiety or depression and those that may indicate the onset of an infection or illness.

Possible explanations for symptoms which resemble those of either anxiety or depression include:

- **infections**
- **side-effects of some medicines**
- **malnutrition.**

Anxiety



Figure

Anxiety, the feeling of nervousness, can have both physical and mental symptoms, including:

- **lack of appetite**
- **feeling short of breath**
- **shaking**
- **a sensation that the heart is pounding**
- **sweating**
- **tingling sensations, for example in the hands**
- **feeling faint**
- **difficulty in sleeping**
- **a feeling of being out of control**
- **difficulty in concentrating**
- **feeling very worried**
- **feeling jumpy.**

Other symptoms include headache, which is discussed in the section on pain.

□ Depression



Figure

When someone has HIV infection or AIDS they experience many losses in a very short period of time. Examples of this might include loss of health, loss of physical beauty, loss of job or ability to function in the community, loss of mobility, loss of eyesight. For all these losses a person must grieve and will at times feel very unhappy. A person may experience depression in the following ways:

- **a feeling of hopelessness**
- **feeling tired and generally without energy**
- **inability to find pleasure and the sense that everything is a chore**
- **irritability**
- **inability to concentrate and poor memory**
- **waking up early in the morning or having trouble getting to sleep at night**
- **eating too much or being unable to eat.**

Everyone gets depressed from time to time. Certainly if someone is facing AIDS it is likely they will be depressed for hours or even days at a time. Periods of depression may come and go, alternating with periods when the person doesn't feel depressed at all.

Depression can be more than a passing mood and is something to be concerned about if it occurs very frequently or is very intense. This sort of depression can make it difficult to deal with everyday life, and ultimately can lead people to harm themselves or to consider suicide, especially those who are isolated and those who have suffered considerable losses and stress.

■ What to do at home

Treatment of anxiety and depression varies from culture to culture. In many communities, support for such problems is often provided by trusted elders in the family and through traditional systems. Together with the suggestions made below, as a health care worker you should help people with AIDS to find the best support in the community.

Chapters Three and Four provide information on emotional support including psychological support and care of the dying. This information will also help you to provide care for anxiety and depression.

The process discussed in the section on psychological reactions to AIDS in Chapter Three is very important here. You can give people an opportunity to progress through the stages of grief simply by encouraging them to talk, and then by listening to them. It is not expected that you will have answers; it is enough that you are there. Encourage them to express their thoughts and feelings.

If you are aware of others in the community with AIDS or with any other chronic or terminal illness who have adjusted to their life and are willing to speak about it, consider finding ways for them to be in contact with those who are anxious or depressed. This peer contact can be a great support and inspiration.

The support you can give people with AIDS will also depend on the resources that the family

and the community have to address major concerns such as child care, finances and transport. Become familiar with any support groups in your community or region which can provide help to people with AIDS and those who care for them. If no such groups are available, start one!

Help sick people plan activities on a daily or weekly basis. This can help them to fight the sense that their life is out of control or that they cannot accomplish anything. The important point here is that these plans should be realistic in terms of the person's abilities and time.

Encourage sick people and their family members to learn how to relax. This is a skill that takes time to master, but it can be very helpful. It is good to have both physical and mental relaxing activities.

Although alcohol and other "drugs" may seem to help people relax, if used in excess they may actually result in a worsening of the anxiety and depression over time.

The use of medicines for treating the symptoms of anxiety can be very helpful and may make an enormous difference to someone's ability to function. However, such medicines can have serious side-effects so their use should be carefully supervised.

■ When sick people and their families must seek help

- If the family or the patient believe that the anxiety or depression is severe enough that the patient may commit suicide, otherwise harm themselves, or harm someone else.**
- If there is a prolonged disruption in the sick person's ability to function, such as in sleeping, eating, relating to their family or friends, or going about their daily life, that is not explained by any physical disability they may have.**

■ Notes on anxiety and depression

Pain



Figure

■ Problems and possible causes

For some people in the later stages of AIDS, pain becomes a part of daily life. For others it is only occasional and easily controlled. The causes of pain are many and include:

- **immobility**

- **infections, such as herpes zoster**
- **swelling of the extremities (caused by poor circulation brought on by Kaposi sarcoma or problems with the heart)**
- **headache alone or associated with meningitis or encephalitis**
- **nerve problems including pain with or without weakness**
- **psychological or emotional causes such as depression and anxiety which may increase the sense of being in physical pain.**

■ **What to do at home**

In attempting to control and relieve pain, people will need to know that pain is also influenced by the person's emotional state and can be frightening. The sick person may need extra reassurance and care.

Encourage people to look out for any clues as to what increases or relieves pain.

People can take an active role in controlling their pain. For example by:

- **learning deep and regular breathing techniques, which may help them to relax**
- **learning to deal with pain through distraction and lessening of their anxiety - see the section on anxiety and depression in this chapter**
- **taking medicines for pain according to an organized schedule - this can help people to feel more in control and reassure them that the pain will not become too great before medicine is taken**
- **engaging in physical activity or receiving gentle massage - both of these can be helpful for some types of pain**



Figure

- **imagining or remembering a favourite place or event.**

A person may experience a strong burning sensation, particularly in the hands or feet, which may be due to nerve problems. This type of pain is made worse by extremes of temperature, touch (even clothing or bed sheets) and dryness. The pain is sometimes relieved by putting the legs and feet in water. If the skin seems to be sensitive, then people should plan things so that all the care and activities that require touching are done at the same time, to allow for periods of rest in between. The sick person's bed can be lined with soft blankets or cushions.

If a person experiences any swelling, they should raise their legs or swollen parts on pillows, or raise the foot of the bed on blocks. They should also keep changing their body position.

Treatment for pain of all types may include mild medicines for pain (analgesics) which are commonly used in the home, such as:

- **aspirin**
- **paracetamol.**

There are other stronger medicines which people can take for pain but these should only be taken with the advice of a health care worker. See the section on medicines for pain in Chapter Seven for further details.

It is important that the sick person takes the mild pain medicines regularly, at least every eight hours, if the problem is long-lasting or chronic. Waiting until the pain is very severe before taking the medicine makes it less likely to work effectively.

If someone is caring for a person with AIDS who is in pain, you should give them advice which will help them to keep the environment as calm as possible. For example you could advise them to:

- **talk slowly to the sick person, and use gentle tones**
- **approach the person slowly and quietly**
- **avoid using bright lights**
- **ask others to be quiet and gentle in the presence of the sick person.**

People should also be encouraged to talk with the person, and to provide comfort and distraction from the pain, perhaps by:

- **playing favourite music quietly**
- **reading aloud or telling stories**
- **applying a cool cloth on the forehead, or giving massage**
- **asking what relieves the pain and then doing it.**

If the sick person is unable to move unaided, they should be helped to change position frequently (see the sections on skin problems, and on tiredness and weakness, in this chapter).

Some people like to be wrapped in a blanket or cloth when they are experiencing pain or to

Tiredness and weakness



Figure

■ Problems and possible causes

AIDS can often make a person feel very tired and weak, particularly in the later stages of the illness. This can have many causes and to some extent is unavoidable. It is important to advise people to do what they can to keep their strength up and not to take on activities that could be dangerous to them (like walking too far). A person's weakness and fatigue could be a result of some or all of the following:

- **HIV infection or HIV-related illnesses (particularly respiratory illnesses)**
- **poor nutrition**
- **depression**
- **anaemia.**

■ What to do at home

If no treatable infection or other problem is found, it is important for people to learn how to adjust to their limited ability. The following advice may help someone to do this:

- **See what can and cannot be done unaided. It can help a family to know when and for what things someone needs assistance, and help them to understand that there are still some things the sick person can do in the home, while other tasks may have to be given to others.**
- **Rest should be taken as often as needed.**
- **Help should be asked for, and accepted, from others. People will usually appreciate being told how they can help rather than having to guess and feel uncertain.**
- **Ways should be found of making some activities easier - for example, sitting rather than standing to bathe or cook; using a bedpan or suitable container rather than going to the toilet or latrine; buying or making a walker, cane or wheelchair.**



Figure

If someone cannot get out of bed at all they will clearly need help - see the section on skin problems in this chapter for information on the prevention of bed sores and skin problems due to prolonged inactivity. The person helping should be advised to:

- **move the sick person's arms and legs gently, several times a day**
- **turn the person from one side onto their back, or to the other side, every few hours**
- **provide a bedpan or suitable container every few hours, or more often if needed, to allow the person to empty their bowels or bladder**
- **keep the sick person's skin clean and dry.**

When someone is caring for a person with AIDS who is tired and weak they should:

Mental confusion and dementia

■ Problems and possible causes

Some degree of mental confusion (or dementia) is common among people with AIDS. These symptoms may be caused by infection of the brain with HIV. The mental changes resulting from this may be barely noticeable or they may become a serious disability.

