

# Palliative Care at Home for Young Children in Africa

## Training Manual for Home-based Care Workers



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THE WORK CONTINUES

# Palliative Care at Home for Young Children in Africa:

## Training and Support Package



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## **Palliative Care for Young Children at Home in Africa: Training and Support Package**

This home-based training and support package is designed to train those involved in caring for very sick young child at home. It is also designed to support families in looking after a very sick child.

**The support and training package contains:**

**1. Guide for Home-based Care Workers**

Groups of home-based care workers will be trained to base their own training courses on this guide and to use it in their own field work.

**2. Training Manual for Home-based Care Workers**

Once they are familiar with the course, the home-based care workers will use this manual to train other groups of home-based care workers.

**3. Caregiver's Toolkit**

As a caregiver, your home-based care worker will go through this toolkit with you so that you become familiar with it. You can always refer back to this toolkit whenever you are in doubt.

**4. Helpful Handouts**

As a caregiver, your home-based care worker will provide you with a set of Helpful Handouts that contain important information on caring for your child.



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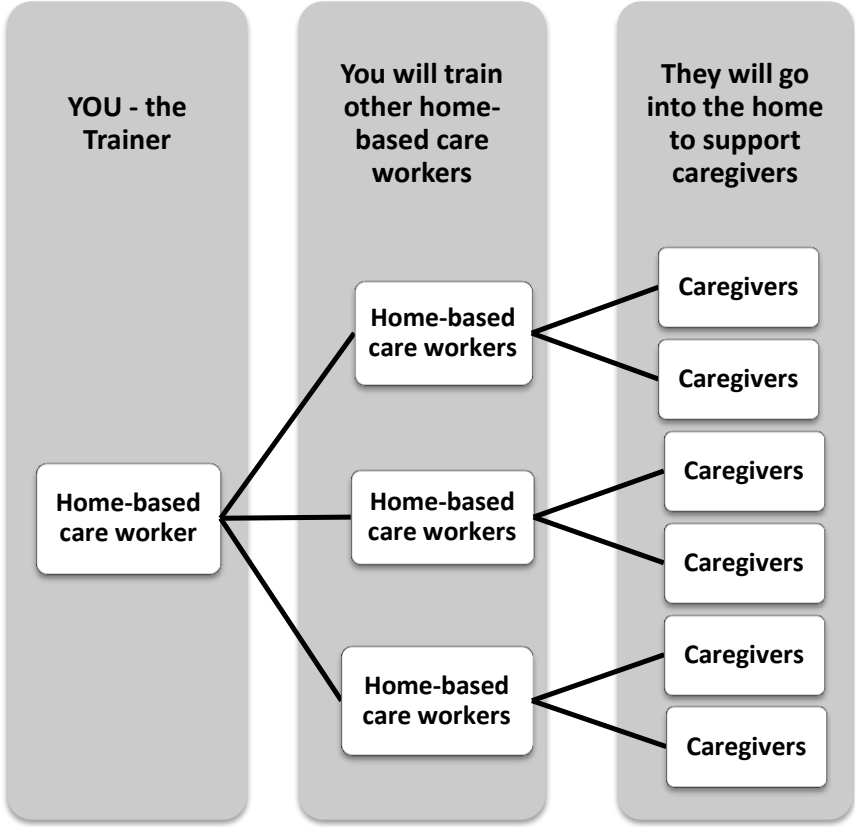
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**Telling you about this course**

We know that across the whole of Africa, people are caring in their own homes for young children who are living with HIV. This course is about palliative care and supporting the caregivers of a young child who has HIV infection.

You will be trained to deliver this course to other home-based care workers. Other home-based care workers will then deliver parts of this course to caregivers, children and families in their own home.

This diagram explains what will happen.



*Diagram 1: Training home-based care workers to support caregivers of young children with HIV*

We want home-based care workers to support those who care for children most of the time and we refer to these people as “caregivers”. We discuss palliative care later.

As a trainer, we hope that you will make sure that home-based care workers do the following when you deliver this course:

- Have the chance to share their ideas and experiences with you and with each other.
- Know that they are respected and valued.
- Learn more about how to support caregivers who care for young children with HIV.
- Want to try out ideas and activities they learn in this course.
- Want to share their new knowledge with others.
- Enjoy the course. We know that learning takes place more easily when people are relaxed and are enjoying themselves. Although some of the topics may be distressing, people can be relaxed and enjoy this time of learning and sharing with others.

Throughout the course, we make use of stories as a means of opening up discussion. Here is a story to remind you about becoming aware of the different learning needs of the home-based care workers you train during this course.



## Mrs. Elephant

**Be aware of the learning needs of the home-based care workers you will train**

A young child has to go to a new school and is very nervous. When she arrives at the school the teacher is talking in a very loud voice - just like an elephant. The children call the teacher "Mrs. Elephant". The child is very frightened of the teacher's loud voice and goes to hide in a tall tree. The tall tree is surrounded by soft, green grass.



The teacher sees the girl hiding in the tree. She takes all the children out to sit under the tree and begins to tell a story in a very loud voice. The story is about a lonely jackal. The teacher lowers her voice as the story continues and the girl leans forward to hear the story. Eventually the teacher is speaking very softly and the girl listens and falls out of the tree and lands on the soft grass. She joins the other children to hear the end of the story.

- You know that people learn in many different ways: some like to learn by reading, some like talking and some like drawing.
- You can encourage people to learn by noticing how they learn best and by being kind to them - like Mrs. Elephant did.
- Trainers are very special people.

We will now look at:

- Pre-course planning
- The aim of this course
- How to deliver the course
- Structure of Parts 1-7
- Size of the group
- Length of the course
- Tips for you

### *Pre-course planning*

You should plan for a training course well in advance.

You will need to do the following:

- Discuss the course and course evaluation with the managers and administrators of a home-based care organisation.
- Find an appropriate venue.
- Organise refreshments.
- Copy books and handouts.
- Get flip-chart paper and pens.
- Prepare name badges for yourself and participants.
- Find out about resources for referral in the area where you will train (we will discuss this further on page 33).

### **Discussing this course with managers and administrators in home-based care organisations**

We want home-based care workers to support caregivers to offer palliative care at home for young children who have HIV. After this course you will not be able to check if the home-based care workers understand this course and do as you request, so it is important that you make sure they understand everything before the course ends.

Before you run this course you must tell the managers and administrators of home-based care organisations about this course.

It is important that managers and administrators know about what you will teach so that they can continue to support their home-based care workers after the course. You should give the managers and administrators a copy of the “Palliative Care at Home for Young Children in Africa: Knowledge and Practical Competencies” (page 81). Explain that they should expect the home-based care workers to have these competencies once they have gone through the training.

You should also give the managers and administrators a copy of the “Palliative Care at Home for Young Children in Africa: Evaluation of Basic Competencies” (page 82). Explain that this gives the managers and administrators some tools to use to check if home-based care workers are doing well at supporting caregivers of young children with HIV at home.

You should also provide managers with copies of the training materials so that they can use them for ongoing revision and assessment.

*What is the aim of this course?*

The aim of this course is to teach home-based care workers how to support caregivers of young children who have HIV. The course will provide home-based care workers with information and practical tools on the following:

- Palliative care.
- Supporting a caregiver who looks after a child with HIV who is well.
- Supporting a caregiver whose child with HIV becomes sick and gets better.
- Supporting a caregiver whose child with HIV is very sick and may not get better.

The home-based care worker will have a chance to practise the following aspects of palliative care:

- Identifying, prioritising and seeking solutions to caregiver, child and family problems (assess, advise, assist and arrange).
- Supporting a caregiver to care for themselves.
- Telling young children about HIV.
- Supporting a caregiver to give medication to a young child.
- Dealing with common problems.
- Knowing when to refer a sick child to a clinic.

- Supporting a young child and the family when a child is very ill and may die.
- Recognising and dealing with abnormal bereavement.

### *How to deliver the course*

The course has the following materials:

- Palliative Care at Home for Young Children in Africa: Training Manual
- Palliative Care at Home for Young Children in Africa: Guide for Home-based Care Workers
- Palliative Care at Home for Young Children in Africa: Caregiver's Toolkit
- Palliative Care at Home for Young Children in Africa: Helpful Handouts 1-7
- **Palliative Care at Home for Young Children in Africa: Training Manual**  
You keep this manual for yourself and use it when delivering this course to home-based care workers.
- **Palliative Care at Home for Young Children in Africa: Guide for Home-based Care Workers**  
Together you and home-based care workers will go through this guide. It covers a lot of important material.
- **Palliative Care at Home for Young Children in Africa: Caregiver's Toolkit**  
This toolkit will be used by both you and home-based care workers during this course. The home-based care workers will receive extra copies of the toolkit which they will take with them into a home. Together the home-based care workers and caregivers at home will go through the toolkit so caregivers at home can learn about palliative care for a young child with HIV.

- **Palliative Care at Home for Young Children in Africa: Helpful Handouts 1-7**

You will make copies of these handouts for home-based care workers and will use them for revising basic home-based care. The handouts are labelled as follows:

1. Ways of keeping germs away
2. Breastfeeding
3. Formula feeding a baby
4. Foods that are good for growth and food hygiene
5. Dealing with diarrhoea and fever
6. Skin and mouth problems
7. Danger signs

**The trainer's course consists of seven parts:**

Part 1 Introducing yourself, participants and the course.

Part 2 Revision: basic home-based care.

Part 3 Palliative care.

Part 4 Supporting a caregiver whose child with HIV is well.

Part 5 Supporting a caregiver whose child with HIV becomes sick but gets better.

Part 6 Supporting a caregiver whose child with HIV is very sick and may not get better.

Part 7 The way forward.

The course is designed to be flexible. For example, if the group feel they know enough about basic aspects of home-based care (Part 2), it is possible to cover these aspects quickly. As you go through this manual you will see that each part has a consistent structure, shown in the box below to help you plan the training session.

## *Structure of Parts 1-7*

### **Trainer's introduction**

This includes:

- The approximate length of the session
- The aims of this session
- The key learning outcomes

### **Trainer's preparation**

- This tells you about activities that will be carried out in each session.
- It provides suggested times for each activity.
- It provides a list of materials you will need for each session.
- If these materials are not available then try and find similar materials that are appropriate and available to you.

### **Trainer's guidance**

- Under this heading we give more details on the activities of the session.
- We offer guidance on how to tackle each activity.
- We suggest key points for discussion.

The times we give are suggestions as sometimes home-based care workers may want to talk a lot about things that are bothering them.

### *Size of the group*

We recommend that you deliver the course to at least nine home-based care workers. This will enable you to divide the group into smaller groups of three people. Groups that are too large (more than 20 people) will be difficult to manage.

### *Length of the course*

The course is intended to run over three days. However, the length will depend on the previous knowledge, training and experiences of the participants in basic home-based care.

If participants are well trained in basic home-based care then you could spend less time on aspects of the course that they already know.

If participants have not covered basic home-based care then you will spend time with them to ensure that they are confident and competent in basic home-based care tasks.

We look at basic home-based care later when we discuss revision of basic home-based care in Part 2.

### *Tips for you*

Here are some tips that may be useful to you:

- Prepare well for the course.
- Participate in the discussions yourself and encourage everyone else to take part.
- Be creative with the way in which you deliver the training. You can use skills that you have and methods that you feel will enhance the training. For example, we use a 'story-string' – this is just a long piece of string that we ask each participant to hold as they sit in a circle while we tell stories. This makes everyone feel included and is a symbol of unity in the training process – remember we are all here together to help each other learn more about the important work that we do.

- Have a list of people who you can turn to if you feel out of your depth.
- Be flexible.
- Be reassured that it is alright if you don't know all the answers to participants' questions.
- If you are tired, take a break.
- Look after yourself well when you are training as you may become exhausted and give yourself a treat when you finish the course.
- You will find a summary of the course with suggested times for each part in Table 1.



Table 1: Outline of course

Part	Main content	Time
Part 1: Introduction to the course	<ul style="list-style-type: none"> <li>Introducing yourself and the participants</li> <li>Looking at the Guide for Home-based Care Workers the Caregiver's Toolkit</li> <li>What is the course about? What will you learn?</li> <li>Who are caregivers?</li> <li>Why focus on caregivers of children with HIV?</li> </ul>	1 hour
Part 2: Revision of basic home-based care	<ul style="list-style-type: none"> <li>Revising basic home-based care</li> </ul> <p>Note: The time for this session will depend on the previous training and experiences of home-based care workers. If there is no previous training, allow 4 hours.</p>	5 hours
Part 3: Palliative care	<ul style="list-style-type: none"> <li>Palliative care</li> <li>The needs of children and the needs of caregivers</li> <li>Anticipating problems that home-based care workers may experience</li> </ul>	2 hours
Part 4: Supporting the caregiver of a child who has HIV infection and is well	<ul style="list-style-type: none"> <li>How to keep the child well</li> <li>How to support the caregiver to care for themselves</li> <li>Telling a young child about HIV</li> <li>Encouraging a young child to take medicine</li> </ul>	2 hours
Part 5: Supporting the caregiver of a sick child who gets better	<ul style="list-style-type: none"> <li>Finding out what is causing an illness</li> <li>ASSESS, ADVISE, ASSIST &amp; ARRANGE</li> <li>Common problems faced by a child with HIV</li> <li>When to refer</li> <li>Possible side effects of ART</li> <li>The special problems of child abuse</li> </ul>	2 hours
Part 6: Supporting the caregiver of a child who may not get better	<ul style="list-style-type: none"> <li>Why keep a sick child at home</li> <li>Looking at the nine messages</li> </ul>	5 hours
Part 7: The way forward	<ul style="list-style-type: none"> <li>Drawing up an action plan</li> </ul>	1 hour
<b>Complete Course</b>		<b>18 hours</b>

## **Part 1: Introducing yourself, the participants and the course**

### **Trainer's introduction**

This part of the course is essential. It tells participants about you and about each other. It tells participants about how the course will be run and what the course is about. It also tells them what they will learn.

Approximate length of Part 1: **1 hour**

### **Aims of Part 1**

The aims of Part 1 are to:

- Introduce yourself.
- Introduce the participants to each other.
- Present the aims of the course.
- Introduce the key learning outcomes of the course.

### **Key learning outcomes of Part 1**

By the end of Part 1 the participants will:

- Know a little bit about you.
- Have introduced themselves to each other.
- Have knowledge about how the course will be run.
- Have knowledge of what the course is about.
- Have knowledge of the key learning outcomes of the course.

## Trainer's preparation

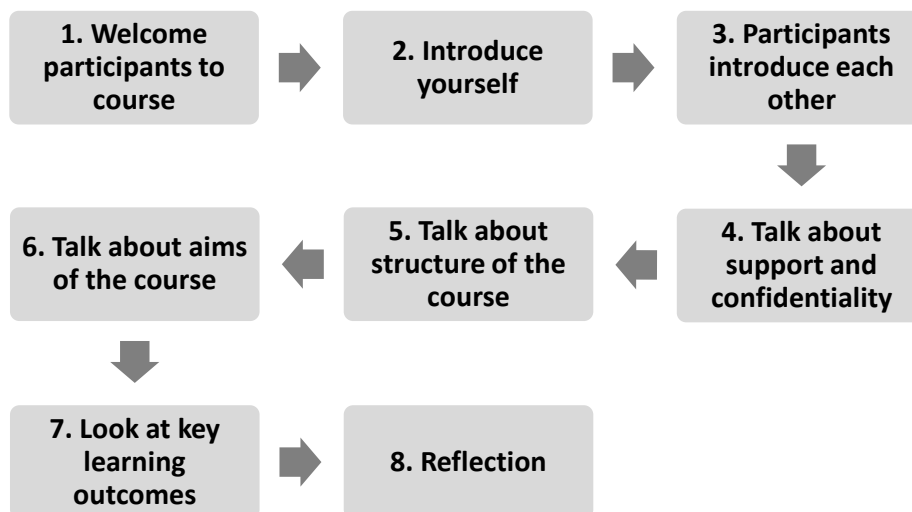
Planning Part 1 (with suggested times):

Introducing yourself	5 minutes
Introduction of participants	15 minutes
Mutual support and confidentiality	5 minutes
Structure of the course	5 minutes
Aims of the course	5 minutes
Discuss key learning outcomes of the course	5 minutes
Reflection	20 minutes

## Materials you will need

- Bean bag (small bag or packet filled with beans or sand)
- Guide for Home-based Care Workers
- Caregiver's Toolkit

## Trainer's guidance



### ☀️ **Activity 1: Welcome and introduction to Part 1**

Welcome everyone to this first part of the training course: **Palliative Care at Home for Young Children in Africa**. Start this session by telling participants that you are going to introduce yourself then they are going to introduce each other. Tell participants that you will tell them about the course.

### ☀️ **Activity 2: Introduce yourself**

Introduce yourself by saying your name and giving some information, such as how long you have been involved in home-based care, where you live, how many children you have, and why you have been selected to be a trainer. Ask the group to ask you questions about yourself. If it suits you and your group, begin the session with a song or prayer.

### ☀️ **Activity 3: Introduction: Home-based care workers**

If the home-based care workers already know one another, you will only need to go around the group and ask each person to say their name.

