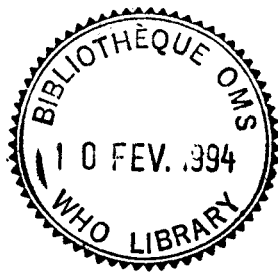


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GLOBAL  
PROGRAMME  
ON AIDS

# AIDS HOME CARE HANDBOOK

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WORLD HEALTH ORGANIZATION

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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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# Preface

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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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# Introduction

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## 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!**

# **PART I**

## **TEACHING GUIDE**



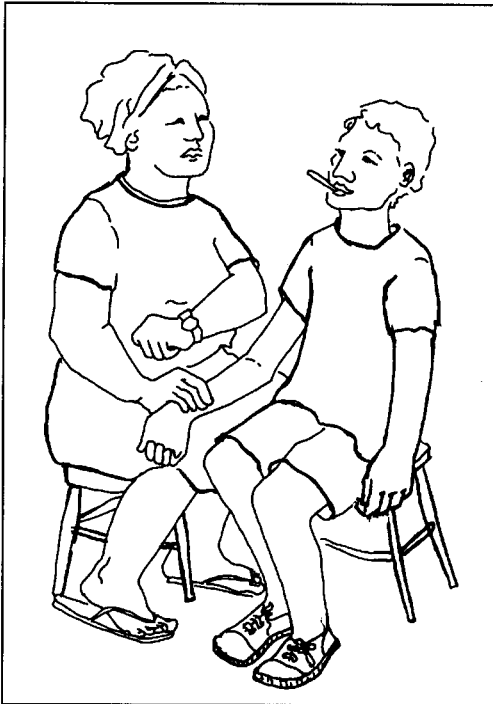
## Chapter One

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# Teaching people with AIDS and their families

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



The answer is that both pictures do.

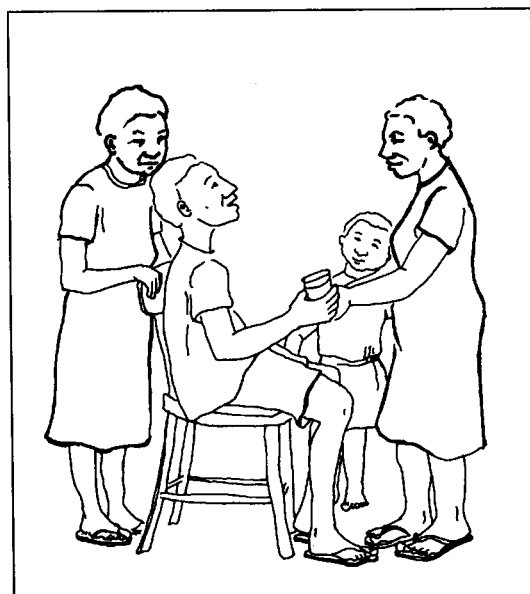
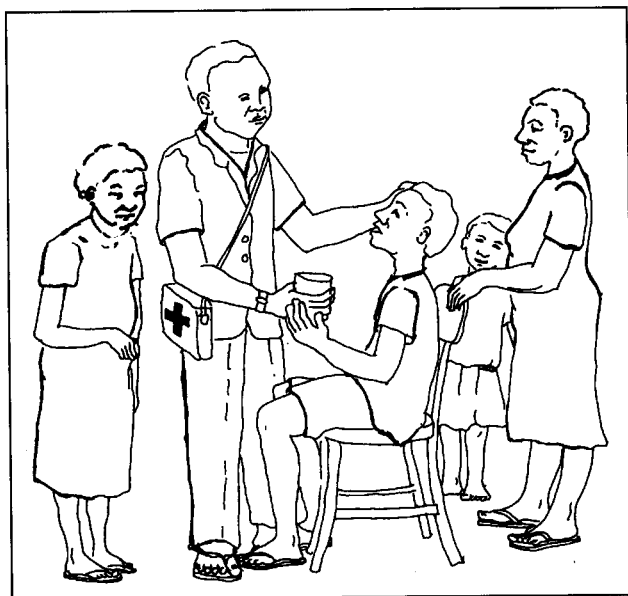
**Your main job as a health care worker and the most important skill you must learn is to teach.**

## 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.



- ◆ **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?

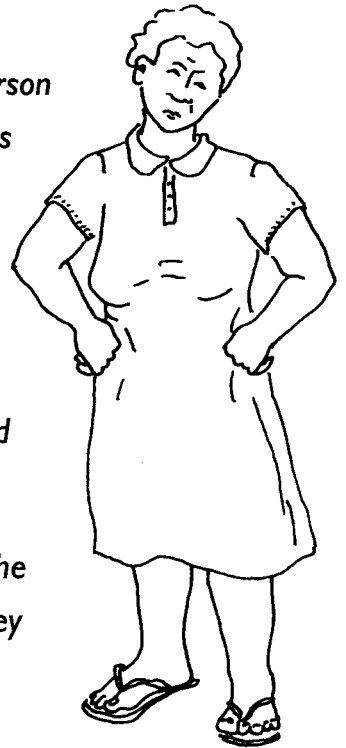
The following three stories are about health care workers. Read them and then think about the questions that follow each one.

### Story 1

*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.*



#### ◆ 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.



### ◆ 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**



- 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.

## Here are some more stories 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.