People with AIDS may describe feeling "dulled" or "slow" in their thinking. However, it is usually the family who are the first to notice the changes.

These problems often start in a mild, barely noticeable way but may gradually worsen over time. It is not possible to predict whether the symptoms will become severe.

The mental changes may include difficulty in one or all of three areas:

- The ability to think clearly. This may be noticed as a problem in concentrating, and losing track of conversations or tasks.**
- Behaviour. The person may become irritable, disinterested or unpredictable.**
- Strength or coordination. The person may start dropping things more often, falling, or may develop slowness in movements, or shakiness.**

HIV infection of the brain is the most common cause of mental confusion in people with AIDS. However, other possible causes include:

- the side-effects of many medicines**

- **infection with numerous other bacteria, viruses, and parasites**
- **severe depression.**

■ **What to do at home**

Mental confusion can be a very upsetting and frightening problem for everyone involved. People with these problems may have moments when they realize that they are not able to think as clearly as before and will be aware of actions they have taken that were inappropriate. This is deeply distressing to them. Family members are also often very upset and not sure what to do. Support and guidance from pastors, counsellors and friends will be very important.

There is no specific treatment for these problems and people must learn to live with them and to make the sick person's environment as safe as possible. Mental confusion in the sick person, perhaps more than any other symptom, can make caregivers feel like giving up and cause them to feel overwhelmed by the demands of caring for someone they love.

A person who has a sudden change in thinking, behaviour or ability to move should seek help. Some of the sudden mental changes may be treatable and the person will recover. However, if such changes are allowed to continue, they may contribute to the rate of mental deterioration.

If it is determined that nothing further can be done, then the family will need to give whatever help they can. This will include protecting the sick person from harm.

Carers may need help to occasionally arrange time away from the home. Taking care of a sick family member for 24 hours a day, every day, is very difficult and people need their physical and emotional strength to deal with this.

□ To prevent accidents in the home, people should:

- **pay attention to open fires or boiling water**
- **provide canes or walkers for people who are weak or off balance when walking**
- **remove loose and potentially dangerous objects, including rugs**

- **keep walkways clear**
- **avoid rearranging furniture**
- **store poisonous or toxic substances safely out of reach**
- **keep medicines out of reach and only give them according to the prescribed schedule**
- **install handrails or put a chair in showers or tubs**
- **store sharp objects like knives, scissors, razors and saws safely and out of reach**
- **try not to leave the sick person alone and unattended for long periods.**

To help the functioning of the confused or demented person, people can:

- **remind the person where he or she is and what time it is - use cues to help, for example:**

- **provide reminders of daily activities in a form the person understands**
- **provide familiar objects in easily visible places, such as pictures, clocks, calendars, etc.**

- **keep a calm, accepting and open manner when dealing with the person**
- **be aware of their actions and consciously slow down and relax**
- **speak slowly**
- **use a low-pitched tone of voice - this is reassuring**
- **ask questions that can be answered "yes" or "no"**
- **give simple short directions, or explanations to questions**
- **be concrete and specific**
- **give the person lots of time to respond to questions, directions or conversation**

- **try to interpret the feelings the person is trying to express rather than just the words**
- **talk about the distant past - the person's memory of events that happened long ago may be good and this will be pleasurable.**

People should avoid:

- **arguing, as it will not convince the person and may only upset him or her**
- **directly challenging the sick person's delusions or fantasies; it is better to cast doubt in a kindly way**
- **giving the person multiple tasks; instead give the person one thing at a time to do**
- **talking to the person as if he or she is a child**
- **giving choices, as this can be confusing.**

To help a confused person who is upset or angry

Distraction is helpful; for example people can:

- **change the subject**
- **provide music or switch on the radio**
- **give the person a manual task, e.g. folding clothes**
- **leave the room for a few minutes; the person may forget why he or she is angry**
- **remove the person from an upsetting situation.**

The following may also help:

- **maintaining a quiet environment**
- **setting limits**
- **saying "no" gently, but firmly**
- **not challenging or responding to the content of the angry words directed at the caregiver or others.**

When sick people and their families must seek help

considering pregnancy or have already become pregnant.

Again the advice is presented in a way that is designed to help you to advise an adult with AIDS - or the family - using the same headings as in Chapter Five.

Tuberculosis

■ Problems and cause

Tuberculosis is a chronic (long-lasting), contagious disease that is caused by a bacterial infection. It can be cured with the correct treatment. It most often strikes young adults (15-35 years old), especially those who are weak, poorly nourished, or who live with someone who has the disease.

Tuberculosis usually affects the lungs and causes coughing and spitting. When it is severe people may cough up blood. Especially in children, young people and those with AIDS, tuberculosis can also affect the bones, brain, lymph nodes and other parts of the body. The symptoms of tuberculosis can appear in many different ways, as indicated below.

In many parts of the world, by the time they reach adulthood most people have been infected by the bacterium that causes tuberculosis (*Mycobacterium tuberculosis*). However, if they are healthy their body's defences - the immune system - will have prevented the bacteria from causing tuberculosis. In this case people are usually unaware that the tuberculosis bacteria are in their body, and they feel well.

The relationship between tuberculosis and HIV can be summarized in the following way:

A. If someone has HIV infection they are more likely to get tuberculosis.

The damage to the immune system caused by HIV means the immune defences are weakened and that they can no longer keep the tuberculosis bacteria from making a person ill. The tuberculosis bacteria, which have remained quiet in the body for years in some people, now cause the disease called tuberculosis.

B. *If someone has HIV infection the symptoms of tuberculosis can be usual or unusual.*

In communities where tuberculosis is very common, most people can readily recognize the disease. The most common symptoms include:

- **chronic cough (lasting more than three weeks), which is often worse just after waking up, and may involve coughing up blood**
- **loss of weight and increasing weakness**
- **mild fever**
- **sweating at night**
- **pain in the upper back or chest**
- **loss of appetite.**

If someone has AIDS, they may also develop less usual tuberculosis symptoms, such as fever without a cough. Tuberculosis can also infect the lymph nodes, especially in children - most often those in the area of the neck and shoulders. These infected nodes may become large lumps under the skin which open and drain pus, close for a time, and open and drain again.

C. *Tuberculosis should be suspected if someone has AIDS and has respiratory or chest symptoms.*



Figure

Because the possibility of having tuberculosis is so high if a person has AIDS, all people with AIDS and respiratory, chest or general symptoms which do not go away within three weeks should go to a health care worker to be tested for tuberculosis. This is particularly true if someone lives in an area where tuberculosis is common. As tuberculosis is treatable with medicines, is highly dangerous if not treated, and can be passed on to others, it is important for people to get a prompt diagnosis through a sputum examination and/or a chest x-ray.

D. HIV infection and AIDS should be considered in every person with tuberculosis.

Because tuberculosis and AIDS have been shown to accompany each other very often, in many areas of the world it is possible that if someone has tuberculosis they are also infected with HIV. People with tuberculosis should consider asking their health care worker to test them for HIV if this has not already been suggested.

■ What to do at home

Tuberculosis prevention

As a first step people should be advised to follow the principles for preventing tuberculosis

which are presented in the following box.

Some Principles for Preventing Tuberculosis

- Everyone - without exception - should seek early assessment and health care if coughing for three weeks or more.
- Everyone - without exception - should cover their mouth when coughing.
- Everyone - without exception - should avoid being in an unventilated space with a person who has been coughing for more than three weeks.
- All homes, health facilities, workplaces and other places where people meet should be ventilated - make sure there is a way in and a way out for fresh air.

In addition, all newborn babies and young children should be immunized against tuberculosis with BCG vaccine. This may cause a spot or slight wound at the point of injection which will usually heal in some months without any treatment. The vaccine gives good protection against the serious childhood forms of the disease. However, if a child is ill at birth or has clinical symptoms of AIDS (see Chapter Three), they should not receive BCG vaccine.