If the home-based care workers do not know each other you will have to think of a way for them to introduce themselves. Choose one of the following or think of an activity you know the participants will enjoy:

- Each person stands up and says his or her name, where he or she lives and why he or she has decided to join your group today.
- Ask participants to work in pairs. Each participant tells his or her partner something about him/herself. For example, the names of his/her children, where he or she lives and what work he or she does. Then each participant introduces his/her partner to the rest of the group by telling them what he/she has learned about their partner.
- Each person stands up and says his/her name and describes him/herself by using a word that starts with the same letter as his/her name. For example, "I am Thandi and I am tiny."
- Toss a bean bag from one person to another - call out the person's name as you toss it to them.

#### ☀️ **Activity 4: Participant support and confidentiality**

In this activity you will discuss issues of confidentiality. Over the next few days you and the participants will share stories, views and experiences. Some of these may be private and sensitive and it is important that you support each other.

It is important that you do not tell anyone else about what others say during this course that is private or confidential.

Ask each participant in turn to say:

- “I participant name will do all I can to support other participants during this course.”
- “I participant name will not repeat anything that is said during this course that is private or confidential.”

#### ☀️ **Activity 5: Telling participants about the structure of this course**

Tell participants how long the course will last. Ask participants to turn to page 105 in the Guide for Home-based Care Workers to look at an outline of the course.

Tell participants about the seven parts of the course (You can write the seven parts on flip-chart paper and stick the piece of paper on a wall).

Tell participants about the books and handouts:

**Palliative Care at Home for Young Children in Africa: Guide for Home-based Care Workers** - this book is for them to keep.

**Palliative Care at Home for Young Children in Africa: Caregiver’s Toolkit** - this book will be used by home-based care workers during this course. They will receive extra copies of this which they will take with them into a home. Together the home-based care workers and caregivers at home will go through the toolkit so caregivers at home learn about palliative care for a young child with HIV infection.

**Palliative Care at Home for Young Children in Africa: Helpful Handouts 1-7.** The handouts will be used when revising basic home-based care.

☀️ **Activity 6: Telling participants about the aims of the course**

Tell the participants the following:

- The course aims to make sure that the caregiver, the child with HIV and the family are supported as best as possible.
- The course aims to show the home-based care worker how to offer palliative care and support caregivers and children with HIV at home.

Turn to pages 2-7 in the Guide for Home-based Care Workers to read about why we are focusing on young children with HIV at home. Read these pages together.

☀️ **Activity 7: Telling participants about the key learning outcomes**

Tell the participants that by the end of the course they will know about:

- Palliative care.
- Supporting a caregiver who looks after a child with HIV who is well.
- Supporting a caregiver whose child with HIV becomes sick and gets better.
- Supporting a caregiver whose child with HIV is very sick and may not get better.

Participants will also have a chance to practise aspects of palliative care:

- Looking at the needs of children, caregivers, families and home-based care workers (look again at page 6 in the Guide for Home-based Care Workers).
- Supporting the caregiver to care for themselves.
- Telling a child about HIV infection.
- Supporting a caregiver to give medication to a young child.
- Recognising and dealing with common problems.

- Knowing when to refer a sick child to a clinic.
- Supporting a young child and family when the child is very ill and may die.
- Recognising and dealing with abnormal bereavement.

### ☀️ **Activity 8: Reflection**

Read the following story out to the participants. When you are done ask them to discuss the story. Below the story are key points that the discussion should include.

#### **Madele – The experienced home-based care worker**

Madele is a home-based care worker like many of the other home-based care workers in rural areas in Africa. Madele visits many children in their homes; there are many types of homes, some are well built and some need repairs. There is a large school in the area and many of the children she cares for go to this school. There is a clinic close by with trained nurses. Madele has many duties, she checks that children are happy and well and makes sure that people get to the clinic when they need healthcare. She gives practical advice to families, for example on what food to eat and how to keep clean.

Today Madele has planned to visit Nonhlanhla and her family in their home. Nonhlanhla is looked after by her aunt. When Madele arrives she discovers that Nonhlanhla's aunt has just passed away. The deceased aunt's sister, Sylvia, is now the primary carer for Nonhlanhla. The family is mourning the loss of a loved one.

Nonhlanhla is at school today and Madele is concerned as she knows that Nonhlanhla had been ill. Madele decides to go to the school to see if Nonhlanhla is alright. When Madele reaches the school she meets Gugu, the Head of Department. Gugu asks Madele to see another child that she is worried about. This child's name is Siphso. Gugu has asked Siphso's granny to come to school so they can talk about Siphso. Siphso's mother and father have passed away and his granny cares for him.

Together with Gugu and Siphso's granny, Madele has a look at Siphso. Siphso has very itchy dry skin. Madele, Gugu and Granny look at Siphso's skin to see if they can find out what is causing the problem. The rash is very bad and has covered Siphso's whole body. Granny is worried and both Siphso and Granny look sad.

Gugu brings Nonhlanhla from class and Madele is surprised and relieved to find that she looks well. But Madele knows that Nonhlanhla's family cannot afford to bury her aunt. So Madele decides to personally call the Provincial Minister for Social Welfare, whose phone number she has, in the hope that he will be able to help. The Provincial Minister refers Madele to the person in the department who can arrange help for the burial cost.

Madele continues to worry about Siphos as his skin is very itchy. Gugu gets permission for Madele to take Nonhlanhla and Siphos back to their homes. Back at Nonhlanhla's house Madele joins in with the family's mourning. Madele explains to the family that money will be available for the funeral costs. Everyone is relieved. There are many other children at this home who may also need her help and so Madele knows that she must visit this house often over the next few weeks and months.

Next Madele goes to Siphos's home and explains that she is concerned about Siphos. Siphos's mother, father and older sister have all passed away. She notices there are other children at home. She sees that the family is very poor and the grandfather is ill in bed. She also notices that the baby's bottle is very dirty and that the baby does not look well. Siphos's granny shows Madele the medicine they got from the clinic; it is for itchy skin and to prevent infection. The medicine is all finished. Madele asks Granny when she last went to the clinic and says that she will try to help the family by speaking to the clinic sister.

Madele is clearly worried about the situation with the children in this home. She checks to see if the baby is dehydrated. His eyes are not sunken and his skin pinch is normal. Madele has seen that the home is dirty. She explains to Granny how to keep the bottle clean and how to disinfect it using boiling water. Madele then goes to the clinic to see if she can get them to help this family.

Today Madele has worked hard to help two young children at risk and their caregivers. Madele is an experienced home-based care worker and cares for many of her own children. She realizes that she must do her best. To do this she knows she has to deal with one problem at a time.



### **Key points for discussion:**

There are two children, two families and Madele, a home-based care worker.

#### **Family 1**

Nonhlanhla is a young orphan. Her caregiver, her aunt, has just died and her body is at home because the family cannot afford the cost of a funeral. The new caregiver is her aunt's sister. Nonhlanhla goes to school the day after her aunt has died.

#### **Family 2**

Sipho's mother, father and sister have all passed away. The child has itchy skin. His caregiver is his granny. The granny is poor and seems to have given up. The grandfather is very ill. There is another baby at home. The home is dirty. The baby's bottle is dirty. There is no food.

#### **The home-based care worker**

Madele, the home-based care worker, is caring for 16 children in her own home.

Ask caregivers to form three groups. Provide flip-chart paper and pens.

**Group 1** Discuss the problems faced by Nonhlanhla, the caregiver and the family.

**Group 2** Discuss the problems faced by Sipho, the caregiver and the family.

**Group 3** Discuss the home-based care worker's problems.

Ask a representative from each group to give feedback to the whole group.

Together they could draw diagrams to show the problems (see tables on the next page).

### Group 1

Problems faced by Nonhlanhla, her caregiver and her family		
<p><b>Child</b></p> <p>Nonhlanhla is an orphan. Her aunt has just died. Nonhlanhla is back at school.</p>	<p><b>Caregiver</b></p> <p>The caregiver is her aunt's sister who now has to provide care for a number of young children.</p>	<p><b>Family</b></p> <p>The family cannot afford to pay for a funeral so the body remains at home.</p>

### Group 2

Problems faced by Sipho, his caregiver and his family		
<p><b>Child</b></p> <p>Most of Sipho's family have passed away. He has itchy skin. He has no medicines. He is ignored. He is sad.</p>	<p><b>Caregiver</b></p> <p>The caregiver is a granny. The granny is very poor. The granny seems to have given up.</p>	<p><b>Family</b></p> <p>The grandfather is very ill. There is another very young child at home. The family has no money to buy food or to go to clinic. The house is dirty. The baby's bottle is dirty.</p>

### Group 3

Problems faced by Madele - the home-based care worker		
<p><b>Herself</b></p> <p>She is caring for others. She is caring for 16 children at home. She is stressed because she doesn't know how to solve all the problems. She needs help.</p>	<p><b>Her Children</b></p> <p>She is caring for many children.</p>	<p><b>Her Family</b></p> <p>She is caring for others, for children who live with her, and her family.</p>

Ask participants to form three groups and provide them with flip-chart paper and pens.

**Group 1** Summarise the key learning outcomes of the course (page 4 of the Guide for Home-based Care Workers).

**Group 2** Discuss: Who a caregiver is (page 4-5 of the Guide for Home-based Care Workers).

**Group 3** Discuss: Why it is good for a home-based care worker to support a caregiver

Ask a representative from each group to give feedback to the whole group.

Tell the participants that Part 1 is coming to a close.

The goal of Part 1 was to allow participants to get to know a little about each other, to become relaxed and to be introduced to the challenges of home-based care to support caregivers looking after children with HIV.

Remind participants about supporting each other and about confidentiality.

Ask for comments or questions.

Thank everyone for participating in Part 1.

## Part 2: Revision of basic home-based care

### **Trainer's introduction**

This part is a revision of basic home-based care.

We describe what we mean by basic home-based care (see key learning outcomes of basic home-based care in Table 2 on the next page).

Some participants may already know something about basic home-based care. It is important that you give information and support to ensure that all participants have knowledge and skills in carrying out basic home-based care.

Approximate length of Part 2:

**The time taken for Part 2 depends on the knowledge and skills of the home-based care workers in basic home-based care.**

### **Aims of Part 2**

The aims of Part 2 are to:

- Revise knowledge of basic home-based care.
- Revise practical skills of basic home-based care.

### **Key learning outcomes of basic home-based care**

The key learning outcomes of basic home-based care are described on the next page in Table 2.

**Table 2: Basic home-based care**

Topic	Key learning outcomes
Keeping germs away from a child who has HIV infection	<ul style="list-style-type: none"> <li>• Knowing how to dispose of body fluids: urine, faeces, blood and sputum</li> <li>• Knowing about washing hands</li> <li>• Dealing with cuts and sores</li> <li>• How to offer advice on cough hygiene and disposing of sputum</li> <li>• Knowing how to protect from mosquitoes</li> </ul>
Breastfeeding	Knowing when to start and stop breastfeeding a baby
Formula feeding	Knowing how to make up a baby's bottle
Feeding	Knowing what foods are good for growth and learning about food hygiene
Common problems	Coping with: <ul style="list-style-type: none"> <li>• Fever</li> <li>• Diarrhoea (Sugar Salt Solution - SSS)</li> <li>• Mouth problems</li> <li>• Skin problems</li> </ul>
Danger signs in young children	Recognising the danger signs
Washing a child	Knowing how to wash a sick child

**Trainer's preparation**

Planning Part 2 (with suggested times):

Keeping germs away	30 minutes
Breastfeeding	15 minutes
Formula feeding	15 minutes
Feeding and food hygiene	30 minutes
Common problems	2 hours
Danger signs	1 hour
Washing a child	10 minutes
Reflection	20 minutes

## Materials you will need

- Guide for Home-based Care Workers
- Caregiver's Toolkit
- Helpful Handouts 1- 7
- Flip chart and pens

## Trainer's guidance

Remember that some people in the group may know more about home-based care than others. As the trainer, you will need to recognise this and decide what parts of home-based care to cover so that no one feels that they are being left behind.



### ☀️ **Activity 1: Revising basic home-based care**

Establish what the participants already know about basic home-based care (together look at the table on page 104 in the Guide for Home-based Care Workers).

### ☀️ **Activity 2: Revising knowledge and skills**

Go around the group and ask if anyone has prior training in basic home-based care.

If yes - ask these participants to present their knowledge to the group (make use of flip-charts and pens, handouts and the Guide for Home-based Care Workers).

Check that their knowledge is correct and give participants ample opportunity for discussion.

If no - go through each topic on basic home-based care using Helpful Handouts 1-7 and give each participant a copy of the handouts.

### ☀️ **Activity 3: Reflection**

Ask participants to form three groups and provide them with flip-charts and pens.

**Group 1**            Ask group 1 to summarise and give feedback on keeping germs away from children.

**Group 2**            Ask group 2 to summarise and give feedback on breastfeeding, formula feeding, good nutrition and food hygiene.

**Group 3**            Ask group 3 to summarise and give feedback on common problems and making Sugar Salt Solution (SSS).

You can summarise and give feedback on danger signs.

Ask for comments or questions.

Read the story below out loud to the participants. When you are done, ask the participants to discuss the story.

#### **Andiswa – The new mother**

Sihle is a home-based care worker who visits many families in her community. One of the families she visits is the Ntuli family. Mother Ntuli is very ill and Sihle knows that she will soon pass away, but she has a small baby who is HIV positive and will need lots of care. The baby has an older sister, Andiswa, who is 17 years old and has just finished school in the city. Andiswa will move back home to care for her baby sister.

When Sihle visits she finds Andiswa very unhappy, Andiswa is afraid that she will not be able to care for little Sindy. Andiswa is now a new mother and does not know how to care for a baby, but Sihle assures Andiswa that she will always be there to help and advise her. Sihle decides to show Andiswa how to wash Sindy.

She begins by explaining to Andiswa that there are two circumstances under which you need to wash a young child – when they are babies and they cannot wash themselves, but also when the young children are older but are sick and cannot wash themselves. Andiswa is eager to learn how to care for Sindy. Sihle sends her to prepare all the things that they will need to wash Sindy – some clean

towels and facecloths, soap, a big bucket, warm water, body cream, nappies and baby clothes. Sihle explains to Andiswa that she must have all the things she will need near her, within arm's reach, so that she does not have to leave the baby unattended on the bathing table.

Together Sihle and Andiswa prepare the water for the baby's bath, first the cold water and then the hot water. Sihle asks Andiswa to test the water to see if it is ok. Andiswa dips her elbow into the bath water; Sihle has taught her that if it is good for your elbow, it is good for the baby. They spread the towel out onto the table and, carrying her carefully, they undress Sindy.

Sihle shows Andiswa how to gently wash Sindy, starting from the top of her head to the bottom of her feet. First, she gently washes her hair then lays her on the towel and dries her hair. Next Sihle wets the facecloth and without any soap she cleans Sindy's face gently, not forgetting behind the ears.

While Sindy is still on the towel Sihle rubs some soap onto another piece of cloth and shows Andiswa how to wash Sindy's body. Sihle is very patient with Andiswa, working slowly and showing her how to turn the baby to one side, using one arm to support the front of her body and gently washing with the other hand from the top of her neck all the way down her back to her toes. Then she turns Sindy onto the other side, again using one hand to support the front of her body and the other to wash her. Afterwards, she lays Sindy on her back and gently washes the front of her body. Sihle tells Andiswa that it is important to talk to Sindy and play with her while she is giving her a bath, this is a very good time to build a bond with your baby.

Once she is done, Sihle rinses the cloth in the water until there is no soap on it and gently wipes Sindy's body. Then she lets Andiswa dry her with the towel, all over, under the arms, in between the buttocks, turning her sideways and supporting her with one arm while gently drying her with the other. On a clean towel they rub cream all over Sindy's body. Sihle reminds Andiswa to remember to rub cream or Vaseline in between Sindy's buttocks to avoid nappy rash. Together they put on Sindy's nappy and gently dress her.

Next Sihle shows Andiswa how to clean Sindy's mouth. She explains that Sindy is too young to use toothpaste. Andiswa must use a soft, clean cloth like gauze with some warm water to gently wipe inside Sindy's mouth, over her gums and around her teeth. Once they are done, Sihle notices that Andiswa seems much happier and much more confident. Sihle explains to Andiswa that as a new mother she may have many questions but she can always ask for help.



**Key points for discussion:**

- How to make sure caregivers have the necessary equipment.
- Understanding and showing caregivers how bathing and cleaning a baby can be a time of bonding.

At the end of the discussion, ask if there are any questions or comments and thank the participants for their hard work.

## Part 3: Palliative care

### Trainer's introduction

This part looks at palliative care and the needs of children, caregivers and families. It also looks at problems that home-based care workers may face.

This part will require a lot of preparation as you must be able to provide some guidance for dealing with anticipated problems faced by home-based care workers.

Approximate length of Part 3: **2 hours**

### Aims of Part 3

The aims of Part 3 are:

- To describe palliative care.
- To look at the child's needs.
- To look at the caregiver's needs.
- To look at the family's needs.
- To prioritise needs and to assess, advise, assist and arrange.
- To look at potential problems that home-based care workers may face.

Before beginning this part of the course you should discuss potential problems with your co-trainers and supervisors, so you can provide positive guidance to participants when they bring up these problems.

### Key learning outcomes

The key learning outcomes are the ability to:

- Describe palliative care.
- Use the palliative care diagram to reflect on a child's needs.
- Use the palliative care diagram to reflect on the needs of caregivers and the family.

- Use the palliative care diagram to prioritise needs.
- Deal with some potential problems that home-based care workers may face.

### Trainer's preparation

Planning Part 3 (with suggested times):

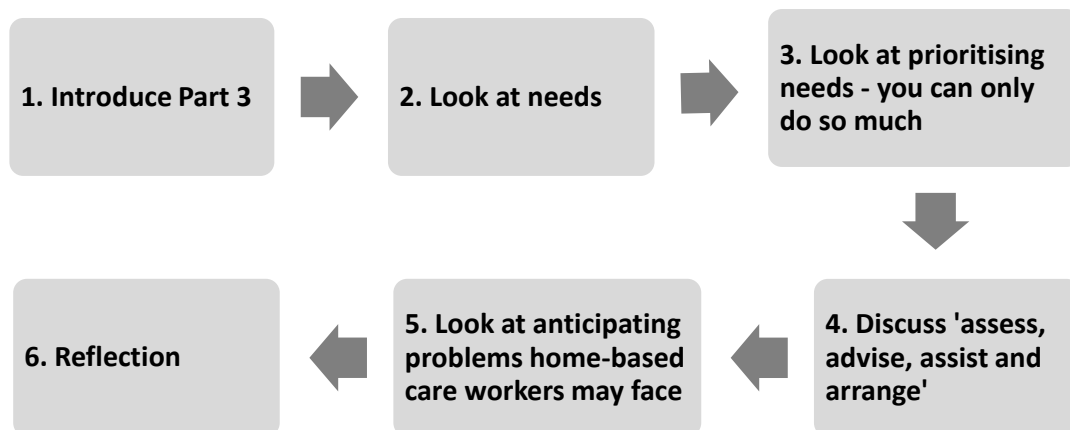
Describing palliative care	15 minutes
Looking at a child's needs	15 minutes
Looking at a caregiver's and family's needs	15 minutes
Looking at potential problems	1 hour
Reflection	15 minutes

### Materials you will need

- Guide for Home-based Care Workers
- Caregiver's Toolkit
- List of resources/referrals available in the area
- Flip-chart
- Pens

### Trainer's guidance

You will need to prepare for Part 3.



You may need to prepare a list of resources/referrals that are available in the area where you will be training. Such resources should include clinics, hospitals, police stations, non-governmental organisations (NGOs), community-based organisations (CBOs), where to refer a suspected abused child, feeding schemes, etc.

Below is an example of a list of resources and referrals in your area that you can put together.

### **Resources and referrals**

- |   |                |
|---|----------------|
| 1. Pastor Nkosi at Siyathemba Church      | - 031 255 6644 |
| 2. Edendale Hospital, Paediatric Ward     | - 031 255 7765 |
| 3. Edendale Police Station                | - 031 266 6457 |
| 4. Salvation Army, Edendale               | - 032 555 6474 |
| 5. ChildLine                              | - 08000 555 55 |
| 6. Support Group: Mrs. Mthembu            | - 073 463 8463 |
| 7. Principal of Fundakahle Primary School | - 082 376 4649 |
| 8. KZN Hospice                            | - 033 763 7462 |
| 9. Social Worker, Mrs. Mkhize             | - 033 452 3748 |

Each home-based care worker can build their own list of resources and referrals depending on the area they live and work in.

Remind the home-based care workers that these lists will continue to grow as they meet new people and organisations that can support them. In this way, their support network will grow stronger and stronger and the list will be a quick and easy way to know who to refer to when there is a need.

### ☀️ **Activity 1: Introducing Part 3**

Tell participants that Part 3 is about palliative care and looking at the needs of children, caregivers, families and home-based care workers.

Ask participants to turn to page 9 of the Guide for Home-based Care Workers. Look at the diagram which explains what we will cover in discussing palliative care.

Together read about palliative care (pages 9-12 in the Guide for Home-based Care Workers).

### ☀️ **Activity 2: Looking at needs**

Ask participants to form three groups and provide them with flip-chart paper and pens.

**Group 1**      Discuss what the needs of a child with HIV are.

**Group 2**      Discuss what a caregiver's needs are.

**Group 3**      Discuss what the family's needs are (for example, younger brothers, sisters, grandparents and friends).

Ask a representative of each group to give feedback to the whole group.

Together, using the flip-chart paper divide the needs into:

- Physical
- Emotional
- Social
- Learning
- Spiritual
- Material

If the groups have not mentioned some needs then you can add these needs to the list and invite the group to comment.

### ☀️ **Activity 3: Prioritising needs**

Describe how to prioritise needs and how to look at one problem at a time (pages 13-15 in the Guide for Home-based Care Workers).

### ☀️ **Activity 4: Explain assess, advise, assist and arrange.**

Assess: We aim to see if we can find a cause for the problem. We also aim to see if we can cope with the problem or if we need to refer to someone else for help.

Advise: We give the caregiver advice on the problem that we have identified together.

Assist: We offer to carry out tasks for the caregiver if we feel that the caregiver needs help with these tasks.

Arrange: If we are worried about a situation then we arrange to ask others for help. If we feel we can cope then we arrange to visit the home often to offer support to the caregiver and child.

### ☀️ **Activity 5: Looking at potential problems the home-based care workers may face**

Ask participants to form three groups. Provide them with flip-chart paper and pens.

Ask each group to list problems that they may face in supporting a caregiver, child living with HIV, and family at home. Ask a representative of each group to give feedback to the rest of the group.

The group should discuss each potential problem and suggest solutions.

On the next page is a list of problems that other home-based care workers have had to deal with. Give each participant a problem from this list to think about.

Ask them to think about this problem and potential solutions to this problem for at least 10 minutes. Then ask each participant to discuss their problem and potential solutions with the rest of the group.

**Potential problems for discussion:**

- a) The caregiver has given up all hope and cannot see a way forward.
- b) The family has no food.
- c) The hospital or clinic staff are not helpful when they refer a child.
- d) The home-based care workers are worried about their own health (TB infection).
- e) The home-based care workers are called noseys and are teased by others.
- f) The home-based care worker sees that a caregiver is abusing young children.
- g) The home-based care worker is refused entry into a home.
- h) The caregiver refuses to tell the child about his or her HIV infection.
- i) The caregiver cannot afford to take the child for medicines.
- j) The home-based care worker feels that she must give away her own money and food.
- k) Caregivers expect the home-based care worker to do everything for them.
- l) A traditional healer gives the young child medicine that is potentially harmful.
- m) The caregiver will not follow advice that the home-based care worker gives.
- n) The family cannot afford the cost of a burial.

Together look at the two key messages for home-based care workers (page 16 in the Guide for Home-based Care Workers).

## ☀️ **Activity 6: Reflection**

Tell the participants that it is time to bring Part 3 to a close by sharing key learning points with each other.

Ask the group to think back to story of Madele – The experienced home-based care worker, Nonhlanhla and Siphso.

Ask the participants to form two groups. Provide them with flip-chart paper and pens.

**Group 1** Review the problems of Nonhlanhla (the child) and her caregiver and family. Discuss what the main problem is today. Discuss that problem in terms of the headings Assess, Advise, Assist and Arrange.

**Group 2** Review the problems of Siphso (the child) and his caregiver and family. Discuss what the main problem is today. Discuss that problem in terms of the headings Assess, Advise, Assist and Arrange.

Ask a representative of each group to give feedback to the whole group.

### **Key points for discussion around the story:**

<b>Points for discussion</b>	<b>Nonhlanhla</b>	<b>Siphso</b>
<b>What is the main problem today?</b>	Body cannot be buried.	Itchy skin.
<b>Assess</b>	Why can't the body be buried?	It seems like the family has no money or energy to take Siphso to the clinic.
<b>Advise</b>	Ask for help.	Advise the granny on support systems available in the community - for example feeding schemes.



<b>Assist</b>	Phoned Minister of Social Support who helped.	Assist the granny to clean the baby's bottle and clean the house.
<b>Arrange</b>	Follow up - does the child know about the death of the caregiver? Should the child go to the funeral? Provide ongoing support to the caregiver.	Went to clinic but nurse was busy. Must follow up as soon as possible as the granny needs a lot of support.

Ask the group to work in pairs for five minutes to talk about Part 3.

Ask them to be ready to say what ideas or thoughts they are taking away with them.

Invite three or four participants to share what they have learnt and their thoughts on Part 3.

This may have been a difficult session as it probably reminded home-based care workers of the many problems they have experienced while trying to support caregivers.

Tell the home-based care workers to sit quietly by themselves for five minutes (they could go outside).

Ask them to think of three people they could turn to if they experience difficulties in supporting a caregiver at home.

Ask if there are any questions or comments.

Thank the participants for their input.

## **Part 4: Supporting a caregiver of a child who has HIV infection and is well**

### **Trainer's introduction**

In Part 4 you will look at how home-based care workers can support the caregiver of a child with HIV who is well.

Approximate length of Part 4: **2 hours**

### **Aims of Part 4**

The aims of Part 4 are:

- To highlight the need for prevention of problems in the child, the caregiver and the family.
- To highlight the need to stimulate a young child with play, storytelling, reading and listening.
- To review techniques of good parenting.
- To facilitate the discussion of HIV status with a young child.
- To encourage adherence to medication.

### **Key learning outcomes**

By the end of Part 4 the participants will:

- Revise universal precautions to prevent HIV infection.
- Revise good nutrition and food hygiene.
- Gain awareness of the importance of play, talk and storytelling.
- Gain an awareness of good parenting skills.
- Gain awareness of the importance of checkups for caregivers.
- Be equipped with tools for talking about HIV status.
- Be equipped with tools for encouraging adherence to medication.

## Trainer's preparation

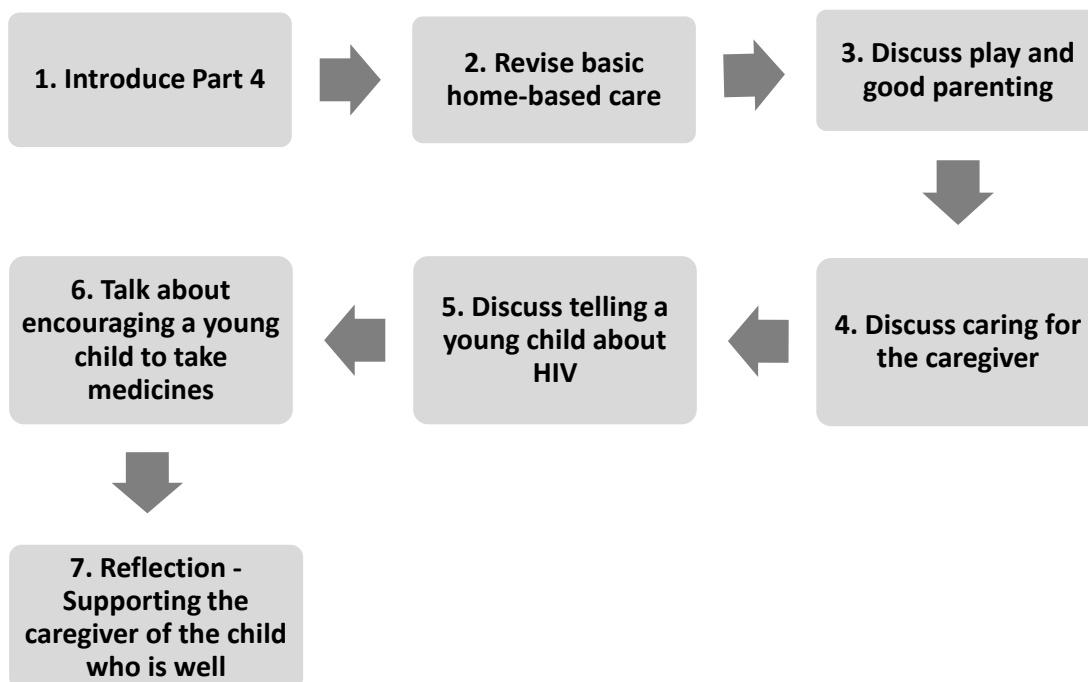
Planning Part 4 (with suggested times):

Revise universal precautions	15 minutes
Revise breastfeeding	5 minutes
Revise formula feeding	5 minutes
Revise nutrition and food hygiene	5 minutes
Look at play, storytelling and talking	10 minutes
Look at parenting skills	10 minutes
Look at checkups for caregivers	10 minutes
Look at discussing HIV status	20 minutes
Look at supporting adherence to medication	20 minutes
Reflection	20 minutes

## Materials you will need

- Guide for Home-based Care Workers
- Caregiver's Toolkit
- Flip-chart paper and pens

## Trainer's guidance



### ☀️ **Activity 1: Introducing Part 4**

Tell the participants that Part 4 is about keeping a child with HIV well.

A well child needs:

- Protection from germs
- Good nutrition
- Play and good parenting

It is important that the caregiver is supported and looks after his or her own health.

A young child should know something about HIV infection. A young child should be encouraged to adhere to medication, especially medicines for HIV, anti-retroviral therapy, ART).

Ask participants to turn to page 19 in the Guide for Home-based Care Workers and look at the diagram: *A Well Child*.

### ☀️ **Activity 2: Revision in basic home-based care**

The participants will revise basic home-based care. Give each participant a topic:

- a) Cleaning up spills
- b) Dealing with a cut or sore
- c) Disposing of waste
- d) Cough hygiene
- e) Disposing of sputum
- f) Protecting from mosquitoes
- g) Breastfeeding
- h) Formula feeding
- i) Good nutrition and food hygiene

Each participant will give a brief presentation on their topic using the handouts, the Guide for Home-based Care Workers (pages 20-22) and the flip-charts and pens.

☀️ **Activity 3: Looking at the importance of play and good parenting**

Ask participants to form two groups. Provide flip-charts and pens.

**Group 1**

Discuss:

- Why and how should a young child play?
- How important is it to talk and listen to young children?
- How important is it to tell young children stories and sing songs for them?
- How important is it to play, talk and listen to a child older than 2 years old? (page 9 in the Caregiver's Toolkit).

**Group 2**

Discuss:

- What does it mean to be a good parent?
- How can we be good parents?
- How important it is to show love and affection to young children?
- What can we do if the child is lonely?
- What can we do if the child is sad? (page 9 in the Caregiver's Toolkit).

Ask a representative of the group to give feedback to the whole group. Together read pages 23 and 24 in the Guide for Home-based Care Workers.

#### ☀️ **Activity 4: Looking at caring for the caregiver**

Ask participants to turn to page 10 of the Caregiver's Toolkit.

Go through the list of checkups for caregivers. Discuss if these checkups are available at clinics.

Ask each home-based care worker in turn to name a way that they could look after their own health.

#### ☀️ **Activity 5: Telling a young child about HIV**

Ask participants to form three groups. Provide flip-charts and pens.

**Group 1**            Discuss why it might be good to tell a young child about HIV infection.

**Group 2**            Discuss potential problems in telling a young child about HIV.

**Group 3**            Discuss how to tell a young child about HIV.

Ask a representative from each group to present their discussion to the larger group.

#### ☀️ **Activity 6: How to tell a young child about HIV**

Ask participants to look at pages 25-28 in the Guide for Home-based Care Workers and look at page 11 in the Caregiver's Toolkit.

Together read and discuss the story "John and the Sleeping Germs," in the Caregiver's Toolkit (pages 12-14). Discuss if participants feel that this story would be useful in telling a young child about HIV.

Discuss how to cope with a child's anticipated emotions if they are told about HIV infection (for example, anger, fear or crying).

Discuss questions that the child may ask:

- Why did it happen to me?
- How did I get this germ?
- What will I do if other children laugh at me?
- What will I do if other children exclude me?

Write replies to these discussions on a flip-chart.

### ☀️ **Activity 7: Supporting a caregiver to give medicines to the child**

Ask participants to form three groups. Provide flip-chart paper and pens.

**Group 1**            Discuss how to support a caregiver to give a young child medicine.

**Group 2**            Discuss how to support a caregiver if the child refuses to take medication.

**Group 3**            Discuss the medicines that a young child may have to take.

Ask a representative of each group to give feedback to the whole group.

Together read pages 29-32 in the Guide for Home-based Care Workers.

Together look at page 15 in the Caregiver's Toolkit.

### ☀️ **Activity 8: Reflection**

Tell participants that Part 4 is coming to a close.

Read the story '**Supporting the caregiver of the child who is well**' to the participants.

Ask if there are any comments or questions and then discuss the story together.

### **Supporting the caregiver of the child who is well**

Today Madele is visiting a new family. When she arrives at the home, Madele makes sure she speaks to each of the family members. She meets the young child's sister and brother and checks that they are well.

Madele sits with the parents and Sizwe, the baby, and talks to them. She finds out that Sizwe is HIV positive. Once she has found out about the family and has told them a little bit about her, she knows that they are comfortable with her. She goes on to ask them how she can help them today. Both the mother and father have questions for Madele and she is happy to see that the whole family is involved in caring for little Sizwe.

Londiwe, Sizwe's mother, is worried about whether or not she should breastfeed her baby. Madele asks Londiwe what the clinic sister has advised her to do. Londiwe replies that the clinic sister has suggested that since Sizwe is on ART he should be breastfed. Madele agrees with her and explains to Londiwe that just like any other baby she should breastfeed Sizwe and begin giving him solids after 6 months.

Next Madele checks with Londiwe that Sizwe has had all the necessary immunizations. Londiwe is happy that the clinic sister has told her that she will let her know if her baby needs anything special. Madele has a look at the clinic card that Londiwe has for the baby. Londiwe has taken Sizwe for all his checkups and he seems to be growing well. Madele encourages Londiwe to keep up the good work of taking Sizwe to the clinic for regular visits. Londiwe knows that Sizwe has to have his blood tested at the clinic every few weeks and marks it on her card so that she does not forget.