Tuberculosis is contagious, particularly when there is prolonged contact with a person with the disease. Those people - and especially children - who live in the same house with someone who has tuberculosis run a risk of becoming infected. To prevent tuberculosis from spreading to others, the whole family should be asked if they have a cough and should have their sputum tested for tuberculosis at the health centre, if necessary.

Tuberculosis treatment

There are many effective treatments available to cure tuberculosis. Treatment always includes at least two different medicines. If only one is used, the tuberculosis bacteria may become resistant (insensitive) to it. Treatment stopped too early is dangerous to both the individual and

the community because this, too, can lead to the development of tuberculosis bacteria that are resistant to drugs. Drug-resistant tuberculosis is much more difficult and expensive to cure. Therefore, it is vitally important to ensure that people take all the medicines they are given for the treatment of tuberculosis, and that they complete the full course. Such medicines, if taken properly, will prevent this infection from spreading among people who live together.

In some countries, treatment for tuberculosis is nearly always started in a clinic or hospital and few people are treated at home. This is because of the type of medicines used and because of the need to be absolutely certain that individuals take their medicines.

Before leaving the clinic or hospital, people should be instructed on how to take the medicines at home, and should be encouraged to ask for clear instructions. When a person returns home, they should have enough anti-tuberculosis medicines to last for about one month or at least until their next scheduled clinic appointment. After returning home from the clinic or hospital, people should be seen by a health care worker and be given a new supply of medicines every month.

It is very important that the medicines are taken regularly, exactly as prescribed. People taking anti-tuberculosis medication will begin to feel better but must still take their medication until the course is completed, otherwise symptoms will reappear and they will again become infectious to their family. Family members can help patients take their medication by reminding them. This is important to the whole family and not only to the patient with tuberculosis. It can take many months to cure tuberculosis completely. Nobody should ever stop taking their medicines, even if they feel better, unless instructed to do so by a health care worker, or unless the side-effects described below, such as reddening of the eyes, unusual itching or a widespread rash, appear.

The medicines given for the treatment of tuberculosis are very strong and may have severe side-effects. It is very important to know about these (see the section on medicines for tuberculosis in Chapter Seven for further details). If a person has any reactions to their medicines, such as reddening of the eyes, unusual itching or widespread rash, they should stop taking the medicines and return to the health care worker who prescribed them as soon as

possible.

IMPORTANT

Be sure that people with tuberculosis know:

- which medicines they must take to cure tuberculosis
- how to take the medicines
- for how long they need to take them
- what side-effects they should watch for
- that prompt, complete treatment will cure tuberculosis
- that prompt, complete treatment is the best way to prevent further spread

Anti-tuberculosis medicines are also expensive. Most governments have programmes that provide them free or at reduced cost. If people are having trouble with the cost you may be able to get help through the government or non-governmental assistance agencies.

If the main problems experienced are with breathing, people should avoid the things that can make their symptoms worse, for example, anxiety, strenuous activity, smoke, dust, aerosol sprays and smoking of any type. People should also avoid lying flat, and instead should sit up or lie with their head raised. See the section on "Coughing and difficulty in breathing" in Chapter Five for more specific information.

■ When sick people and their families must seek help

- **If the sick person has AIDS and has a cough or other signs that suggest they might also have tuberculosis.**
- **If the sick person has a reaction to the anti-tuberculosis medicines, such as a reddening of the eyes, unusual itching or a widespread rash.**

Though there are many aspects of HIV transmission during pregnancy that doctors and scientists do not yet understand, some information is available that can help women to decide whether or not to start a pregnancy, or to prepare women for the possible consequences of pregnancy.

If a woman is infected with HIV and becomes pregnant, her risk of having an HIV-infected child is approximately one in three. Some children who become infected are infected in the womb, some during delivery, and some through breast-feeding.

If a woman has AIDS, she is in addition more likely to have a "complicated" pregnancy, with problems during the pregnancy itself, during delivery of the baby, or after the birth. Such problems may include:

- **miscarriage - loss of the baby during pregnancy**
- **fevers and infections**
- **premature labour - delivery occurring earlier than it should, often causing the death of the baby**
- **a smaller baby - the weight at birth of even a full-term baby can be much lower than normal; babies with a low birth weight are more likely to have subsequent problems**
- **infections after birth - these are much more common in women with AIDS and can be life-threatening; women who are HIV-positive might have unexpected severe infections after delivery (puerperal sepsis) which do not respond to the usual treatments with antibiotics.**

■ What to do at home

Antenatal care

All pregnant women should receive antenatal care during pregnancy. This is even more

important if they have AIDS. Women should be advised to follow the routine recommendations for all pregnant women - these are:

- **The mother should eat for herself and for her growing child. She should eat from the three main groups of foods described in the section on "Nutrition problems" in Chapter Five.**
- **Good hygiene should be practised including the general practices discussed in the section on "Avoiding other infections" in Chapter Three.**
- **No medicines should be taken except those prescribed by a health care worker (women should always tell their health care worker that they are pregnant if they see them for another reason). Some medicines can be harmful to both the mother and her developing baby so it is best not to take any risks.**
- **Pregnant women should continue to be active but should not overexert themselves.**
- **Pregnant women should ensure that they are properly immunized against tetanus, to protect both themselves and the baby. Depending on previous immunizations against tetanus, a woman may need to be immunized more than once during pregnancy.**

Before delivery

You may recommend that the mother plan to deliver in a health centre or hospital. If this is not possible, then people, with the help of a health care worker, should prepare for delivery in the home so that it poses the least risk to the mother, to the baby, and to those who help with the delivery.

Advise people to prepare beforehand the things which they will need for a safe delivery. These are:

- **several large pieces of cloth for wiping and wrapping the baby (about 1 metre by 1.5 metres each)**

- **two clean ties or thick threads for tying the umbilical cord**
- **one clean new razor blade for cutting the cord**
- **one container of antiseptic solution such as iodine solution or gentian violet**
- **cotton wool or clean cloths for applying antiseptic solution to the cord stump**
- **gloves or plastic bags for the delivery assistant and for handling the afterbirth**
- **one container of clean (boiled and cooled) water for cleaning the mother, the baby and the assistant's hands and arms**
- **soap**
- **pads for the vaginal area for the mother to catch drainage following the birth - these can be made from pieces of old but clean cotton cloth**
- **warm clean clothing for the baby following birth**
- **clean clothing for the mother to change into after the delivery.**

Make sure that anyone who is helping in a delivery knows that they must cover any open wounds on their skin.

After delivery or miscarriage good hygiene should be carefully followed, especially in the genital area. Washing with soap and water should be done twice dally.

Breast-feeding

Breast milk has many benefits. It contains substances which protect the infant against infections. It is the best possible food for infants. In addition, breast-feeding helps postpone further pregnancies. Also, since breast milk is clean, the infant is not at the same risk of getting

infections and diarrhoea as with breast-milk substitutes. Unfortunately, it is true that HIV can be transmitted during breast-feeding.

With the help of a health care worker, women will have to weigh up the possible risks of breast-feeding their child, taking into account such things as:

- **whether they have AIDS**
- **whether many of the children in their area are sick, or die from infections unrelated to AIDS, or from poor nutrition**
- **whether an alternative to breast milk is available to them which is clean, nutritious and affordable throughout the time it will be required.**

The risk of transmission of HIV by breast-feeding may be low compared to some of the other risks to which a baby is exposed if it is not breast-fed. Thus it is recommended that, if a woman lives in a place where many children die at a young age from infectious diseases (like respiratory infections or diarrhoea), she should breast-feed her infant, even if she is infected with HIV or has AIDS.

However, if a clean, safe, affordable and nutritious substitute for breast milk is readily available and will be readily available for the entire period it will be required, then women should be encouraged to discuss this with a health care worker before making their choice. If they decide to feed their baby using breast-milk substitutes (infant formulas) rather than breast milk, they must use clean water (boiled, then cooled), and clean equipment (teats and bottles). Also, they must be sure that when they prepare the breast-milk substitute they do so in the right concentration. They must follow the directions and must not mix the formula with more water than is recommended in an effort to save money. This can lead to malnutrition in their child. If all the things mentioned here cannot be done all of the time, then women should breast-feed their child.

A woman, usually with her partner, might wish to seek counselling for the following reasons:

- **to decide whether to become pregnant or not**
- **to discuss methods of contraception and other forms of fertility regulation**
- **to manage a pregnancy**
- **to plan for an infant.**

In addition, as with all women, she should seek antenatal care regularly throughout the pregnancy.