Madele asks Londiwe about the food she cooks for the children. Londiwe takes Madele into her kitchen and shows her the fresh fruit and vegetables she has. She explains to Madele that she prepares porridge, fruit and vegetables every day for the children. Madele reminds Londiwe to keep uncooked and cooked food separately and to always cover all food. She explains that all food should be prepared with clean water. Madele takes a small container and puts a little bit of uncooked rice into it. She explains to Londiwe that she can make small toys like this for Sizwe to play with. The bright colours of the container and the sound of the rice will keep him interested and happy.

Bongani, Sizwe's father tells Madele that he is worried about Sizwe's little sister, Thandi, who is also HIV positive. Thandi was on ART but has stopped taking her



medication; she spits out the medication and refuses to listen to her parents. Madele explains to Londiwe and Bongani that sometimes it is difficult for young children to accept that they need to take medication, especially if no other children around them do. It would help if Thandi’s parents used a story to help her understand why it is important for her to take her medication. Madele gives them an example of what they can tell Thandi to help her take her medication:

*“Germs can make a child sick. You have some germs in your blood. There are soldiers in your blood that help put the germs to sleep. Your medicine makes the soldiers in your blood strong. You need medicine every day. If you don’t take medicine the germs can wake up.”*

Madele explains to the parents that they can also sit with Thandi and draw with her pictures of how she can be strong and well by taking her medication and how it will protect her. Madele shows both parents how they can make little containers to keep the medication in, one little container for each day. This will help them remember when to give both Thandi and Sizwe their medication. Thandi can help to make her medicine containers and to decorate them.

Both the family and Madele are satisfied with the visit. Madele leaves, promising to visit again soon.

**Key points for discussion from the story:**

What was the main problem today?

- a) Mum concerned about breastfeeding and immunisation
- b) Dad concerned that child would not take medicine

<b>Did the home-based care worker do the following:</b>	<b>YES</b>	<b>NO</b>
<b>Assess</b>		
<b>Advise</b>		
<b>Assist</b>		
<b>Arrange</b>		

In the story Madele covered the following:

- a) Exclusive breastfeeding
- b) Immunisation
- c) Monitoring growth
- d) Blood tests
- e) Good, clean food
- f) Play (home-made toys)
- g) Ways of telling a young child about HIV
- h) Ways of remembering to take medicine

Ask if there are any questions or comments.

Thank the participants for taking part in Part 4.

## **Part 5: Supporting the caregiver of a child who becomes sick and gets better**

### **Trainer's introduction**

This part is about supporting the caregiver of a child with HIV infection who becomes sick and gets better. You will look at coping with common problems and when to refer a sick, young child to a clinic or hospital. We look, in particular at possible side-effects of ART and to be aware of child abuse.

Approximate length of Part 5: **2 hours**

### **Aims of Part 5**

The aims of Part 5 are to:

- Facilitate participants in dealing with common problems in looking after a young child with HIV.
- Revise when to refer for help.
- Gain awareness of the common problems associated with ART.
- Gain awareness of recognising and dealing with child abuse.

### **Key learning outcomes**

The key learning outcomes are as follows:

- Assessing common problems.
- Advising caregivers about common problems.
- Assisting the caregiver with common problems.
- Arranging transport to the clinic or follow up.
- Revising danger signs.
- Recognising the common problems of ART.
- Recognising and referring children where abuse is suspected.

## Trainer's preparation

Planning Part 5 (suggested times):

Assessing, advising, assisting and arranging 10 minutes

Common problems:

- |                       |            |
|-----------------------|------------|
| 1. Active feeding     | 15 minutes |
| 2. Fever              | 5 minutes  |
| 3. Diarrhoea          | 5 minutes  |
| 4. Constipation       | 5 minutes  |
| 5. Dry and sore mouth | 5 minutes  |
| 6. Skin problems      | 5 minutes  |
| 7. Cough              | 5 minutes  |

Danger signs 20 minutes

ART problems 10 minutes

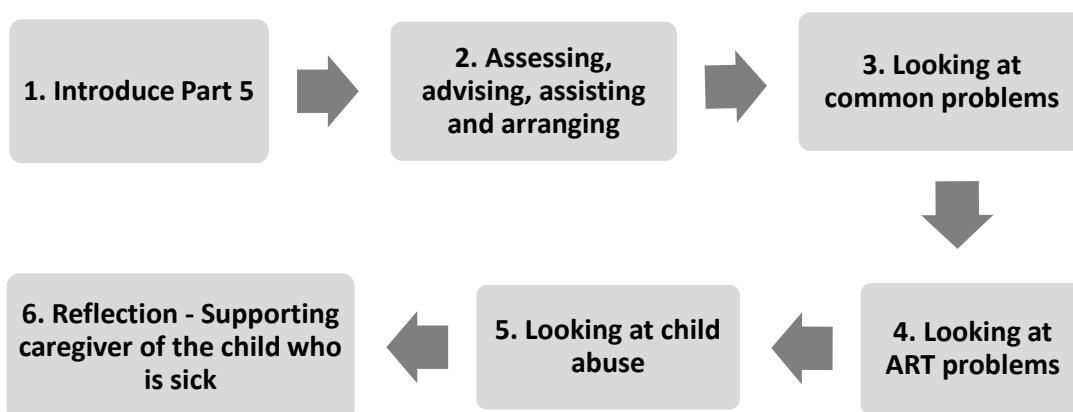
Child abuse 10 minutes

Reflection 25 minutes

## Materials you will need

- Guide for Home-based Care Workers
- Caregiver's Toolkit
- Flip-chart paper and pens

## Trainer's guidance



### ☀️ **Activity 1: Introducing Part 5**

You will explain to participants that Part 5 is about assessing, advising, assisting and arranging with common problems.

You will look at when to refer the sick child to a clinic. You will also discuss the special problems of ART and the danger of child abuse.

Ask participants to look at the diagram on page 35 in the Guide for Home-based Care Workers, *The Sick Child*.

### ☀️ **Activity 2: Assessing, advising, assisting and arranging**

Ask participants to turn to pages 36-38 in the Guide for Home-based Care Workers and together read the section on assessing, advising, assisting and arranging.

Ask participants if they have any comments or suggestions.

### ☀️ **Activity 3: Common problems we may face**

Give each participant a problem to work with:

1. Child not wanting to eat or drink
2. Fever
3. Diarrhoea
4. Constipation
5. Mouth problems
6. Skin problems
7. Cough
8. Danger signs (1-4)
9. Danger signs (5-10)

Ask the participants to read about their problem in the Guide for Home-based Care Workers (pages 39-49).

Each participant will stand in front of the group and discuss their problem, describing what they would do to:

- Assess
- Advise
- Assist
- Arrange

#### ☀️ **Activity 4: The special problems of ART**

Ask participants to turn to page 50 in the Guide for Home-based Care Workers and read this page together.

Together look at pages 17-20 in the Caregiver's Toolkit. Ask participants if they have any questions or comments.

#### ☀️ **Activity 5: Looking at the problems of child abuse**

Ask participants to form three groups. Provide flip-chart paper and pens.

**Group 1**      Discuss the different types of abuse that a child can suffer from: physical abuse, sexual abuse, emotional abuse and neglect.

**Group 2**      Discuss the signs or what would make you suspect that a child was being abused in any way.

**Group 3**      Discuss the different things you can do to help a child who is being abused in any way.

Ask a representative of each group to give feedback to the whole group.

Together read pages 51-53 in the Guide for Home-based Care Workers.

Together complete pages 21 and 22 in the Caregiver's Toolkit.

Ask the group what they would do if they suspected that a child was being abused.

It is very important that you (the trainer) know something about resources and referrals for abused children in the area so you can provide positive guidance.

### ☀️ **Activity 6: Reflection**

Read the story '**Supporting the caregiver of a child who is sick**' to the participants. This story deals with:

- a) Feeding a sick child
- b) Dealing with a distressed child

#### **Supporting the caregiver of a child who is sick**

It has been a few months since Madele began visiting Londiwe, Bongani and little Sizwe. She has visited them every second week but recently Sizwe has not been well and Madele is worried about him. She decides to visit the family. When she arrives at the home she finds that Londiwe is troubled. Sizwe has diarrhoea and he is crying.

Together Madele and Londiwe read through what needs to be done for Sizwe in the Caregiver's Toolkit. They see that there are some options for helping Sizwe. Madele explains that the most important thing is to increase the amount of fluids that Londiwe gives to Sizwe. Londiwe also needs to give Sizwe small amounts of food frequently. Together Madele and Londiwe go through the Helpful Handouts and revise on how to make Sugar Salt Solution which Londiwe can feed to Sizwe. Madele suggests that Londiwe can also give Sizwe some cornflower or custard powder mixed with a small amount of water or some peach and guava leaves crushed and boiled. Bananas are also good as well as plain yoghurt. Londiwe tells Madele that Sizwe usually likes to drink Coca Cola; Madele explains that this is fine as long as Londiwe leaves the coke to stand for a few minutes until all the bubbles have disappeared.

Madele reminds Londiwe to keep Sizwe's anal area clean by washing it gently with warm water after every loose motion. She should then pat the skin dry and gently rub aqueous cream or Vaseline.

Londiwe is a little unsure of whether or not she should take Sizwe to the clinic. Madele asks her a few questions to check. She asks Londiwe if Sizwe is passing urine, if there is any blood in his stools and if he has sunken eyes. Londiwe replies that Sizwe is passing urine normally, that there is no blood in his stools and his eyes are not sunken in. Madele then shows Londiwe how to use the skin pinch to check if Sizwe is dehydrated. Since his skin returns to normal after the skin pinch they decide that Sizwe is not dehydrated and does not need to go to the clinic. Madele suggests that Londiwe gives Sizwe lots of fluids and that she watches him carefully. Madele takes out her referral list and gives Londiwe Sister Dlamini's number and tells Londiwe to contact the sister at the clinic if she has any problems. Madele reminds Londiwe to keep all the food preparation clean, to wash her hands before and after preparing food and after cleaning Sizwe.

Madele asks Londiwe if there is anything else she needs help with. Londiwe explains to Madele that she finds it difficult to feed Sizwe when he is sick. Madele explains to Londiwe that it is very important to feed a sick child so that they can get better quickly and we have to find ways to encourage them to eat. It is important for Londiwe to pay close attention to Sizwe's eating habits, especially when he is sick. Breast milk is the best source of nutrition for any sick child and Londiwe should continue breastfeeding Sizwe. Madele explains that a child's stomach is small so they need to eat and drink often and they need to eat and drink enough of the right things to get their strength back. Londiwe should try to give Sizwe little amounts of food and drink as often as she can, even if Sizwe spits it out, Londiwe should be patient and keep trying.

Madele tells Londiwe about active feeding. She explains that active feeding is when we encourage the child to eat and keep the child interested in the food. There are many ways for Londiwe to encourage Sizwe to eat, she could talk to Sizwe and tell him how nice the food is, play games with the food, give him little amounts on a spoons and praise him when he eats. Madele explains that it is important to keep Sizwe close to her on her lap and feed him.

Londiwe tells Madele that she is concerned because she does not know why Sizwe won't eat. Madele explains that when children are sick they often lose their appetites and do not eat properly. They might not want to eat because of sickness, nausea, weakness or a sore mouth but it is important for Londiwe to continue trying to feed Sizwe small amounts of food and drink frequently.

Madele explains to Londiwe that feeding time is more than just giving a child food; it is also a time for Londiwe and Sizwe to bond. Londiwe should keep eye



contact with Sizwe, smile, talk and touch him. She should encourage him to eat and praise him when he does and be patient with him.

Sizwe begins to cry again and Londiwe seems very tired. Madele knows that dealing with a sick child who is distressed can be very hard for a caregiver and she decides to encourage Londiwe. She explains to Londiwe that children are too young to explain exactly what they want so they cry for many reasons – to let us know he is unhappy or in pain or to try to get our attention to tell us he needs to be changed or fed. It is normal for Sizwe to cry, especially when he is sick, and Londiwe should always be around when Sizwe is distressed. If she cannot be there, Londiwe can ask someone else for help.

To comfort Sizwe, Madele suggests that Londiwe pick him up and hold him close to her. She can move around, rock him gently and sing to him. Madele shows Londiwe how to massage Sizwe to comfort him. Londiwe picks up a soft blanket and gives it to Sizwe. She explains to Madele that Sizwe loves this little blanket and it comforts him sometimes. Londiwe thinks it is because it smells like her. Madele agrees, this blanket has special meaning for Sizwe and can comfort him even when Londiwe is not around. Madele explains that Sizwe can even suck on this blanket, a small cloth or his fingers as this can help him manage his pain.

Before Madele leaves she tells Londiwe that she should also be patient with herself. Dealing with a child who is sick and distressed can be very hard and sometimes Londiwe will need to take a break. When Londiwe feels this way, Madele offers to help find someone close to the family, like a relative, to take care of Sizwe for a little while.

Ask participants to comment on the story.

Recap the ways to encourage feeding and to comfort a distressed child.

Remind participants that it is also important for the caregiver to take every moment to offer comfort to the child when feeding, cleaning and washing – these are all times for the caregiver and child to bond.

### **Key messages for discussion from the story:**

The child had diarrhoea. Did the home based care worker:

- Assess, advise, assist and arrange?
- Did she check for danger signs?
- Did she check food and food hygiene?

This session may be distressing as home-based care workers may experience difficulties when dealing with sick and abused children.

It is good to unwind after a session like this.

1. Explain to participants that you are going to ask them to walk around the room or walk outside. Every now and again you will ask them to stop and talk a little to the person closest to them.
2. Ask participants to slowly walk this way and that way and call, "Stop."
3. When they stand still ask them to chat briefly to the person who is standing closest to them.
4. Ask participants to talk about the session. What did they feel about it? What was important to them?

Ask if there are any questions or comments.

Thank the participants for taking part in Part 5.

## **Part 6: Supporting the caregiver of a child who is sick and may not get better**

### **Trainer's introduction**

In Part 6 we look at the difficult topic of supporting a caregiver who has been told by a doctor or nurse that their child with HIV is very ill and may not get better.

Approximate length of Part 6: **5 hours**

### **Aim of Part 6**

The aim of Part 6 is:

- To facilitate the home-based care worker to support the caregiver, the child and the family when the child is very sick and may face death.

### **Key learning outcomes**

The key learning outcomes of Part 6 are:

- To increase awareness of the need to support a caregiver of a very sick child.
- To facilitate a caregiver to care for themselves.
- To support a caregiver in seeking assistance.
- To facilitate listening to a very sick child.
- To look at coping with a distressed child.
- To review preventing and treating common problems.
- To prepare for difficult questions and difficult situations.
- To facilitate involving the caregiver and child in decision making.
- To gain awareness of memory boxes.
- To recognise and deal with abnormal bereavement.

### **Trainer's preparation**

Planning Part 6 (with suggested times):

Why may it be good to care for a young, sick child at home?	10 minutes
Message 1	½ hour
Message 2	½ hour
Message 3	½ hour
Message 4	½ hour
Message 5	½ hour
Message 6	½ hour
Message 7	½ hour
Message 8	½ hour
Message 9	½ hour
Reflection	20 minutes

### **Materials you will need**

- Guide for Home-based Care Workers
- Caregiver's Toolkit
- Flip-chart paper and pens
- A ball of string

## Trainer's guidance



### ☀️ Activity 1: Introduction to Part 6

You will tell participants that Part 6 is about supporting the caregiver of a child, when the doctor or nurse has told the caregiver that the child is very ill and may not get better.

Ask participants to look at the diagram on page 59 in the Guide for Home-based Care Workers, *The Child Who May Not Live*.

You will look at nine messages when supporting the caregiver of a very ill child.

Together read pages 57-58 in the Guide for Home-based Care Workers.

### ☀️ **Activity 2: Why it may be good to keep a young, sick child at home**

Ask participants to look at page 23 in the Caregiver's Toolkit.

Ask them to write or draw reasons why it may be good to keep a young, sick child at home.

Would anyone like to share what they have written with the whole group? Together again read page 59 in the Guide for Home-based Care Workers.

### ☀️ **Activity 3: Message 1 - Giving a little can mean a lot**

We focus on the importance of giving and of encouraging caregivers. Sometimes we may feel that we are not able to do a lot, but it is the small things we do that make a difference.

Ask participants to sit in a large circle.

Take out the ball of string. Ask everyone to hold the string in their hands so you form a "story-string". Each time you tell a story participants should hold this story-string.

Turn to pages 60-61 in the Guide for Home-based Care Workers and together read the story of *Daisy Flowers*.

Ask participants to talk together about what the story means to them. Allow them at least 10 minutes to discuss the story among themselves.

#### **Key messages:**

- Caregivers can make a big difference to the lives of young, sick children by doing even a little that is kind and comforting.
- Sick children are grateful for everything that is done to make them more comfortable and to feel better.

Ask participants to turn to the Caregiver's Toolkit, page 26. Draw a picture of a time when they have done something small and made a difference to people's lives. Ask if anyone wants to share their drawing with the group.

#### ☀️ **Activity 4: Message 2 - Be kind to yourself**

In this message we focus on how important it is that caregivers are kind to themselves.

Ask participants to hold the story-string. Ask participants to turn to pages 62-63 in the Guide for Home-based Care Workers and together read the story: *The Big Flowerpot*.

Ask participants to discuss the story.

Allow them at least 10 minutes to discuss the story among themselves.