■ **When women and their families must seek help**

During pregnancy, a woman should be advised to seek help immediately if she:

- **begins to pass blood**
- **has fevers**
- **experiences a sharp pain in her abdomen.**

After delivery or miscarriage help should be sought if the woman:

- **develops a fever**
- **has bad-smelling vaginal discharge**
- **has vaginal discharge with fresh blood.**

■ **Notes on pregnancy**

Chapter Seven: General guide on the use of medicines

People seeking a cure for AIDS may spend a lot of money on medicines from shops, health care workers and traditional healers. Unfortunately much of this money is wasted because such medicines are not effective, may cause other problems, and use up money that would be much better spent on food, clothing, or other essential items for all the family.

This chapter provides the information you need in order to teach people how to use medicines safely and effectively. It also provides a brief description of the medicines commonly used to treat symptoms that occur in people with AIDS.

Please note that not all the medicines listed in this guide are needed in a medicine kit or in the home. Because different medicines are available in different countries, information has sometimes been given number of medicines that do the same job, It is wise to:

Keep and use only a small number of medicines

(It is best to use familiar medicines that you understand well.)

Teaching notes on the use of medicines

It is essential that anyone taking medicines (whether prescribed or bought from a shop) follows the instructions for their safe and effective use. Medicines not taken according to instructions can be useless or even harmful, causing further illness. It can be very confusing for a person and their family when they are provided with several different medicines, all with different instructions. You must make sure that your patients and their families know how to take the medicines you recommend.

There is some danger in the use of any medicine.

Whenever you recommend a medicine, it is a good idea to give the patient and the family written instructions. This can be useful to anyone involved with the care of a sick person.

Someone can always be found to read it. You should explain the instructions and ask the patient or members of the family to repeat them to you. Make sure they understand. Below is an example of a written schedule.

To help remind people who cannot read when to take their medicine, you can give them a note like this:



Figure

In the blanks below the pictures, draw the amount of medicine they should take and explain carefully what it means.

Here are three examples:

(a) This means one tablet four times a day: one at sunrise, one at noon, one at sunset, and one in the middle of the night.

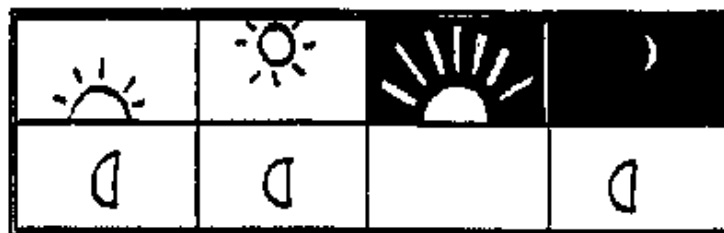


Figure

Written medicine schedule				
Name of	Purpose	Description	When to give	Comments

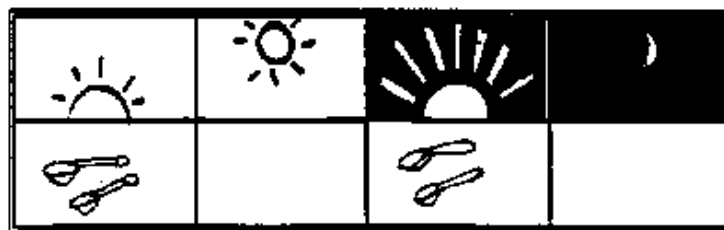
medicine				
Aspirin or paracetamol	for fever, headaches, pain	white tablet	take 1 or 2 at least every 8 hours	take with meals or food
Calamine lotion	for itching and irritated skin	tan liquid	apply to skin as necessary	do not take by mouth

(b) This means half a tablet three times a day.



Figure

(c) This means two teaspoonfuls twice a day.



Figure

■ How to use medicines

People may have been advised to take medicines by a health care worker or may have decided to buy their own medicines without such advice. In either case, people must know how to use medicines correctly to get the most benefit from them and to avoid any harmful effects.

□ How can people learn about medicines?

You, the health care worker, should give people the information they need to know. The people who sell medicines may also be helpful but remember, their primary goal is to make money through selling. Instructions about taking any medicine and the name of the medicine should be written on the container it is sold in.

For any medicine a person has been given, they should know and understand the answers to the following questions:

- **Why has it been prescribed?**
- **How will it help them?**
- **How should it be taken?**
- **For how long should it be taken?**
- **What side-effects, if any, should they watch for?**

The ability to use medicines correctly is very important for health and safety. All labels should be checked by the person before they leave the health centre or shop. If the label says:

- **Keep cool - the medicine should be kept out of sunlight and out of damp places.**
- **Shake - the medicine should be shaken for a full minute before measuring out each dose.**

How should medicines be taken?

It is important to take medicines as near as possible to the time recommended. Some medicines should be taken only once a day, but others must be taken more often. If the person does not have a clock, it does not matter. If the directions say "1 tablet every 8 hours", they should take three a day: one in the morning, one in the afternoon, and one at night. If they say "1 tablet every 6 hours", they should take four a day: one in the morning, one at midday, one in the afternoon, and one at night. Before they leave the health centre or the shop with the medicine they must be sure they understand how often to take it. If the directions say:

- **On an empty stomach - the medicine should be taken at least one hour after a meal, or**

30 minutes before a meal.

- **With meals - this can also mean with snacks. People should make sure that they have eaten something before taking the medicine.**

If vomiting occurs immediately after taking a medicine, the dose should be taken again. But if the vomiting occurs 20 or more minutes after taking the medicine, the dose should not be repeated.

☐ Advice for people who are giving medicines to children

- **Liquid medicines can be squirted slowly into the side of the child's mouth with a dropper or syringe, or poured from a spoon.**
- **Always praise a child after he or she has taken medicine.**
- **If the medicine tastes bad, tell the child so in advance.**
- **If a pill cannot be swallowed, crush it and mix it with the smallest amount possible of something the child likes to eat. However, do not "hide" medicine in food or the child may begin to refuse food.**
- **If the child vomits immediately after taking a medicine, give the dose again. But if vomiting occurs 20 or more minutes after taking the medicine, do not repeat the dose.**

☐ Medicines to be used with caution in people with AIDS

There are certain medicines that can have more side-effects, or can cause more problems, in people with AIDS. People should be aware of which these are so that they can watch for any reactions they might have to them. They include medicines commonly given to treat infections, and medicines that are used only rarely:

- **the anti-tuberculosis medicine, thiacetazone, often called "thiazina"**

- **sulfonamides**
- **steroids.**

Steroids (such as cortisone and hydrocortisone) deserve special mention. These medicines suppress the immune system and so they are particularly dangerous for people with AIDS because their immune system is already weakened by the disease. Steroids worsen the problems that come with AIDS by reducing even further the body's ability to fight off common infections. People with AIDS should only take steroids after very serious consideration by a medical doctor. They should only take them as part of the treatment for another problem.

Which medicines should people use?

The next section describes the medicines that might be used at home for treating the symptoms that can develop in people with AIDS. They are grouped here according to the symptoms they are used to treat. For example, medicines used to treat pain are listed under the heading, "Medicines for pain". The symptoms themselves and how they can be treated at home are described in Chapters Five and Six.

Medicines commonly used to treat symptoms in people with AIDS

Medicines in this section are listed under each heading according to their generic names (scientific names) rather than their brand names (the names given by the manufacturers). Medicines are described under the following symptoms:

- **Medicines for infections:**

- *antibiotics*

- **Medicines for fever:**

- *aspirin*

- *paracetamol*

- **Medicines for diarrhoea:**

- Acute**

- *oral rehydration salts*
 - *antibiotics*

- Persistent**

- *adsorbents*
 - *antimotility medicines*

- **Medicines for skin problems:**

- General**

- *calamine lotion*

- Bacterial infections**

- *gentian violet*
 - *potassium permanganate*
 - *hydrogen peroxide*

- Yeast infections (oral and vaginal)**

- *gentian violet*
 - *ketoconazole*
 - *nystatin*

- *clotrimazole*
- *potassium permanganate*

- **Medicines for nutrition problems:**

- *vitamin and mineral supplements*

- **Medicines for nausea and vomiting:**

- *anti-emetics*

- **Medicines for pain:**

- *aspirin*
- *paracetamol*
- *narcotic painkillers*

- **Medicines for tuberculosis:**

- *streptomycin*
- *isoniazid*
- *ethambutol*
- *thiacetazone*
- *rifampicin*
- *pyrazinamide*

■ Medicines for infections

□ Antibiotics - a general guide

Almost every person with AIDS will be given an antibiotic at some point during his or her illness to fight an infection.