#### **Key messages:**

- It is important for caregivers to be kind to themselves.
- Sometimes things do not turn out the way you expect them to.

Ask participants to form three groups. Provide a flip-chart and pens.

**Group 1**            Discuss what happens to our body if we are not kind to ourselves.

**Group 2**            Discuss what happens to our emotions if we are not kind to ourselves.

**Group 3**            Discuss what happens to our thoughts if we are not kind to ourselves.

Ask a representative from each group to give feedback to the larger group.

Together read pages 64-67 in the Guide for Home-based Care Workers.

Ask participants to turn to pages 27-28 in the Caregiver's Toolkit.

Ask participants to complete the table and write down or draw at least three ways that they can be kind to themselves.

## **Breathing relaxer**

Ask participants to stand up and make a big circle.

Ask them to imagine something that is worrying them today.

Take a big breath.

All blow out. Blow the worry away.

Participants may blow softly at first, so say “Come on, I didn’t hear you.”

Encourage them to use their whole body to blow out.

## **Massage**

Ask one participant to be seated. Ask another to stand behind and gently massage their neck and hands. Participants usually love this exercise.

## **Walk**

Ask participants to go for a short walk outdoors and bring back something from nature that will remind them to be kind to themselves.

## **☀️Activity 5: Message 3 - Ask for help**

In this session we learn how important it is for caregivers to ask for help when they are unsure of what to do. They must also know who to ask for help.

Ask participants to hold the story-string. Turn to pages 68-69 in the Guide for Home-based Care Workers. Together read the story *The Empty Cup*.

Ask participants to comment on the story. Allow them at least 10 minutes to discuss the story among themselves.

### **Key messages:**

- Know when to ask for help.
- Know who to ask for help.
- You are not alone with your problems.

Ask participants to turn to pages 29 and 30 in the Caregiver’s Toolkit.



Ask participants to form two groups and provide them with flip-chart paper and pens.

**Group 1**            Ask participants to draw circles of support to represent their own situation.

**Group 2**            Ask participants to complete a community map to represent their own situation.

Ask a representative from each group to give feedback to the whole group.

**Key point for discussion:**

- You may want to discuss the traditional healer as a potential source for help and also as a potential source for harm.

Together read pages 69-71 in the Guide for Home-based Care Workers.

**☀Activity 6: Message 4 - Listen to the child**

This session looks at how it may be difficult to listen to babies and young children. We know that it is very important to try our best to listen to sick, young children as they may be frightened or in pain.

Ask participants to hold the story-string. Turn to pages 72-73 in the Guide for Home-based Care Workers. Together read the story of *The Snake's Ears*.

Ask participants to discuss this story.

Allow them at least 10 minutes to discuss the story among themselves.

**Key messages:**

- Listen to the child not only with your ears but also watch the child carefully.
- Listen with your heart as well as your ears.
- Repeat what the child has said so you can be sure that you understood the child properly.

- Sit close to the child – she might want to sit on your lap, or very close to you on a chair or on her bed or on a mat on the floor.
- Hold her hand, give her a hug, look into her eyes when you listen to her, and talk gently and lovingly.

Ask three participants to volunteer for a role play:

- 1 participant acts as a frightened young child
- 1 participant acts as a caregiver
- 1 participant acts as a home-based care worker

Take the participant acting as a child aside and tell them they must act as a child who is being bullied at school because of their HIV status.

The child is angry and frightened and very withdrawn.

The caregiver and home-based care worker must try to get information from the child.

The child should not give information unless the caregiver makes a big effort (sings, tells a story or asks child to draw a picture).

After the role play ask participants to turn to pages 31-32 of the Caregiver's Toolkit.

Read these pages and ask participants to complete the following:

- List three reasons why it is good to listen to a young child.
- List five ways that they could listen better to a young child.

Would anyone share what they have written with the rest of the group?

Together read pages 74-77 in the Guide for Home-based Care Workers.

### ☀️ **Activity 7: Message 5 - Offer comfort to a distressed child**

In this session we look at how to comfort and manage distress in young children. We want caregivers to understand that they can do a lot to offer comfort.

Ask participants to hold the story-string. Turn to page 78 in the Guide for Home-based Care Workers. Together read the story of the *Snow White Flower*.

Ask caregivers to discuss the story. Allow them at least 10 minutes to discuss the story among themselves.

#### **Key message:**

- You can always offer some comfort.

Ask participants to turn to page 33 of the Caregiver's Toolkit.

Ask them to draw three things they could do at home to comfort a sick, young child.

Ask if participants would like to discuss their drawings with the larger group.

Together read pages 79-80 in the Guide for Home-based Care Workers.

### ☀️ **Activity 8: Message 6 - Prepare**

In this session we look at preparing the caregiver to answer difficult questions that the sick, young child or young brothers, sisters and friends may ask. We also look at preparing the caregiver for difficult situations.

Ask participants to hold the story-string. Turn to page 81 in the Guide for Home-based Care Workers. Together read the story of *Flowers from Heaven*.

Ask participants to discuss the story.

Allow them at least 10 minutes to discuss the story among themselves.

**Key messages:**

- A child may ask about illness, dying or death.
- We must be prepared to answer a child's difficult questions.
- A caregiver should be prepared to cope with difficult situations.

Ask the group to discuss why it may be difficult to talk to a young child and caregiver about dying and death.

Ask them to write their answers on a flip-chart.

Together read pages 82-83 in the Guide for Home-based Care Workers. Look at pages 34-35 in the Caregiver's Toolkit.

Ask participants to draw three reasons why it may be good to talk about dying and death.

Together look at the story on pages 36-38 of the Caregiver's Toolkit - *John and James*. Read this story and ask participants what they think about the story.

Ask participants to form two groups and provide them with flip-chart paper and pens.

**Group 1**            Discuss why it may be good to talk about dying and death.

**Group 2**            Discuss why it may **not** be good to talk about dying and death.

Ask a representative from each group to give feedback to the larger group.

Ask participants to form three groups:

**NOTE: Some groups may not want to carry out these role plays. Discuss this with the group first. If they do not feel comfortable then skip this exercise.**

- Group 1**            Role play caregiver and home-based care worker - my sick child no longer wants to eat or drink.
- Group 2**            Role play caregiver and home-based care worker - what will happen with the child immediately before death.
- Group 3**            Role play caregiver and home-based care worker - what will happen with the child immediately after death.

Together again read pages 84-86 in the Guide for Home-based Care Workers.

Ask participants to hold the story-string.

Together read the stories:

a) *The Turtle and the Eagle*, and b) *The Giant called Fear* on pages 44 and 45 of the Caregiver's Toolkit.

Ask participants to go for a ten minute walk and think about what has been discussed.

### ☀️ **Activity 9: Message 7 - Prevent and treat**

In this session we look at preventing and treating problems experienced by young children who are very ill. Caregivers should be supported to prevent problems arising and to be able to offer treatments.

Ask participants to hold the story-string. Turn to page 87 in the Guide for Home-based Care Workers. Together read the story of *The Red Moon*.

Ask participants to discuss this story.

Allow them at least 10 minutes to discuss the story among themselves.

**Key messages:**

- It is better to prevent problems before they arise.
- Treat problems that do occur.

Ask participants to form three groups and provide them with flip-chart paper and pens.

**Group 1**      Discuss how to prevent stiff joints.

**Group 2**      Discuss how to prevent bed sores.

**Group 3**      Discuss possible causes of pain in a very sick child.

Ask a representative from each group to give feedback to the whole group.

Together read pages 88-89 in the Guide for Home-based Care Workers (reading about bed sores and stiff joints).

Look at page 40 in the Caregiver's Toolkit: Draw a picture of how to prevent stiff joints.

Together read pages 90-93 in the Guide for Home-based Care Workers (reading about children's pain).

Ask participants to turn to pages 39 and 40 in the Caregiver's Toolkit. Explain about the pain-faces and the pain table (looking at pain in a young child).

Ask participants to call out the names of any medication they know for pain. Write the names on a flip-chart.

Describe a little about each of the medicines that have been listed. Add and discuss any medicines they have left out.

Ask participants to read pages 107 and 108 in the Guide for Home-based Care Workers.

**Key point for discussion:**

Pain medicine must be given as follows:

- The right medicine
- The right time
- The right way
- The right amount
- Give regularly to stop pain from coming back

☀️**Activity 10: Message 8 - Empower**

In this session we look at why it is very important to empower young children, caregivers and their families.

Empowering others means that you help people come up with solutions to their problems and do not try to do everything for them as if they were helpless.

Ask participants to hold the story-string. Turn to pages 94-95 in the Guide for Home-based Care Workers. Together read the story *The Boy and the Flowers*.

Ask participants to discuss this story. Allow at least ten minutes for feedback about this story.

**Key messages:**

- Allow the child, caregiver and family to come up with a possible solution.
- Work out how together you can make the solution happen.

Ask participants to form two groups and provide them with flip-chart paper and pens.

**Group 1** Discuss reasons why it would be good to empower a child, caregiver and family.

**Group 2** Ask the group to provide specific examples of how they have empowered families or will empower families.

Ask a representative from each group to give feedback to the larger group. Together read pages 95-96 in the Guide for Home-based Care Workers.

Look at page 41 in the Caregiver's Toolkit.

Ask participants to quietly draw their own main problem today. Ask them to draw the main problem of a child they care for.

Draw one thing they can do to solve their own problem.

Draw one thing they can do to support a child solve a problem.

Ask if anyone would like to give feedback to the whole group.

### ☀️ **Activity 11: Message 9 - Remember**

In this session we look at the importance of remembering those who have died and discuss some ways to do this. We also look at abnormal bereavement.

Ask participants to hold the story-string. Turn to pages 97-98 in the Guide for Home-based Care Workers. Together read the story of *The Wax Child*.

Ask participants to discuss this story. Allow at least ten minutes for feedback about this story.



**Key messages:**

- People can find much comfort in remembering those who have died.
- People should be helped to remember those who have died.
- We should support caregivers and their families during bereavement.
- We should know about abnormal bereavement.

Ask participants to turn to pages 99-102 in the Guide for Home-based Care Workers. Read these pages together.

Ask caregivers to write or draw in the Caregiver's Toolkit what they think could go into a memory box (Page 42 of Caregiver's Toolkit). Everyone will be able to think of things themselves but here are some ideas:

- Stories: children, caregivers, families and friends can write or draw pictures that tell a story.
- Photographs: home-based care workers could try and get a photograph of the child with a family member. Write the date on the back of the photograph. Also write who is in the photograph.
- Familiar objects: caregivers and children can put something they have used a lot in the memory box. They could put in a cup or plate that they like.
- Drawings: adults and children could place a drawing in the box.
- Letter: an adult could write a child a letter telling her how much the child is loved. The caregiver could write a short note to tell the child about things that are important.

Ask participants to again turn to page 101 in the Guide for Home-based Care Workers. Again read the section on memory boxes.

Ask participants to form two groups and provide them with flip-chart paper and pens.

**Group 1** Discuss how adults grieve the loss of a loved one.

**Group 2** Discuss how children grieve the loss of a loved one.

Ask a representative of the group to give feedback to the whole group.

Look at page 43 in the Caregiver's Toolkit.

Ask participants to draw a picture of how they would feel if a young child dies. Ask them to draw a picture of how young children feel if someone they know dies.

Ask if anyone would like to give feedback to the larger group.

### ☀️ **Activity 12: Reflection**

Part 6 has been a long session.

Remind the participants of the nine messages and the name of each story we used when looking at the nine messages.

Read the story '**Supporting the caregiver of child who is ill, memory work and bereavement**' to the participants.

#### **Supporting the caregiver of child who is ill - memory work and bereavement**

A few weeks after Madele last visited Londiwe and Sizwe, she gets a call from Londiwe who tells Madele that the doctors have told the family that Sizwe will soon die. Madele promises to visit the family. That afternoon Madele goes to the home to find that the parents are very sad. Madele asks Bongani and Londiwe if Sizwe is still in pain. Both parents agree that Sizwe is in pain because he cries a lot. Madele takes out her Pain Faces Scale and explains to Sizwe's parents that each face shows a level of pain. She asks them to show her which face matches Sizwe's pain. They both agree on a face on the lower end of the scale, showing that Sizwe does not have a lot of pain. Madele asks Londiwe if she has any pain

medication for Sizwe. Londiwe shows her the bottle of Panado syrup that she was given at the clinic and explains that the clinic sister told her to give Sizwe half a teaspoon no more than 3 times a day whenever Sizwe is in pain. Madele shows Londiwe and Bongani how to massage Sizwe and tells them that this will also help to take away some of his pain and comfort him.

Madele asks the parents if there is anything else that is bothering them. Bongani says that they do not know whether they should tell Sizwe's brothers and sisters that he will soon die. They would like to tell them but do not know how to.

Madele suggests that they tell the children a story and let them ask questions. She reads them the story of the water insects and dragonflies which she finds on page 37 of her Caregiver's Toolkit. Bongani and Londiwe both love the story and feel comfortable sharing it with the other children.

Madele has brought her own memory box with her. She explains that she has made this memory box with her own children so that they have something to remember her by one day when she is no longer with them. Madele explains that together Bongani, Londiwe and Sizwe's brothers and sisters can make their own memory box for Sizwe and it will help them remember him when he is gone.

Madele leaves the family to work together.

Ask for questions or comment on the story.

**Key points for discussion on story:**

- Why may it be a good idea to tell the sick child's brothers and sisters about dying and death?
- Discuss the home-based care worker telling the story and the family's reaction to the story
- Did she assess the cause of pain?
- Did she advise?
- Did she assist?
- Did she arrange?
- Was the home-based care worker right in telling the caregiver to give medicine only when the child has pain?

- Do the home-based care workers in your group feel that they could make use of memory boxes?
- Who could the home-based care worker refer to if she felt that the caregiver or child was experiencing abnormal bereavement?

Tell participants that this part may be emotionally challenging.

Ask each participant to turn to the person next to them and tell that person how they are feeling.

Allow five minutes for this.

Ask for any questions or comments.

Thank everyone for taking part in this difficult Part 6.

## Part 7: A way forward

### Trainer's introduction

This part is essential. It is vital that this course closes in a way so the participants feel prepared to continue with their work and remain positive.

Approximate length of Part 7: **1 hour**

### Aims of Part 7

The aims of Part 7 are:

- To plan how home-based care workers will use the Caregiver's Toolkit with caregivers at home.
- To allow participants to debrief.
- To get feedback on the course.

### Key learning outcomes

The key learning outcomes of Part 7 are:

- Participants have a plan of how to support the delivery of palliative care in the home.
- Participants experience a positive end to the course.
- To say goodbye to the group.
- To make appropriate links for the future.

### Trainer's preparation

Planning Part 7 (with suggested times):

Planning how to deliver palliative care using Caregiver's Toolkits	30 minutes
Reflecting on the course	20 minutes
Closing the course	10 minutes

## Materials you will need

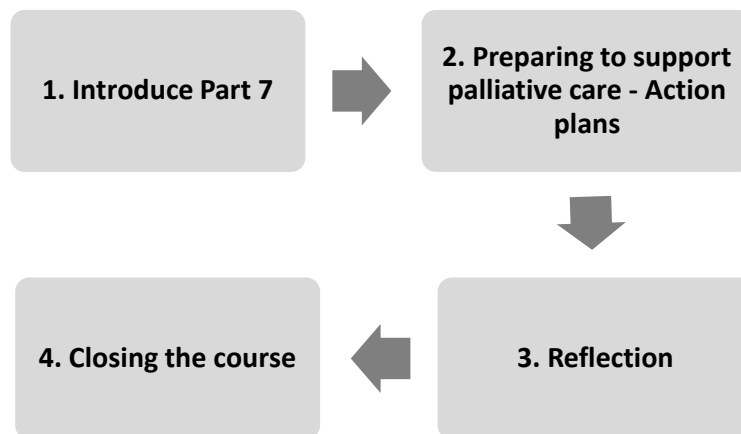
Paper and pens so participants can get each other's contact details.

Flip-chart paper and pens.

Scissors to cut story-sting

Signed certificates

## Trainer's guidance



### ☀️Activity 1: Introducing Part 7

Say that the group has worked well together. It is important to acknowledge all their hard work.

Part 7 is about preparing to deliver palliative care and about saying goodbye.

### ☀️Activity 2: Preparing to deliver palliative care

Ask participants to form three groups and provide them with flip-chart paper and pens.

Give participants 15 minutes to discuss caregivers they already support.

How do they plan to use this course and the Caregiver's Toolkit in caregiver homes?

Participants must give specific details of their plan.

You may want to ask them to make up an action plan like the one below.

<b>ACTION</b>	<b>Caregiver Name</b>	<b>Caregiver Name</b>	<b>Caregiver Name</b>
<b>Talk about palliative care</b>			
<b>Look at needs</b>			
<b>Discuss caring for well child</b>			
<b>Discuss caring for sick child</b>			
<b>Discuss checkups for caregiver</b>			
<b>Look at discussing HIV status</b>			
<b>Look at adhering to medicine</b>			
<b>Look at caring for child who may not get better</b>			
<b>Make a memory box</b>			

Ask each person to give individual feedback to the whole group.

Ask the group for comments, suggestions and questions.

### ☀️ **Activity 3: Reflecting on the course**

Ask participants to form three groups and provide them with flip-chart paper and pens.

Ask each group to reflect on the following:

- a) What are the most important things you learned during this course?
- b) What would you like to spend more time on?

- c) What skills have you developed?
- d) What strengths have you identified: in yourself, among participants, in your families, in your community?
- e) What support is available to take forward ideas from this course?
- f) What have you most enjoyed about this course?
- g) If you have a chance to attend another course, what would you change next time?

Bring the groups back together.

Ask volunteers to report back on their group's discussion.

Read the story '**Andiswa and Cindy**' to the participants.

Tell the participants to pay special attention because you are going to ask them to decide what to do at the end of the story.

#### **Andiswa and Cindy**

During a very busy week Madele decides to pay a quick visit to Andiswa, the new mother. Andiswa's mother has passed away and she is left alone to care for little Cindy. When Madele enters the home she notices that the house is dirty, there is a pot of open food on the stove and there are clothes lying around the floor.

Andiswa seems overwhelmed and Cindy is crying. Andiswa shows Madele the bed that Cindy sleeps in, it is stained because Cindy has diarrhoea. Andiswa tells Madele that Cindy cries often and she suspects she is in pain because of something on her upper thigh. Madele asks Andiswa if she has been to the clinic. Andiswa tells Madele that she has been to the clinic, the medication she received from the clinic is finished and she has no money to get more medication.

Madele has a look at Cindy and notices that Cindy's face, arms, legs and tummy are all swollen. Andiswa tells Madele that Cindy is almost 1 and half years old but does not walk; Cindy does not want to stand up either. Andiswa seems to be having a hard time caring for Cindy on her own and Madele knows that she has to pay special attention to this family and provide extra care and support.



**Key points for discussion from the story:**

What were the child's problems?
<ul style="list-style-type: none"><li>• Diarrhoea</li><li>• Pain</li><li>• Not walking</li><li>• Distressed</li><li>• Rash</li><li>• Kwashiorkor</li></ul>
What were the caregiver's problems?
<ul style="list-style-type: none"><li>• No money</li><li>• Not coping</li></ul>
What were the family's problems?
<ul style="list-style-type: none"><li>• No food</li><li>• Dirty house</li></ul>

- How would you assess the cause of diarrhoea - what are the possible causes?
- How would you assess for pain - what were the possible causes?
- How would you assess why Sindy is not walking?
- What advice would you give Andiswa e.g.:
  - SSS
  - Hygiene (food and home)
  - Danger signs
  - Pain medication
  - Referral

Problems that need attention a) diarrhoea b) hygiene c) pain and d) referral to find out why the child is not walking.

#### ☀️Activity 4: Closing the course

Thank the groups for their feedback.

Say that you hope they have learned a lot from this course and that they will carry on the good work they have started.

Also say that their feedback will help you improve the course for other participants.

Please be aware the participants may feel a sense of loss. This is because they have covered sensitive topics with each other and have worked hard.

For some participants this may be the first time that they have had an opportunity to discuss sensitive things around illness, dying and death. These people may experience a strong sense of loss.

Explain that the aim of this last activity is to bring the time of working together as a group to an end. Say that because people may have strong emotions that it is necessary to “close” the group.

Cut the story-string into nine pieces and give each participant a piece of the string as a memento of this course.

Give each participant a signed copy of the certificate “Palliative Care for Young Children at Home in Africa: Home-based Care Workers”

Remind participants of confidentiality. Say that it is important that private information shared within the group is not shared with other people.

Remind everyone of the action plans they have written. Encourage the group to take these action plans forward.

Finish by thanking the group for their contributions and their hard work.

Say that you have enjoyed working with them.

Wish them well.

Finish with a song and a prayer if this suits your group.

At the end of the course you will discuss the participant feedback with your co-trainers and supervisors.

## Palliative Care at Home for Young Children in Africa: Knowledge and Practical Competencies

### Information for Managers and Administrators

By the end of the course: “Palliative Care at Home for Young Children in Africa: Training and Support Package” we expect your home-based care workers to have knowledge and skills in the following key areas:

### Knowledge and Skills Competencies

<b>Knowledge and skills on palliative care</b>	An understanding of palliative care? How to prioritise problems using the ‘assess, advise, assist and arrange’ method.
<b>Keeping a child well</b>	How to protect a child from germs. Know about breastfeeding, bottle/formula feeding and preparing good, clean food. Knowing about the importance of play and good parenting. How to support caregivers to care for themselves. Telling a young child age-specific messages on HIV. Encouraging a young child to take medicine.
<b>Caring for the sick child who gets better</b>	Finding out what is causing an illness. ASSESS ADVISE ASSIST ARRANGE Common problems faced by a child with HIV* Knowing the “danger signs” and when to refer. Knowing about the special problems of ART. Knowing about the special problems of child abuse.
<b>Caring for the sick child who may not get better</b>	Why might it be good to care for a child at home. Delivering the nine messages in caring for very sick children at home.
<b>*Common problems</b>	Pain, not eating, fever, vomiting, diarrhoea, constipation, skin problems, mouth problems and cough.

### Knowing about medicines used in caring for sick, young children at home

1. The child should take the right amount of medicine - the medicine container usually tells you how much to give. Do not give too much. Do not give too little.
2. The child should take the medicine at the right time - the times to take the medicine are usually written on the medicine container or in the child’s clinic/hospital records.
3. The child should finish all the medicine.
4. With ART the child must take the medicine every day.

**Palliative Care at Home for Young Children in Africa: Knowledge and Practical Competencies**

**Evaluation of Basic Competencies**

Topic	Competency	Yes	No
<b>Part 1: Palliative care</b>	A good understanding of palliative care.		
	Being able to prioritise problems and assess, assist, advise and arrange.		
<b>Part 2: Keeping a child well and preventing germs from spreading</b>	Cleaning up body fluids		
	How to hand wash		
	Dealing with cuts and sores		
	Cough hygiene and disposing of sputum		
	Protecting from mosquitoes		
<b>Feeding</b>	Know about breastfeeding		
	Knowing about bottle/formula feeding		
	Knowing about preparing good, clean food		
<b>Playing and parenting</b>	Knowing about the importance of play and giving advice on playing.		
	Knowing about good parenting and giving advice on parenting		
	Knowing how support caregivers to care for themselves		
<b>Telling a young child about their HIV infection</b>	<b>Knowing:</b>		
	WHY		
	WHEN		
	WHO		
	WHAT		
	HOW		
<b>Encouraging adherence to medicines</b>	How much medicine to give		
	How to give the medicine		
	When to give the medicine		
	How to remember to give the medicine		

**Palliative Care at Home for Young Children in Africa: Knowledge and Practical Competencies**

**Evaluation of Basic Competencies**

<b>Topic</b>	<b>Competency</b>	<b>Yes</b>	<b>No</b>
	How to encourage taking medicine		
<b>Part 3: Caring for a sick child</b>	<b>Dealing with:</b>		
	Poor feeding		
	Fever		
	Diarrhoea		
	Vomiting		
	Constipation		
	Mouth problems		
	Skin problems		
	Cough		
<b>Danger signs</b>	Recognising danger signs and knowing when to refer for help.		
<b>ART</b>	Knowing the side effects of ART		
<b>Child abuse</b>	Recognising child abuse and knowing what to do and who to ask for help.		
<b>Part 4: Caring for the child who may not get better</b>	Dealing with pain		
	Dealing with distress		
	Dealing with a child who no longer wants to eat		
<b>Talking about dying and death</b>	Assisting a caregiver to discuss dying and death with very sick young child and siblings.		
<b>Memory boxes</b>	Knowing when and how to use memory boxes		
<b>Bereavement</b>	Recognising abnormal bereavement and knowing where to get help.		

# Palliative Care at Home for Young Children in Africa:

## Training and Support Package



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## **Palliative Care for Young Children at Home in Africa: Training and Support Package**

This home-based training and support package is designed to train those involved in caring for very sick young child at home. It is also designed to support families in looking after a very sick child.

### **The support and training package contains:**

#### **1. Guide for Home-based Care Workers**

Groups of home-based care workers will be trained to base their own training courses on this guide and to use it in their own field work.

#### **2. Training Manual for Home-based Care Workers**

Once they are familiar with the course, the home-based care workers will use this manual to train other groups of home-based care workers.

#### **3. Caregiver's Toolkit**

As a caregiver, your home-based care worker will go through this toolkit with you so that you become familiar with it. You can always refer back to this toolkit whenever you are in doubt.

#### **4. Helpful Handouts**

As a caregiver, your home-based care worker will provide you with a set of Helpful Handouts that contain important information on caring for your child.



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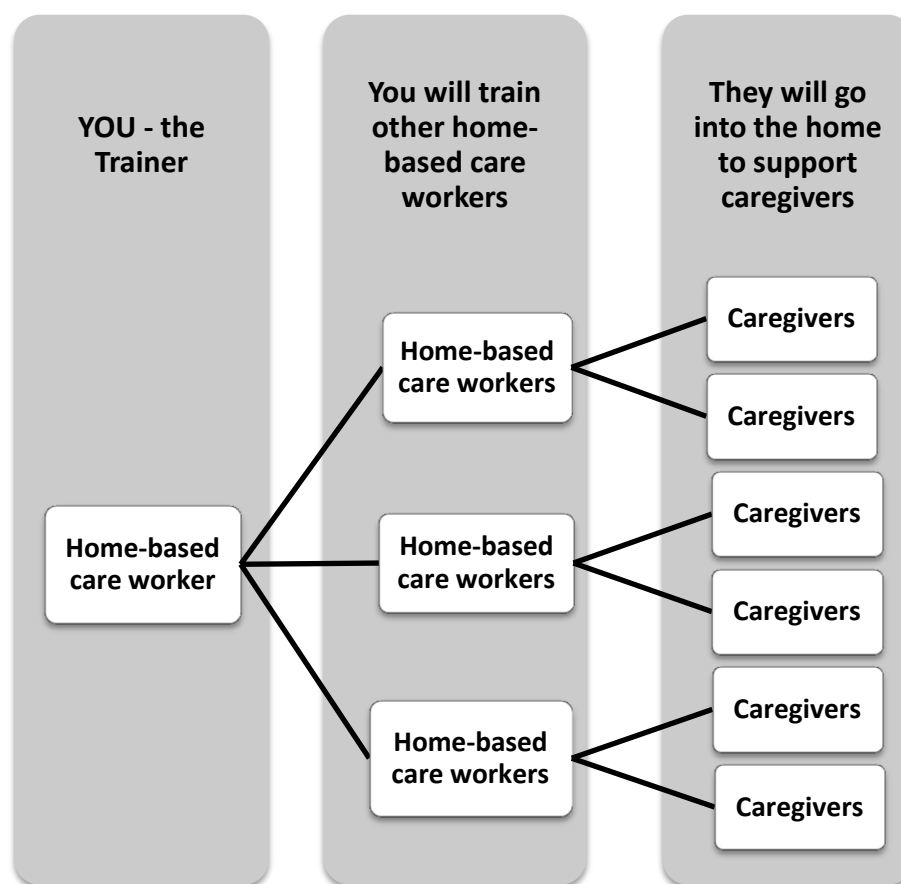
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## Telling you about this course

We know that across the whole of Africa, people are caring in their own homes for young children who are living with HIV. This course is about palliative care and supporting the caregivers of a young child who has HIV infection.

You will be trained to deliver this course to other home-based care workers. Other home-based care workers will then deliver parts of this course to caregivers, children and families in their own home.

This diagram explains what will happen.



*Diagram 1: Training home-based care workers to support caregivers of young children with HIV*

We want home-based care workers to support those who care for children most of the time and we refer to these people as “caregivers”. We discuss palliative care later.

As a trainer, we hope that you will make sure that home-based care workers do the following when you deliver this course:

- Have the chance to share their ideas and experiences with you and with each other.
- Know that they are respected and valued.
- Learn more about how to support caregivers who care for young children with HIV.
- Want to try out ideas and activities they learn in this course.
- Want to share their new knowledge with others.
- Enjoy the course. We know that learning takes place more easily when people are relaxed and are enjoying themselves. Although some of the topics may be distressing, people can be relaxed and enjoy this time of learning and sharing with others.

Throughout the course, we make use of stories as a means of opening up discussion. Here is a story to remind you about becoming aware of the different learning needs of the home-based care workers you train during this course.

## *Mrs. Elephant*

*Be aware of the learning needs of the home-based care workers you will train*

*A young child has to go to a new school and is very nervous. When she arrives at the school the teacher is talking in a very loud voice - just like an elephant. The children call the teacher "Mrs. Elephant". The child is very frightened of the teacher's loud voice and goes to hide in a tall tree. The tall tree is surrounded by soft, green grass. The teacher sees the girl hiding in the tree. She takes all the children out to sit under the tree and begins to tell a story in a very loud voice. The story is about a lonely jackal. The teacher lowers her voice as the story continues and the girl leans forward to hear the story. Eventually the teacher is speaking very softly and the girl listens and falls out of the tree and lands on the soft grass. She joins the other children to hear the end of the story.*



- You know that people learn in many different ways: some like to learn by reading, some like talking and some like drawing.
- You can encourage people to learn by noticing how they learn best and by being kind to them - like Mrs. Elephant did.
- Trainers are very special people.

We will now look at:

- Pre-course planning
- The aim of this course
- How to deliver the course
- Structure of Parts 1-7
- Size of the group
- Length of the course
- Tips for you

## *Pre-course planning*

You should plan for a training course well in advance.

You will need to do the following:

- Discuss the course and course evaluation with the managers and administrators of a home-based care organisation.
- Find an appropriate venue.
- Organise refreshments.
- Copy books and handouts.
- Get flip-chart paper and pens.
- Prepare name badges for yourself and participants.
- Find out about resources for referral in the area where you will train (we will discuss this further on page 33).

## **Discussing this course with managers and administrators in home-based care organisations**

We want home-based care workers to support caregivers to offer palliative care at home for young children who have HIV. After this course you will not be able to check if the home-based care workers understand this course and do as you request, so it is important that you make sure they understand everything before the course ends.

Before you run this course you must tell the managers and administrators of home-based care organisations about this course.

It is important that managers and administrators know about what you will teach so that they can continue to support their home-based care workers after the course. You should give the managers and administrators a copy of the “Palliative Care at Home for Young Children in Africa: Knowledge and Practical Competencies” (page 81). Explain that they should expect the home-based care workers to have these competencies once they have gone through the training.

You should also give the managers and administrators a copy of the “Palliative Care at Home for Young Children in Africa: Evaluation of Basic Competencies” (page 82). Explain that this gives the managers and administrators some tools to use to check if home-based care workers are doing well at supporting caregivers of young children with HIV at home.

You should also provide managers with copies of the training materials so that they can use them for ongoing revision and assessment.

### *What is the aim of this course?*

The aim of this course is to teach home-based care workers how to support caregivers of young children who have HIV. The course will provide home-based care workers with information and practical tools on the following:

- Palliative care.
- Supporting a caregiver who looks after a child with HIV who is well.
- Supporting a caregiver whose child with HIV becomes sick and gets better.
- Supporting a caregiver whose child with HIV is very sick and may not get better.

The home-based care worker will have a chance to practise the following aspects of palliative care:

- Identifying, prioritising and seeking solutions to caregiver, child and family problems (assess, advise, assist and arrange).
- Supporting a caregiver to care for themselves.
- Telling young children about HIV.
- Supporting a caregiver to give medication to a young child.
- Dealing with common problems.
- Knowing when to refer a sick child to a clinic.



- Supporting a young child and the family when a child is very ill and may die.
- Recognising and dealing with abnormal bereavement.

### *How to deliver the course*

The course has the following materials:

- Palliative Care at Home for Young Children in Africa: Training Manual
- Palliative Care at Home for Young Children in Africa: Guide for Home-based Care Workers
- Palliative Care at Home for Young Children in Africa: Caregiver's Toolkit
- Palliative Care at Home for Young Children in Africa: Helpful Handouts 1-7
- **Palliative Care at Home for Young Children in Africa: Training Manual**  
You keep this manual for yourself and use it when delivering this course to home-based care workers.
- **Palliative Care at Home for Young Children in Africa: Guide for Home-based Care Workers**  
Together you and home-based care workers will go through this guide. It covers a lot of important material.
- **Palliative Care at Home for Young Children in Africa: Caregiver's Toolkit**  
This toolkit will be used by both you and home-based care workers during this course. The home-based care workers will receive extra copies of the toolkit which they will take with them into a home. Together the home-based care workers and caregivers at home will go through the toolkit so caregivers at home can learn about palliative care for a young child with HIV.

- **Palliative Care at Home for Young Children in Africa: Helpful Handouts 1-7**

You will make copies of these handouts for home-based care workers and will use them for revising basic home-based care. The handouts are labelled as follows:

1. Ways of keeping germs away
2. Breastfeeding
3. Formula feeding a baby
4. Foods that are good for growth and food hygiene
5. Dealing with diarrhoea and fever
6. Skin and mouth problems
7. Danger signs

**The trainer's course consists of seven parts:**

Part 1 Introducing yourself, participants and the course.

Part 2 Revision: basic home-based care.

Part 3 Palliative care.

Part 4 Supporting a caregiver whose child with HIV is well.

Part 5 Supporting a caregiver whose child with HIV becomes sick but gets better.

Part 6 Supporting a caregiver whose child with HIV is very sick and may not get better.

Part 7 The way forward.

The course is designed to be flexible. For example, if the group feel they know enough about basic aspects of home-based care (Part 2), it is possible to cover these aspects quickly. As you go through this manual you will see that each part has a consistent structure, shown in the box below to help you plan the training session.