When used correctly antibiotics are extremely useful and important medicines. They fight certain infections and diseases caused by bacteria. Well-known antibiotics are penicillin, tetracycline, cotrimoxazole and chloramphenicol. The sulfonamides have a similar effect and are also considered here. It should be noted that medicines containing sulfonamides can cause severe allergic reactions in people with AIDS, such as unusual itching or widespread rashes.

Different antibiotics work in different ways against specific infections. All antibiotics have dangers in their use, but some are far more dangerous than others. Great care must be taken in the choice and use of antibiotics:

- People should never take an antibiotic unless it has been prescribed by a health care worker for a specific reason. Left-over antibiotics should not be used to treat a new infection.**
- People must continue to use the antibiotics they have been prescribed for the full length of time they are told. Some illnesses, like tuberculosis, need to be treated for many months or years after the person feels better.**
- If the antibiotic causes a skin rash, itching, difficulty in breathing, or any other reaction, people should stop using it and immediately contact a health care worker. If these reactions do occur people should always mention this to the health care worker who prescribes medicine for them. People should be encouraged to remember the name of any medicine they have a bad reaction to so that they can tell a health care worker in the future.**
- The antibiotic should only be used at the recommended dose - no more, no less. You should explain to people that the dose depends on the illness and on their age or weight, and that increasing or decreasing the dose can be harmful, or can make the medicine useless.**
- Antibiotics can kill bacteria. However, not all bacteria are harmful and antibiotics often kill good bacteria along with the harmful ones. For example, people with AIDS given**

antibiotics often develop fungal infections of the mouth (thrush - see the section on "Mouth and throat problems" in Chapter Five), skin or vagina (see the section on "Genital problems" in Chapter Five). This is because the antibiotics kill the bacteria that help keep the fungus under control in the body. Similarly, certain antibiotics may lead to diarrhoea - the antibiotics kill some of the bacteria necessary for digestion, upsetting the natural balance of bacteria in the intestines.

- **When antibiotics are used incorrectly, they become less effective. When attacked many times by the same antibiotic, bacteria become stronger and are no longer killed by it. They become resistant to the antibiotic. For this reason, certain diseases like tuberculosis can become more difficult to treat over time if the antibiotics for them are not used in the right way.**

■ Medicines for fever

These include aspirin and paracetamol. The recommended doses for these medicines are given in the section on medicines for pain in this chapter.

■ Medicines for diarrhoea

□ Treatment of acute diarrhoea

Oral rehydration salts (ORS). For diarrhoea with no blood in the stools, no specific medicines are needed. An oral rehydration solution made with ORS is the best means of preventing dehydration resulting from diarrhoea. See the section on "Diarrhoea" in Chapter Five for instructions on how to prepare ORS solution.

Antibiotics are effective against only some of the diarrhoea-causing organisms. When they are effective their benefit should be seen after 2 days and the medicine should be continued as prescribed. If not effective, the person should be advised to seek additional care. Prolonged or frequent use of antibiotics may increase the resistance of some disease-causing organisms to antibiotics. Also, antibiotics are costly, and should only be used when most effective. Therefore,

antibiotics should not be used routinely. They may be appropriate for the treatment of dysentery, cholera, and some infections common in people with AIDS, but this should be determined by a health care worker.

Treatment of persistent diarrhoea

Relieving the symptoms of persistent diarrhoea, especially in people with AIDS, can be a difficult task. The diarrhoea does not usually have a known cause and when it begins to interfere with normal activity, eating, or is very emotionally burdensome, a health care worker may prescribe specific medicines. In addition to ORS, the medicines most commonly used are:

- **Adsorbents, such as kaolin, pectin and activated charcoal.**
- **Antimotility medicines, such as tincture of opium, loperamide and diphenoxylate.**

These can be dangerous when used in children less than 5 years of age, and should not be used in this age group. In adults these medicines may temporarily reduce cramps and pain, but may also delay elimination of the organisms causing the diarrhoea, and therefore prolong the illness. When used by adults, directions should be given carefully to avoid overdose. Possible side-effects include:

- **dryness of the mouth**
- **sleepiness**
- **loss of coordination**
- **blurred vision**
- **a gaseous distended abdomen.**

Medicines for skin problems

General

Calamine lotion may be rubbed on the skin to soothe itching or irritation. It should never be taken by mouth.

Bacterial infections

Gentian violet comes as a ready-made solution or as dark blue crystals that should be mixed with clean water to make a solution. To use the crystals, people need to dissolve one teaspoonful in half a litre of water. This medicine helps fight certain skin infections, and has many uses.

Potassium permanganate comes as dark red crystals. It makes a good antiseptic (bacteria-killing) solution for soaking infected sores. A pinch of the crystals should be added to one litre of clean water or one teaspoonful in a four to five litre bucket of water for soaking infected sores.

Hydrogen peroxide comes as a liquid. It should be kept in a dark bottle, as the light destroys its effect. This medicine helps to clean deeply infected wounds on the skin.

Oral yeast infections (thrush)

Before using home remedies or medicines prescribed by a health care worker, a person should try cleaning the mouth with a soft toothbrush and then rinsing with salt water or lemon juice. Next, people can use gentian violet or potassium permanganate. See the section on "Mouth and throat problems" in Chapter Five.

The medicines most commonly prescribed by a health care worker for treatment of oral fungal infections are antifungal agents such as nystatin or clotrimazole. A solution or suspension should be held in the mouth for at least one minute and then swallowed. Lozenges should be sucked in the mouth until dissolved. It may be necessary to take these medicines three or four times a day.

In some people, the thrush involves not only the mouth but the entire esophagus, causing pain on swallowing and a burning sensation in the chest. Treatment for this can be provided by a health care worker and includes antifungal medicines such as ketoconazole which is taken by mouth every 12 hours for 14 days.

☐ Vaginal yeast infections

Antifungal agents (creams or suppositories) may be prescribed to cure vaginal yeast infections. These should be used once or twice a day for 5-7 days. It may help to line underclothes with cotton cloth of some sort since the medicine will drain from the vagina.

■ Medicines for nutrition problems

Vitamin and mineral supplements come in many forms, but tablets are usually cheapest and work well. Injections of vitamins are rarely necessary, are a waste of money, cause unnecessary pain, and sometimes cause abscesses. Tonics and elixirs often do not contain the most important vitamins and are usually too expensive for the good they do. Nutritious food is the best source of vitamins and minerals. If additional vitamins and minerals are needed, tablets can be used but people should make sure the tablets contain the important vitamins and minerals they need.

With standard "multivitamin" tablets (tablets that contain several different vitamins), one tablet each day is usually enough. Vitamins should be taken with, or soon after, meals. In addition, pregnant women need extra amounts of iron and folic acid.

■ Medicines for nausea and vomiting

Round-the-clock treatment with medicines for nausea and vomiting (anti-emetics) may become necessary if these symptoms become a big problem. They should only be taken on the advice of a health care worker. Some have serious side-effects, for example:

- nervous system effects with trembling or inability to control the movements of the neck or eyes**
- fatigue, sleepiness and possibly depression; people taking anti-emetics should therefore not drive or operate machinery.**

■ Medicines for pain

Aspirin can be useful to reduce pain, to lower fever, and to reduce inflammation. It may also help to calm a cough and reduce itching. Aspirin usually comes in tablets of 300-500 mg and should be given to adults at least every eight hours (or two to three times per day). For someone suffering from severe joint pains a higher dose may be recommended.

Aspirin should not be used by people who have indigestion or heartburn because it can make these problems much worse. In some people, aspirin causes stomach upsets. To avoid this, aspirin can be taken with milk, some bicarbonate of soda, a lot of water, or with meals. If ringing in the ears is experienced, this is a sign that the amount of aspirin which is being taking should be lowered. Aspirin must be kept out of reach of children as large amounts can poison them.

Paracetamol is used for many of the same problems as aspirin, such as pain and fever. However, it is safer for children and does not cause stomach problems, such as ulcers, so it can be used instead of aspirin if such problems are experienced. Paracetamol, rather than aspirin, should be given to children.

Paracetamol usually comes in tablets of 500 mg and should be given at least every eight hours (or two to three times per day) as follows:

- **adults: 1 or 2 tablets (500-1000 mg)**
- **children 8-12 years: 1 tablet (500 mg)**
- **children 3-7 years: half a tablet (250 mg)**
- **children 6 months-2 years: quarter of a tablet (125 mg)**
- **babies under 6 months: one eighth of a tablet (62 mg).**

Narcotic painkillers, such as codeine and morphine, may be prescribed by a health care worker and are used only for severe pain. These medicines are addictive, which means that if someone continues to take them they may need increasingly higher doses to get the same therapeutic effect, and may find that they crave for them at times when they are not having pain. Other side-effects that may be troublesome include nausea, drowsiness, constipation, depression, fatigue and itching. Make sure that people are advised to take extra fluids to prevent

constipation if they are taking such medicines. If people are taking this type of medicine make sure they follow the directions carefully and do not drive or operate machinery.

■ Medicines for tuberculosis

Almost all countries in the world have guidelines or standard treatment protocols which they use in the treatment of tuberculosis, you should follow your country's standard treatments. This section describes the most common medicines used in the treatment of tuberculosis. At least two medicines to treat tuberculosis should always be given at the same time. This section is meant to supplement the information given in Chapter Six on tuberculosis and you should refer back to that section. The most important points about the treatment of tuberculosis are shown in the box below.

Streptomycin is given by injection. It is an important medicine for treating tuberculosis; however, it should always be used in combination with other medicines. In some places it is being used less often because there are other medicines that can be used in its place and because there is a risk of HIV and hepatitis transmission if the needles or syringes used to inject the medicine are not sterilized adequately.

The dose depends on age, weight and the severity of the tuberculosis. Treatment regimes can vary from country to country depending on the national policies adopted - for example, in some places one injection is given each day for two months, in others injections may be given two or three times a week for two months.

Great care must be taken not to give more than the correct dose. Too much streptomycin for too long may cause ringing in the ears or dizziness, particularly in people aged 50 years or more. If either of these symptoms occur, people should return immediately to the health care worker who prescribed the medicine.

Streptomycin is not suitable for use in pregnant women because it can cause hearing and kidney problems in the unborn baby. It is also unsuitable for children since they develop the side-effects more often and do not tolerate the painful injections well.

Isoniazid comes in tablet form and should be taken before the morning meal. Tablets should be stored out of direct sunlight.

Isoniazid occasionally causes liver problems. If this happens people will notice itching and the white part of their eyes turn yellow. They should return immediately to the health care worker who prescribed this medicine. In rare cases, the medicine causes anaemia, nerve pains in the hands and feet, muscle twitching or even fits. These side-effects can usually be prevented by taking a tablet of vitamin B6 (pyridoxine) every day.

Isoniazid is usually given for a long period of time, for example six months to one year, until the tuberculosis is considered completely cured.

This medicine is safe to use during pregnancy.

Ethambutol comes in tablet form.

It may cause eye problems if taken in large doses for a long time. If people notice that their eyesight seems worse, with blurring of vision or colour blindness, they should return to the health care worker who prescribed this medicine.

It is usually given once a day for two to twelve months.

Ethambutol is not advised for use in children less than six years old.

Thiacetazone often comes in tablet form and is always given in a combined form, usually mixed with isoniazid in a tablet called "thiazina".

Side-effects occur fairly frequently and include reddening of the eyes, unusual itching, widespread rashes, vomiting, dizziness and loss of appetite. In people with AIDS these reactions can be very severe. If people who are taking this medicine begin to have these types of problems they should stop taking the medicine and return immediately to the health care worker who prescribed it. In many countries this medicine is no longer used for people with AIDS because the side-effects occur so frequently in such people.

Thiacetazone is usually given once a day, for between 6 months and one year.

Rifampicin comes as single tablets of 150-300 mg or in a combined form, mixed with isoniazid, as tablets that contain 150-300 mg of *rifampicin* and 100-150 mg of isoniazid.

Rifampicin should be taken on an empty stomach, at least 30 minutes before the morning meal, since food interferes with the absorption of the medicine. It should be stored out of direct sunlight and in a dry place.

Rifampicin can be used in pregnancy.

Side-effects are not very common. This medicine may cause liver problems which can cause the white part of the eye to turn yellow. If this happens the person should return immediately to the health care worker who prescribed the medicine.

Rifampicin is likely to stain urine, tears, saliva, faeces and other body fluids an orange colour. If people notice this discoloration, they should not stop taking the medicine, as it is a normal reaction and is completely harmless.

Occasionally the medicine may cause flushing, itching, rash, fever or flu-like symptoms. If people experience any of these problems, they should discuss them with their health care worker.

Pyrazinamide comes in tablet form and should be taken in the morning with or without food.

Pyrazinamide is safe to take during pregnancy.

The most common side-effect of this medicine is joint pains. These pains tend to occur in the shoulders and are relieved by mild pain medicines. The pain usually goes away within a short period of time. This medicine may also cause liver problems which makes the white part of the eye turn yellow. If this happens the patient should return to the health centre or hospital immediately.



Aids Home Care Handbook (WHO, 1993, 178 p.)

Annexes

Annex One: Resource List

The resources listed below are publications, documents or videos that can provide very useful information and support to those working with HIV/AIDS or to those directly affected by it.

Newsletters

- ***AIDS ACTION* - (English, French, Spanish and Portuguese), AHRTAG, 1 London Bridge Street, London SE1 9SG, United Kingdom**
- ***AIDS Health Promotion Exchange* - (English), Royal Tropical Institute, Department of Information and Documentation, Mauritskade 63, 1092 AD Amsterdam, The Netherlands**
- ***AIDS-WATCH* - International Planned Parenthood Federation (IPPF), P.O. Box 759, Inner Circle, Regents Park, London NW1 ULQ, United Kingdom**
- ***World AIDS* - (English, French, Portuguese and Spanish), The Panos Institute, 9 White Lion Street, London N1 9PD, United Kingdom**

World Health Organization Documents and Publications

- WHO AIDS Series 2. *Guidelines on Sterilization and Disinfection Methods against Human Immunodeficiency Virus (HIV), 2nd ed.*
- WHO AIDS Series 3. *Guidelines for Nursing Management of People Infected with Human Immunodeficiency Virus (HIV)*
- WHO AIDS Series 5. *Guide to Planning Health Promotion for AIDS Prevention and Control*
- WHO AIDS Series 6. *Prevention of Sexual Transmission of Human Immunodeficiency Virus*
- WHO AIDS Series 7. *Guidelines on AIDS and First Aid in the Workplace*
- WHO AIDS Series 8. *Guidelines for Counselling about HIV Infection and Disease*

• ***Guidelines for the Clinical Management of HIV Infection in Adults - World Health Organization, Global Programme on AIDS, Geneva. December, 1991 (WHO/GPA/IDS/HCS/91.6)***

• ***Guidelines for the Clinical Management of HIV Infection in Children - World Health Organization, Global Programme on AIDS, Geneva, 1993 (WHO/GPA/IDS/HCS/93.3)***

• ***Consensus Statement from the WHO/UNICEF Consultation on HIV Transmission and Breast-feeding - World Health Organization, Global Programme on AIDS, Geneva. 30 April to 1 May 1992 (WHO/GPA/INF/92.1)***

• ***AIDS in Africa: A manual for physicians - World Health Organization, Geneva, 1992***

• ***AIDS Prevention Through Health Promotion: Facing Sensitive Issues - World Health Organization/Royal Tropical Institute (Amsterdam), Geneva, 1991***

• ***Supervisory Skills: "Treatment of Diarrhoea" - World Health Organization, WHO Programme for the Control of Diarrhoeal Diseases, Geneva, Revised 1987***

- ***Living with AIDS in the Community - World Health Organization/UNICEF, Geneva, 1992 (WHO/GPA/IDS/HCS/92.1 Rev 1)***
- ***The Community Health Worker - World Health Organization, Geneva, 1987 (1994 edition in press).***

Order from:

Global Programme on AIDS, World Health Organization, 1211 Geneva, Switzerland.