## *Structure of Parts 1-7*

### **Trainer's introduction**

This includes:

- The approximate length of the session
- The aims of this session
- The key learning outcomes

### **Trainer's preparation**

- This tells you about activities that will be carried out in each session.
- It provides suggested times for each activity.
- It provides a list of materials you will need for each session.
- If these materials are not available then try and find similar materials that are appropriate and available to you.

### **Trainer's guidance**

- Under this heading we give more details on the activities of the session.
- We offer guidance on how to tackle each activity.
- We suggest key points for discussion.

The times we give are suggestions as sometimes home-based care workers may want to talk a lot about things that are bothering them.

### *Size of the group*

We recommend that you deliver the course to at least nine home-based care workers. This will enable you to divide the group into smaller groups of three people. Groups that are too large (more than 20 people) will be difficult to manage.

### *Length of the course*

The course is intended to run over three days. However, the length will depend on the previous knowledge, training and experiences of the participants in basic home-based care.

If participants are well trained in basic home-based care then you could spend less time on aspects of the course that they already know.

If participants have not covered basic home-based care then you will spend time with them to ensure that they are confident and competent in basic home-based care tasks.

We look at basic home-based care later when we discuss revision of basic home-based care in Part 2.

### *Tips for you*

Here are some tips that may be useful to you:

- Prepare well for the course.
- Participate in the discussions yourself and encourage everyone else to take part.
- Be creative with the way in which you deliver the training. You can use skills that you have and methods that you feel will enhance the training. For example, we use a 'story-string' – this is just a long piece of string that we ask each participant to hold as they sit in a circle while we tell stories. This makes everyone feel included and is a symbol of unity in the training process – remember we are all here together to help each other learn more about the important work that we do.

- Have a list of people who you can turn to if you feel out of your depth.
- Be flexible.
- Be reassured that it is alright if you don't know all the answers to participants' questions.
- If you are tired, take a break.
- Look after yourself well when you are training as you may become exhausted and give yourself a treat when you finish the course.
- You will find a summary of the course with suggested times for each part in Table 1.

**Table 1: Outline of course**

<b>Part</b>	<b>Main content</b>	<b>Time</b>
<b>Part 1: Introduction to the course</b>	<ul style="list-style-type: none"> <li>• Introducing yourself and the participants</li> <li>• Looking at the Guide for Home-based Care Workers the Caregiver's Toolkit</li> <li>• What is the course about? What will you learn?</li> <li>• Who are caregivers?</li> <li>• Why focus on caregivers of children with HIV?</li> </ul>	1 hour
<b>Part 2: Revision of basic home-based care</b>	<ul style="list-style-type: none"> <li>• Revising basic home-based care</li> </ul> <p>Note: The time for this session will depend on the previous training and experiences of home-based care workers. If there is no previous training, allow 4 hours.</p>	5 hours
<b>Part 3: Palliative care</b>	<ul style="list-style-type: none"> <li>• Palliative care</li> <li>• The needs of children and the needs of caregivers</li> <li>• Anticipating problems that home-based care workers may experience</li> </ul>	2 hours
<b>Part 4: Supporting the caregiver of a child who has HIV infection and is well</b>	<ul style="list-style-type: none"> <li>• How to keep the child well</li> <li>• How to support the caregiver to care for themselves</li> <li>• Telling a young child about HIV</li> <li>• Encouraging a young child to take medicine</li> </ul>	2 hours
<b>Part 5: Supporting the caregiver of a sick child who gets better</b>	<ul style="list-style-type: none"> <li>• Finding out what is causing an illness</li> <li>• ASSESS, ADVISE, ASSIST &amp; ARRANGE</li> <li>• Common problems faced by a child with HIV</li> <li>• When to refer</li> <li>• Possible side effects of ART</li> <li>• The special problems of child abuse</li> </ul>	2 hours
<b>Part 6: Supporting the caregiver of a child who may not get better</b>	<ul style="list-style-type: none"> <li>• Why keep a sick child at home</li> <li>• Looking at the nine messages</li> </ul>	5 hours
<b>Part 7: The way forward</b>	<ul style="list-style-type: none"> <li>• Drawing up an action plan</li> </ul>	1 hour
<b>Complete Course</b>		18 hours

## **Part 1: Introducing yourself, the participants and the course**

### **Trainer's introduction**

This part of the course is essential. It tells participants about you and about each other. It tells participants about how the course will be run and what the course is about. It also tells them what they will learn.

Approximate length of Part 1: **1 hour**

### **Aims of Part 1**

The aims of Part 1 are to:

- Introduce yourself.
- Introduce the participants to each other.
- Present the aims of the course.
- Introduce the key learning outcomes of the course.

### **Key learning outcomes of Part 1**

By the end of Part 1 the participants will:

- Know a little bit about you.
- Have introduced themselves to each other.
- Have knowledge about how the course will be run.
- Have knowledge of what the course is about.
- Have knowledge of the key learning outcomes of the course.

## Trainer's preparation

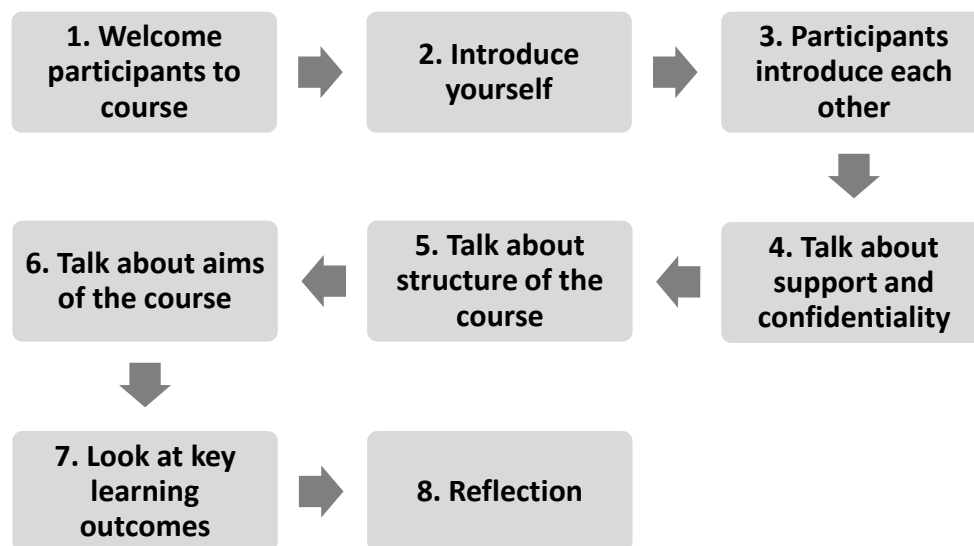
Planning Part 1 (with suggested times):

Introducing yourself	5 minutes
Introduction of participants	15 minutes
Mutual support and confidentiality	5 minutes
Structure of the course	5 minutes
Aims of the course	5 minutes
Discuss key learning outcomes of the course	5 minutes
Reflection	20 minutes

## Materials you will need

- Bean bag (small bag or packet filled with beans or sand)
- Guide for Home-based Care Workers
- Caregiver's Toolkit

## Trainer's guidance





### ☀️ **Activity 1: Welcome and introduction to Part 1**

Welcome everyone to this first part of the training course: **Palliative Care at Home for Young Children in Africa**. Start this session by telling participants that you are going to introduce yourself then they are going to introduce each other. Tell participants that you will tell them about the course.

### ☀️ **Activity 2: Introduce yourself**

Introduce yourself by saying your name and giving some information, such as how long you have been involved in home-based care, where you live, how many children you have, and why you have been selected to be a trainer. Ask the group to ask you questions about yourself. If it suits you and your group, begin the session with a song or prayer.

### ☀️ **Activity 3: Introduction: Home-based care workers**

If the home-based care workers already know one another, you will only need to go around the group and ask each person to say their name.

If the home-based care workers do not know each other you will have to think of a way for them to introduce themselves. Choose one of the following or think of an activity you know the participants will enjoy:

- Each person stands up and says his or her name, where he or she lives and why he or she has decided to join your group today.
- Ask participants to work in pairs. Each participant tells his or her partner something about him/herself. For example, the names of his/her children, where he or she lives and what work he or she does. Then each participant introduces his/her partner to the rest of the group by telling them what he/she has learned about their partner.
- Each person stands up and says his/her name and describes him/herself by using a word that starts with the same letter as his/her name. For example, "I am Thandi and I am tiny."
- Toss a bean bag from one person to another - call out the person's name as you toss it to them.

#### ☀️ **Activity 4: Participant support and confidentiality**

In this activity you will discuss issues of confidentiality. Over the next few days you and the participants will share stories, views and experiences. Some of these may be private and sensitive and it is important that you support each other.

It is important that you do not tell anyone else about what others say during this course that is private or confidential.

Ask each participant in turn to say:

- “I participant name will do all I can to support other participants during this course.”
- “I participant name will not repeat anything that is said during this course that is private or confidential.”

#### ☀️ **Activity 5: Telling participants about the structure of this course**

Tell participants how long the course will last. Ask participants to turn to page 105 in the Guide for Home-based Care Workers to look at an outline of the course.

Tell participants about the seven parts of the course (You can write the seven parts on flip-chart paper and stick the piece of paper on a wall).

Tell participants about the books and handouts:

**Palliative Care at Home for Young Children in Africa: Guide for Home-based Care Workers** - this book is for them to keep.

**Palliative Care at Home for Young Children in Africa: Caregiver’s Toolkit** - this book will be used by home-based care workers during this course. They will receive extra copies of this which they will take with them into a home. Together the home-based care workers and caregivers at home will go through the toolkit so caregivers at home learn about palliative care for a young child with HIV infection.

**Palliative Care at Home for Young Children in Africa: Helpful Handouts 1-7.** The handouts will be used when revising basic home-based care.

☀️**Activity 6: Telling participants about the aims of the course**

Tell the participants the following:

- The course aims to make sure that the caregiver, the child with HIV and the family are supported as best as possible.
- The course aims to show the home-based care worker how to offer palliative care and support caregivers and children with HIV at home.

Turn to pages 2-7 in the Guide for Home-based Care Workers to read about why we are focusing on young children with HIV at home. Read these pages together.

☀️**Activity 7: Telling participants about the key learning outcomes**

Tell the participants that by the end of the course they will know about:

- Palliative care.
- Supporting a caregiver who looks after a child with HIV who is well.
- Supporting a caregiver whose child with HIV becomes sick and gets better.
- Supporting a caregiver whose child with HIV is very sick and may not get better.

Participants will also have a chance to practise aspects of palliative care:

- Looking at the needs of children, caregivers, families and home-based care workers (look again at page 6 in the Guide for Home-based Care Workers).
- Supporting the caregiver to care for themselves.
- Telling a child about HIV infection.
- Supporting a caregiver to give medication to a young child.
- Recognising and dealing with common problems.

- Knowing when to refer a sick child to a clinic.
- Supporting a young child and family when the child is very ill and may die.
- Recognising and dealing with abnormal bereavement.

### ☀️ **Activity 8: Reflection**

Read the following story out to the participants. When you are done ask them to discuss the story. Below the story are key points that the discussion should include.

#### **Madele – The experienced home-based care worker**

Madele is a home-based care worker like many of the other home-based care workers in rural areas in Africa. Madele visits many children in their homes; there are many types of homes, some are well built and some need repairs. There is a large school in the area and many of the children she cares for go to this school. There is a clinic close by with trained nurses. Madele has many duties, she checks that children are happy and well and makes sure that people get to the clinic when they need healthcare. She gives practical advice to families, for example on what food to eat and how to keep clean.

Today Madele has planned to visit Nonhlanhla and her family in their home. Nonhlanhla is looked after by her aunt. When Madele arrives she discovers that Nonhlanhla's aunt has just passed away. The deceased aunt's sister, Sylvia, is now the primary carer for Nonhlanhla. The family is mourning the loss of a loved one.

Nonhlanhla is at school today and Madele is concerned as she knows that Nonhlanhla had been ill. Madele decides to go to the school to see if Nonhlanhla is alright. When Madele reaches the school she meets Gugu, the Head of Department. Gugu asks Madele to see another child that she is worried about. This child's name is Siphoh. Gugu has asked Siphoh's granny to come to school so they can talk about Siphoh. Siphoh's mother and father have passed away and his granny cares for him.

Together with Gugu and Siphoh's granny, Madele has a look at Siphoh. Siphoh has very itchy dry skin. Madele, Gugu and Granny look at Siphoh's skin to see if they can find out what is causing the problem. The rash is very bad and has covered Siphoh's whole body. Granny is worried and both Siphoh and Granny look sad.

Gugu brings Nonhlanhla from class and Madele is surprised and relieved to find that she looks well. But Madele knows that Nonhlanhla's family cannot afford to bury her aunt. So Madele decides to personally call the Provincial Minister for Social Welfare, whose phone number she has, in the hope that he will be able to help. The Provincial Minister refers Madele to the person in the department who can arrange help for the burial cost.

Madele continues to worry about Siphos as his skin is very itchy. Gugu gets permission for Madele to take Nonhlanhla and Siphos back to their homes. Back at Nonhlanhla's house Madele joins in with the family's mourning. Madele explains to the family that money will be available for the funeral costs. Everyone is relieved. There are many other children at this home who may also need her help and so Madele knows that she must visit this house often over the next few weeks and months.

Next Madele goes to Siphos's home and explains that she is concerned about Siphos. Siphos's mother, father and older sister have all passed away. She notices there are other children at home. She sees that the family is very poor and the grandfather is ill in bed. She also notices that the baby's bottle is very dirty and that the baby does not look well. Siphos's granny shows Madele the medicine they got from the clinic; it is for itchy skin and to prevent infection. The medicine is all finished. Madele asks Granny when she last went to the clinic and says that she will try to help the family by speaking to the clinic sister.

Madele is clearly worried about the situation with the children in this home. She checks to see if the baby is dehydrated. His eyes are not sunken and his skin pinch is normal. Madele has seen that the home is dirty. She explains to Granny how to keep the bottle clean and how to disinfect it using boiling water. Madele then goes to the clinic to see if she can get them to help this family.

Today Madele has worked hard to help two young children at risk and their caregivers. Madele is an experienced home-based care worker and cares for many of her own children. She realizes that she must do her best. To do this she knows she has to deal with one problem at a time.

### **Key points for discussion:**

There are two children, two families and Madele, a home-based care worker.

#### **Family 1**

Nonhlanhla is a young orphan. Her caregiver, her aunt, has just died and her body is at home because the family cannot afford the cost of a funeral. The new caregiver is her aunt's sister. Nonhlanhla goes to school the day after her aunt has died.

#### **Family 2**

Sipho's mother, father and sister have all passed away. The child has itchy skin. His caregiver is his granny. The granny is poor and seems to have given up. The grandfather is very ill. There is another baby at home. The home is dirty. The baby's bottle is dirty. There is no food.

#### **The home-based care worker**

Madele, the home-based care worker, is caring for 16 children in her own home.

Ask caregivers to form three groups. Provide flip-chart paper and pens.

**Group 1** Discuss the problems faced by Nonhlanhla, the caregiver and the family.

**Group 2** Discuss the problems faced by Sipho, the caregiver and the family.

**Group 3** Discuss the home-based care worker's problems.

Ask a representative from each group to give feedback to the whole group.

Together they could draw diagrams to show the problems (see tables on the next page).

### Group 1

Problems faced by Nonhlanhla, her caregiver and her family		
<p><b>Child</b></p> <p>Nonhlanhla is an orphan. Her aunt has just died. Nonhlanhla is back at school.</p>	<p><b>Caregiver</b></p> <p>The caregiver is her aunt's sister who now has to provide care for a number of young children.</p>	<p><b>Family</b></p> <p>The family cannot afford to pay for a funeral so the body remains at home.</p>

### Group 2

Problems faced by Siphso, his caregiver and his family		
<p><b>Child</b></p> <p>Most of Siphso's family have passed away. He has itchy skin. He has no medicines. He is ignored. He is sad.</p>	<p><b>Caregiver</b></p> <p>The caregiver is a granny. The granny is very poor. The granny seems to have given up.</p>	<p><b>Family</b></p> <p>The grandfather is very ill. There is another very young child at home. The family has no money to buy food or to go to clinic. The house is dirty. The baby's bottle is dirty.</p>

### Group 3

Problems faced by Madele - the home-based care worker		
<p><b>Herself</b></p> <p>She is caring for others. She is caring for 16 children at home. She is stressed because she doesn't know how to solve all the problems. She needs help.</p>	<p><b>Her Children</b></p> <p>She is caring for many children.</p>	<p><b>Her Family</b></p> <p>She is caring for others, for children who live with her, and her family.</p>

Ask participants to form three groups and provide them with flip-chart paper and pens.

**Group 1** Summarise the key learning outcomes of the course (page 4 of the Guide for Home-based Care Workers).

**Group 2** Discuss: Who a caregiver is (page 4-5 of the Guide for Home-based Care Workers).

**Group 3** Discuss: Why it is good for a home-based care worker to support a caregiver

Ask a representative from each group to give feedback to the whole group.

Tell the participants that Part 1 is coming to a close.

The goal of Part 1 was to allow participants to get to know a little about each other, to become relaxed and to be introduced to the challenges of home-based care to support caregivers looking after children with HIV.

Remind participants about supporting each other and about confidentiality.

Ask for comments or questions.

Thank everyone for participating in Part 1.



## **Part 2: Revision of basic home-based care**

### **Trainer's introduction**

This part is a revision of basic home-based care.