Other Publications

"Strategies for Hope" booklets*

*** Organizations in African countries south of the Sahara may order up to 10 copies free of charge. Requests for larger quantities will also be considered, on receipt of an explanatory letter.**

- ***From Fear to Hope: AIDS Care and Prevention at Chikankata Hospital, Zambia***
- ***Living Positively with AIDS: The AIDS Support Organisation (TASO), Uganda***
- ***AIDS Management: An Integrated Approach***
- ***Meeting AIDS with Compassion: AIDS Care and Prevention in Agomanya, Ghana***
- ***AIDS Orphans: A Community Perspective from Tanzania***
- ***The Caring Community: Coping with AIDS in Urban Uganda***
- ***All Against AIDS: The Copperbelt Health Education Project, Zambia***
- ***Work Against AIDS, Zimbabwe***

Order from:

TALC, P.O. Box 49, St Albans, Herts. AL1 4AX, United Kingdom.

Population Reports

- ***Counselling Makes a Difference* - Population Reports Series J, No. 35, Vol. XV, No. 3, November 1987**
- ***Why Counselling Counts* - Population Reports Series J, No. 36, Vol. XV, No. 4, December 1987**
- ***AIDS Education: A Beginning* - Population Reports Series L, No. 8, September 1989**

Order from:

**Population Information Program, The John Hopkins University, 527 St. Paul Place,
Baltimore, MD 21202, USA.**

International Planned Parenthood Federation (IPPF)

- ***Talking AIDS: A Guide for Community Workers* by G. Gordon and T. Klouda, 1988, Macmillan Publishers, UK (Available in English and French)**
- ***Preventing a Crisis: AIDS and Family Planning Work* by G. Gordon and T. Klouda, 1988 (A manual for workers, trainers and counsellors, available in English and French)**

Order from:

**IPPF AIDS Prevention Unit, P.O. Box 759, Inner Circle, Regents Park, London NW1 4LQ,
United Kingdom.**

General health care reference books

- ***Where There is No Doctor* by Werner, D., Hesperian Foundation, Palo Alto, CA, USA, 1992**

Order from:

The Hesperian Foundation, P.O. Box 1692, Palo Alto, CA 94302, USA.

Teaching Videos

- **TASO: Living Positively with AIDS Part I: *The TASO story* (25 minutes) Part II: *AIDS Counselling: The TASO experience* (30 minutes)**

- **The Orphan Generation**

These are Our Children (10 minutes)

The Orphan Generation (40 minutes)

Order from:

TALC, P.O. Box 49, St Albans, Herts, AL1 4AX, United Kingdom.

- **Challenges in AIDS Counselling, Ministry of Health, Zambia and USAID (with a training guide for counsellors for use with the video)**

Order from:

USA - DSR: 9650 Santiago Rd # 10, Colombia MD 21045

Tel: 410-964-0037. Fax: 410-730-8322

ZIMBABWE - MFD: 135 Union Ave, Box 6755, Harare

Tel: 729066. Fax: 729066 (nights)

KENYA - DSR (Kenya): Box 38941, Nairobi

Tel: 581332. Fax: 581332 (nights)

SENEGAL - ACI: 509 Sicap Baobab, BP 5270, Dakar-Fann

Tel: 253637. Fax: 254521

**BANGLADESH - VHSS, 273 Baitul Aman Housing, Adabar Rd # 1,
Shyamoli, Dhaka
Tel: 812962**

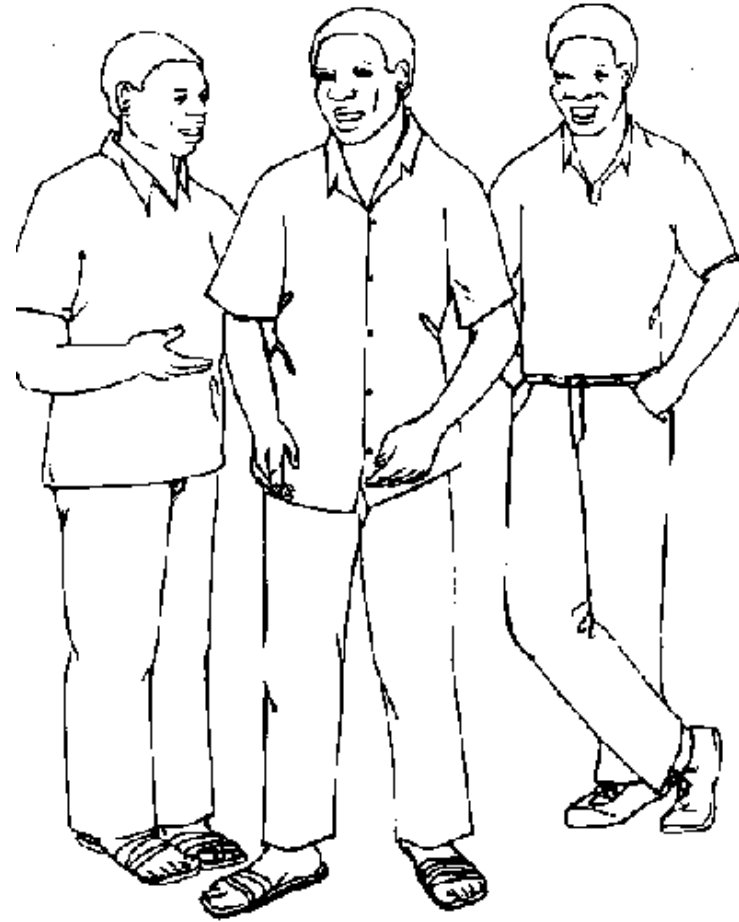
Annex Two: Pictures for Teaching

The story of Yulia and Mukasa that was presented earlier in the book shows how HIV comes into a family, and what happens over several years. The characters are shown in pictures to make it more interesting. These pictures are reproduced in the following section for use during teaching.

The original TASO story, from which this version has been adapted, used symbols to help explain the processes of HIV infection, HIV transmission and development of AIDS-related conditions - using circles for HIV infection, squares for HIV antibodies and triangles for HIV-related symptoms. If you feel this makes the story easier to explain to others, you can add these symbols to the pictures in the following section. Other possibilities are to colour the clothing in some way or try to draw what is happening inside the body but cannot be seen on the outside.



Figure



Figure



Figure



Figure



Figure



Figure



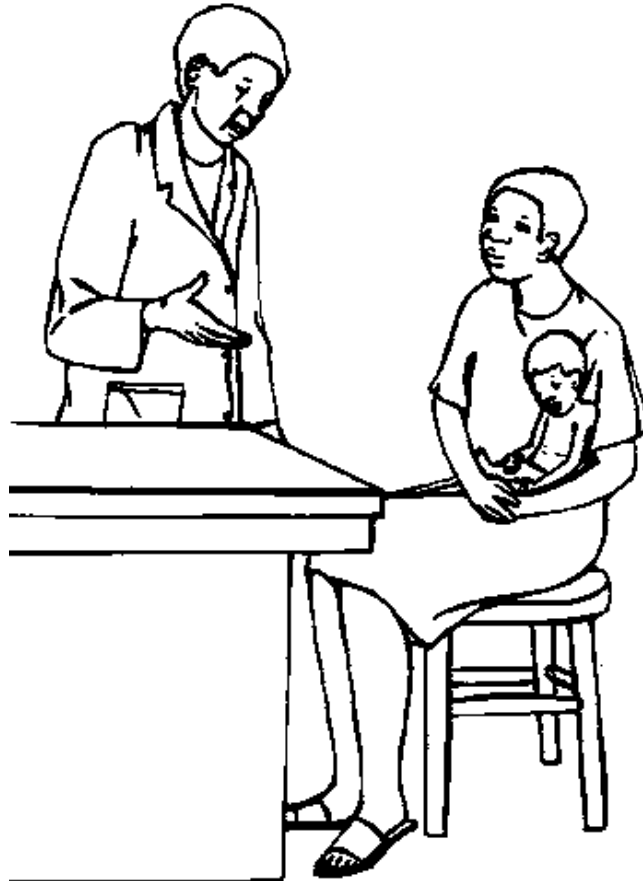
Figure



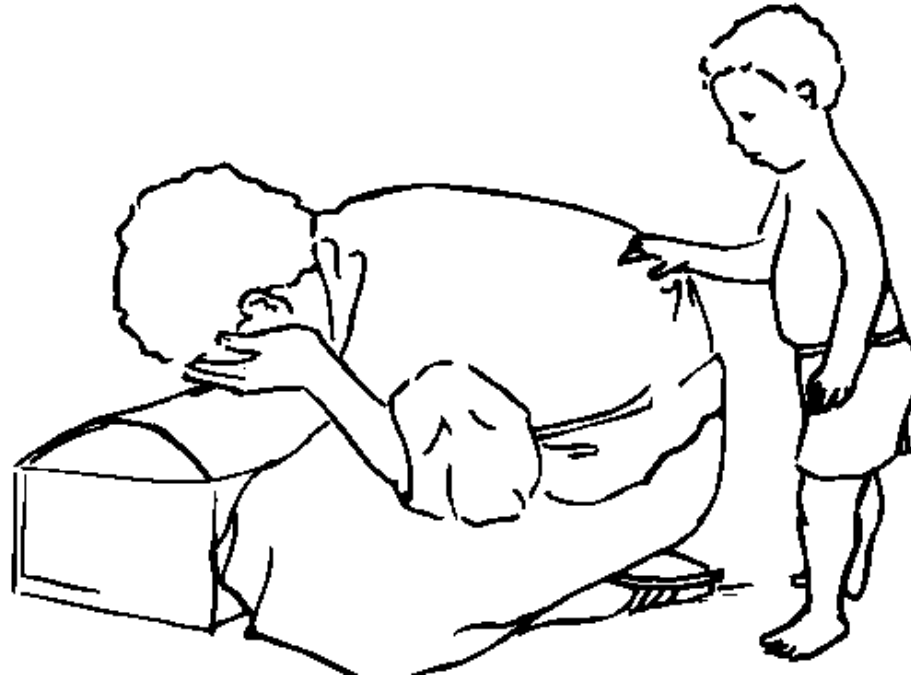
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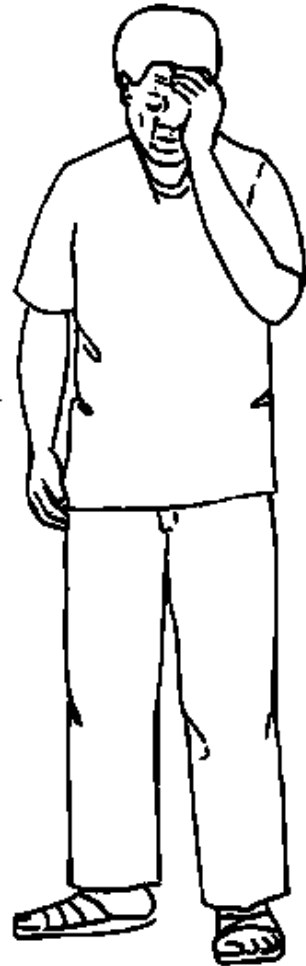
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Figure



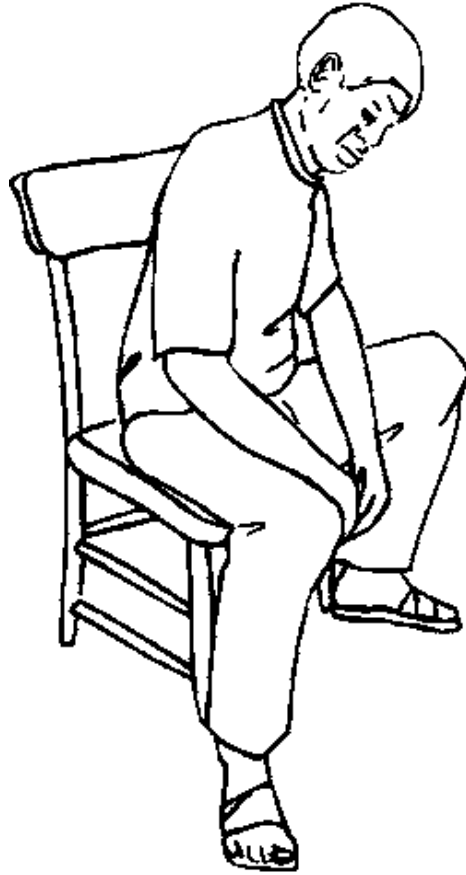
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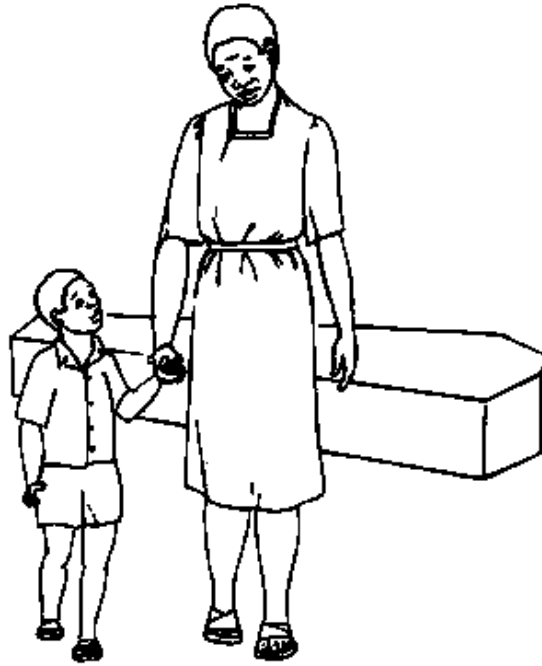
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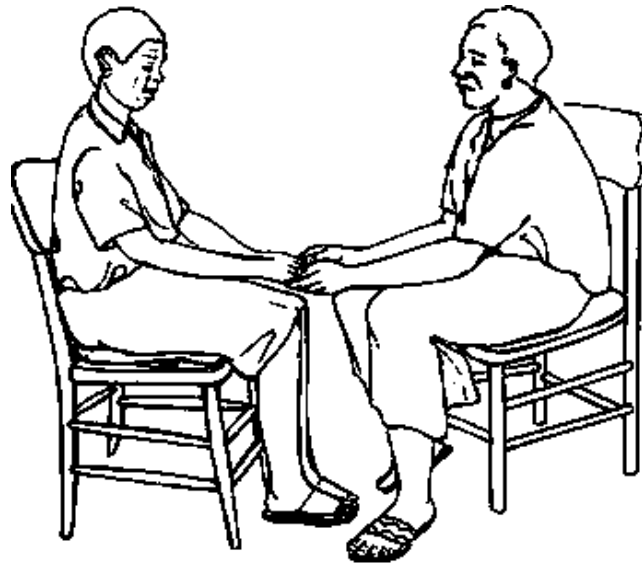
Figure



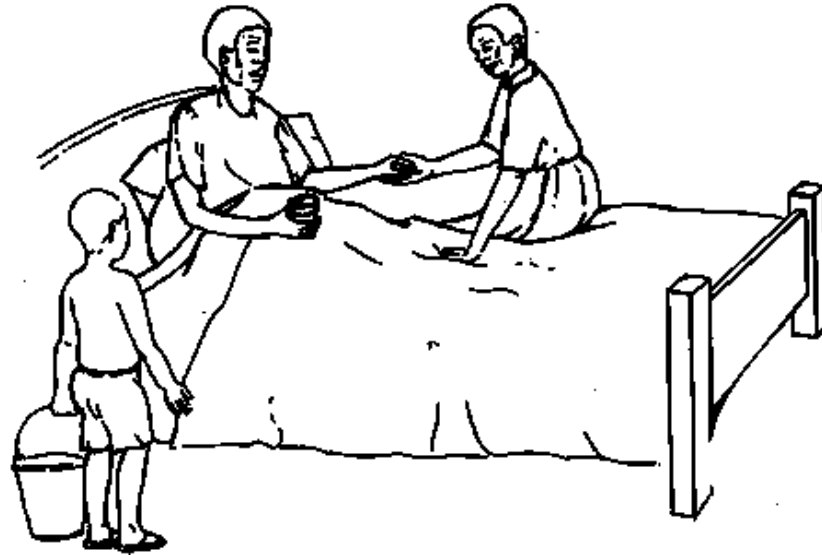
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Figure



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Figure



Figure



Figure

AIDS is a chronic disease lasting months or years, and during this time the person with AIDS may move between home and hospital several times. Much of the care of those with AIDS therefore occurs in the home. Home care relies on two strengths - the family and the community. The aim of the AIDS HOME CARE HANDBOOK is to enable health care workers to help individuals, families and communities to manage AIDS - related problems and confidence in their ability to provide safe and compassionate AIDS care at home.

Part I of the handbook is an illustrated teaching guide that helps health care workers give important advice about HIV and AIDS. Part II is a reference guide containing detailed information about common AIDS-related problems and possible causes, what can be done at home to alleviate these problems, and when to seek further help.