We describe what we mean by basic home-based care (see key learning outcomes of basic home-based care in Table 2 on the next page).

Some participants may already know something about basic home-based care. It is important that you give information and support to ensure that all participants have knowledge and skills in carrying out basic home-based care.

Approximate length of Part 2:

**The time taken for Part 2 depends on the knowledge and skills of the home-based care workers in basic home-based care.**

### **Aims of Part 2**

The aims of Part 2 are to:

- Revise knowledge of basic home-based care.
- Revise practical skills of basic home-based care.

### **Key learning outcomes of basic home-based care**

The key learning outcomes of basic home-based care are described on the next page in Table 2.

**Table 2: Basic home-based care**

Topic	Key learning outcomes
Keeping germs away from a child who has HIV infection	<ul style="list-style-type: none"> <li>• Knowing how to dispose of body fluids: urine, faeces, blood and sputum</li> <li>• Knowing about washing hands</li> <li>• Dealing with cuts and sores</li> <li>• How to offer advice on cough hygiene and disposing of sputum</li> <li>• Knowing how to protect from mosquitoes</li> </ul>
Breastfeeding	Knowing when to start and stop breastfeeding a baby
Formula feeding	Knowing how to make up a baby's bottle
Feeding	Knowing what foods are good for growth and learning about food hygiene
Common problems	Coping with: <ul style="list-style-type: none"> <li>• Fever</li> <li>• Diarrhoea (Sugar Salt Solution - SSS)</li> <li>• Mouth problems</li> <li>• Skin problems</li> </ul>
Danger signs in young children	Recognising the danger signs
Washing a child	Knowing how to wash a sick child

**Trainer's preparation**

Planning Part 2 (with suggested times):

Keeping germs away	30 minutes
Breastfeeding	15 minutes
Formula feeding	15 minutes
Feeding and food hygiene	30 minutes
Common problems	2 hours
Danger signs	1 hour
Washing a child	10 minutes
Reflection	20 minutes

## Materials you will need

- Guide for Home-based Care Workers
- Caregiver's Toolkit
- Helpful Handouts 1- 7
- Flip chart and pens

## Trainer's guidance

Remember that some people in the group may know more about home-based care than others. As the trainer, you will need to recognise this and decide what parts of home-based care to cover so that no one feels that they are being left behind.



### ☀️ **Activity 1: Revising basic home-based care**

Establish what the participants already know about basic home-based care (together look at the table on page 104 in the Guide for Home-based Care Workers).

### ☀️ **Activity 2: Revising knowledge and skills**

Go around the group and ask if anyone has prior training in basic home-based care.

If yes - ask these participants to present their knowledge to the group (make use of flip-charts and pens, handouts and the Guide for Home-based Care Workers).

Check that their knowledge is correct and give participants ample opportunity for discussion.

If no - go through each topic on basic home-based care using Helpful Handouts 1-7 and give each participant a copy of the handouts.

### ☀️ **Activity 3: Reflection**

Ask participants to form three groups and provide them with flip-charts and pens.

**Group 1**            Ask group 1 to summarise and give feedback on keeping germs away from children.

**Group 2**            Ask group 2 to summarise and give feedback on breastfeeding, formula feeding, good nutrition and food hygiene.

**Group 3**            Ask group 3 to summarise and give feedback on common problems and making Sugar Salt Solution (SSS).

You can summarise and give feedback on danger signs.

Ask for comments or questions.

Read the story below out loud to the participants. When you are done, ask the participants to discuss the story.

#### **Andiswa – The new mother**

Sihle is a home-based care worker who visits many families in her community. One of the families she visits is the Ntuli family. Mother Ntuli is very ill and Sihle knows that she will soon pass away, but she has a small baby who is HIV positive and will need lots of care. The baby has an older sister, Andiswa, who is 17 years old and has just finished school in the city. Andiswa will move back home to care for her baby sister.

When Sihle visits she finds Andiswa very unhappy, Andiswa is afraid that she will not be able to care for little Sindy. Andiswa is now a new mother and does not know how to care for a baby, but Sihle assures Andiswa that she will always be there to help and advise her. Sihle decides to show Andiswa how to wash Sindy.

She begins by explaining to Andiswa that there are two circumstances under which you need to wash a young child – when they are babies and they cannot wash themselves, but also when the young children are older but are sick and cannot wash themselves. Andiswa is eager to learn how to care for Sindy. Sihle sends her to prepare all the things that they will need to wash Sindy – some clean

towels and facecloths, soap, a big bucket, warm water, body cream, nappies and baby clothes. Sihle explains to Andiswa that she must have all the things she will need near her, within arm's reach, so that she does not have to leave the baby unattended on the bathing table.

Together Sihle and Andiswa prepare the water for the baby's bath, first the cold water and then the hot water. Sihle asks Andiswa to test the water to see if it is ok. Andiswa dips her elbow into the bath water; Sihle has taught her that if it is good for your elbow, it is good for the baby. They spread the towel out onto the table and, carrying her carefully, they undress Sindy.

Sihle shows Andiswa how to gently wash Sindy, starting from the top of her head to the bottom of her feet. First, she gently washes her hair then lays her on the towel and dries her hair. Next Sihle wets the facecloth and without any soap she cleans Sindy's face gently, not forgetting behind the ears.

While Sindy is still on the towel Sihle rubs some soap onto another piece of cloth and shows Andiswa how to wash Sindy's body. Sihle is very patient with Andiswa, working slowly and showing her how to turn the baby to one side, using one arm to support the front of her body and gently washing with the other hand from the top of her neck all the way down her back to her toes. Then she turns Sindy onto the other side, again using one hand to support the front of her body and the other to wash her. Afterwards, she lays Sindy on her back and gently washes the front of her body. Sihle tells Andiswa that it is important to talk to Sindy and play with her while she is giving her a bath, this is a very good time to build a bond with your baby.

Once she is done, Sihle rinses the cloth in the water until there is no soap on it and gently wipes Sindy's body. Then she lets Andiswa dry her with the towel, all over, under the arms, in between the buttocks, turning her sideways and supporting her with one arm while gently drying her with the other. On a clean towel they rub cream all over Sindy's body. Sihle reminds Andiswa to remember to rub cream or Vaseline in between Sindy's buttocks to avoid nappy rash.

Together they put on Sindy's nappy and gently dress her.

Next Sihle shows Andiswa how to clean Sindy's mouth. She explains that Sindy is too young to use toothpaste. Andiswa must use a soft, clean cloth like gauze with some warm water to gently wipe inside Sindy's mouth, over her gums and around her teeth. Once they are done, Sihle notices that Andiswa seems much happier and much more confident. Sihle explains to Andiswa that as a new mother she may have many questions but she can always ask for help.

**Key points for discussion:**

- How to make sure caregivers have the necessary equipment.
- Understanding and showing caregivers how bathing and cleaning a baby can be a time of bonding.

At the end of the discussion, ask if there are any questions or comments and thank the participants for their hard work.

## Part 3: Palliative care

### Trainer's introduction

This part looks at palliative care and the needs of children, caregivers and families. It also looks at problems that home-based care workers may face.

This part will require a lot of preparation as you must be able to provide some guidance for dealing with anticipated problems faced by home-based care workers.

Approximate length of Part 3: **2 hours**

### Aims of Part 3

The aims of Part 3 are:

- To describe palliative care.
- To look at the child's needs.
- To look at the caregiver's needs.
- To look at the family's needs.
- To prioritise needs and to assess, advise, assist and arrange.
- To look at potential problems that home-based care workers may face.

Before beginning this part of the course you should discuss potential problems with your co-trainers and supervisors, so you can provide positive guidance to participants when they bring up these problems.

### Key learning outcomes

The key learning outcomes are the ability to:

- Describe palliative care.
- Use the palliative care diagram to reflect on a child's needs.
- Use the palliative care diagram to reflect on the needs of caregivers and the family.

- Use the palliative care diagram to prioritise needs.
- Deal with some potential problems that home-based care workers may face.

### Trainer’s preparation

Planning Part 3 (with suggested times):

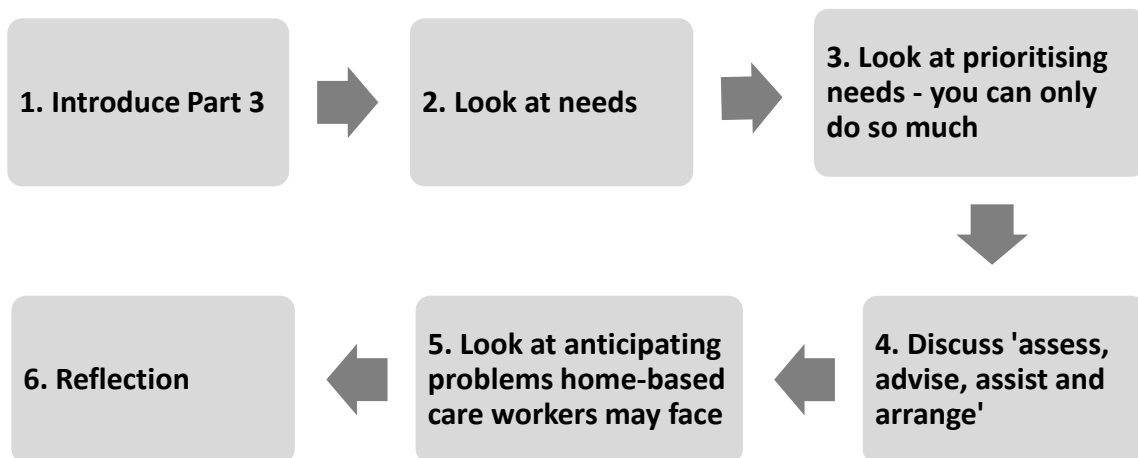
Describing palliative care	15 minutes
Looking at a child’s needs	15 minutes
Looking at a caregiver’s and family’s needs	15 minutes
Looking at potential problems	1 hour
Reflection	15 minutes

### Materials you will need

- Guide for Home-based Care Workers
- Caregiver’s Toolkit
- List of resources/referrals available in the area
- Flip-chart
- Pens

### Trainer’s guidance

You will need to prepare for Part 3.





You may need to prepare a list of resources/referrals that are available in the area where you will be training. Such resources should include clinics, hospitals, police stations, non-governmental organisations (NGOs), community-based organisations (CBOs), where to refer a suspected abused child, feeding schemes, etc.

Below is an example of a list of resources and referrals in your area that you can put together.

### **Resources and referrals**

- |   |                |
|---|----------------|
| 1. Pastor Nkosi at Siyathemba Church      | - 031 255 6644 |
| 2. Edendale Hospital, Paediatric Ward     | - 031 255 7765 |
| 3. Edendale Police Station                | - 031 266 6457 |
| 4. Salvation Army, Edendale               | - 032 555 6474 |
| 5. ChildLine                              | - 08000 555 55 |
| 6. Support Group: Mrs. Mthembu            | - 073 463 8463 |
| 7. Principal of Fundakahle Primary School | - 082 376 4649 |
| 8. KZN Hospice                            | - 033 763 7462 |
| 9. Social Worker, Mrs. Mkhize             | - 033 452 3748 |

Each home-based care worker can build their own list of resources and referrals depending on the area they live and work in.

Remind the home-based care workers that these lists will continue to grow as they meet new people and organisations that can support them. In this way, their support network will grow stronger and stronger and the list will be a quick and easy way to know who to refer to when there is a need.

### ☀️ **Activity 1: Introducing Part 3**

Tell participants that Part 3 is about palliative care and looking at the needs of children, caregivers, families and home-based care workers.

Ask participants to turn to page 9 of the Guide for Home-based Care Workers. Look at the diagram which explains what we will cover in discussing palliative care.

Together read about palliative care (pages 9-12 in the Guide for Home-based Care Workers).

### ☀️ **Activity 2: Looking at needs**

Ask participants to form three groups and provide them with flip-chart paper and pens.

**Group 1**      Discuss what the needs of a child with HIV are.

**Group 2**      Discuss what a caregiver's needs are.

**Group 3**      Discuss what the family's needs are (for example, younger brothers, sisters, grandparents and friends).

Ask a representative of each group to give feedback to the whole group.

Together, using the flip-chart paper divide the needs into:

- Physical
- Emotional
- Social
- Learning
- Spiritual
- Material

If the groups have not mentioned some needs then you can add these needs to the list and invite the group to comment.

### ☀️ **Activity 3: Prioritising needs**

Describe how to prioritise needs and how to look at one problem at a time (pages 13-15 in the Guide for Home-based Care Workers).

### ☀️ **Activity 4: Explain assess, advise, assist and arrange.**

Assess: We aim to see if we can find a cause for the problem. We also aim to see if we can cope with the problem or if we need to refer to someone else for help.

Advise: We give the caregiver advice on the problem that we have identified together.

Assist: We offer to carry out tasks for the caregiver if we feel that the caregiver needs help with these tasks.

Arrange: If we are worried about a situation then we arrange to ask others for help. If we feel we can cope then we arrange to visit the home often to offer support to the caregiver and child.

### ☀️ **Activity 5: Looking at potential problems the home-based care workers may face**

Ask participants to form three groups. Provide them with flip-chart paper and pens.

Ask each group to list problems that they may face in supporting a caregiver, child living with HIV, and family at home. Ask a representative of each group to give feedback to the rest of the group.

The group should discuss each potential problem and suggest solutions.

On the next page is a list of problems that other home-based care workers have had to deal with. Give each participant a problem from this list to think about.

Ask them to think about this problem and potential solutions to this problem for at least 10 minutes. Then ask each participant to discuss their problem and potential solutions with the rest of the group.

**Potential problems for discussion:**

- a) The caregiver has given up all hope and cannot see a way forward.
- b) The family has no food.
- c) The hospital or clinic staff are not helpful when they refer a child.
- d) The home-based care workers are worried about their own health (TB infection).
- e) The home-based care workers are called nosey and are teased by others.
- f) The home-based care worker sees that a caregiver is abusing young children.
- g) The home-based care worker is refused entry into a home.
- h) The caregiver refuses to tell the child about his or her HIV infection.
- i) The caregiver cannot afford to take the child for medicines.
- j) The home-based care worker feels that she must give away her own money and food.
- k) Caregivers expect the home-based care worker to do everything for them.
- l) A traditional healer gives the young child medicine that is potentially harmful.
- m) The caregiver will not follow advice that the home-based care worker gives.
- n) The family cannot afford the cost of a burial.

Together look at the two key messages for home-based care workers (page 16 in the Guide for Home-based Care Workers).

## ☀️ **Activity 6: Reflection**

Tell the participants that it is time to bring Part 3 to a close by sharing key learning points with each other.

Ask the group to think back to story of Madele – The experienced home-based care worker, Nonhlanhla and Siphso.

Ask the participants to form two groups. Provide them with flip-chart paper and pens.

**Group 1** Review the problems of Nonhlanhla (the child) and her caregiver and family. Discuss what the main problem is today. Discuss that problem in terms of the headings Assess, Advise, Assist and Arrange.

**Group 2** Review the problems of Siphso (the child) and his caregiver and family. Discuss what the main problem is today. Discuss that problem in terms of the headings Assess, Advise, Assist and Arrange.

Ask a representative of each group to give feedback to the whole group.

### **Key points for discussion around the story:**

<b>Points for discussion</b>	<b>Nonhlanhla</b>	<b>Siphso</b>
<b>What is the main problem today?</b>	Body cannot be buried.	Itchy skin.
<b>Assess</b>	Why can't the body be buried?	It seems like the family has no money or energy to take Siphso to the clinic.
<b>Advise</b>	Ask for help.	Advise the granny on support systems available in the community - for example feeding schemes.

<b>Assist</b>	Phoned Minister of Social Support who helped.	Assist the granny to clean the baby's bottle and clean the house.
<b>Arrange</b>	Follow up - does the child know about the death of the caregiver? Should the child go to the funeral? Provide ongoing support to the caregiver.	Went to clinic but nurse was busy. Must follow up as soon as possible as the granny needs a lot of support.

Ask the group to work in pairs for five minutes to talk about Part 3.

Ask them to be ready to say what ideas or thoughts they are taking away with them.

Invite three or four participants to share what they have learnt and their thoughts on Part 3.

This may have been a difficult session as it probably reminded home-based care workers of the many problems they have experienced while trying to support caregivers.

Tell the home-based care workers to sit quietly by themselves for five minutes (they could go outside).

Ask them to think of three people they could turn to if they experience difficulties in supporting a caregiver at home.

Ask if there are any questions or comments.

Thank the participants for their input.

## **Part 4: Supporting a caregiver of a child who has HIV infection and is well**

### **Trainer's introduction**

In Part 4 you will look at how home-based care workers can support the caregiver of a child with HIV who is well.

Approximate length of Part 4: **2 hours**

### **Aims of Part 4**

The aims of Part 4 are:

- To highlight the need for prevention of problems in the child, the caregiver and the family.
- To highlight the need to stimulate a young child with play, storytelling, reading and listening.
- To review techniques of good parenting.
- To facilitate the discussion of HIV status with a young child.
- To encourage adherence to medication.

### **Key learning outcomes**

By the end of Part 4 the participants will:

- Revise universal precautions to prevent HIV infection.
- Revise good nutrition and food hygiene.
- Gain awareness of the importance of play, talk and storytelling.
- Gain an awareness of good parenting skills.
- Gain awareness of the importance of checkups for caregivers.
- Be equipped with tools for talking about HIV status.
- Be equipped with tools for encouraging adherence to medication.

## Trainer's preparation

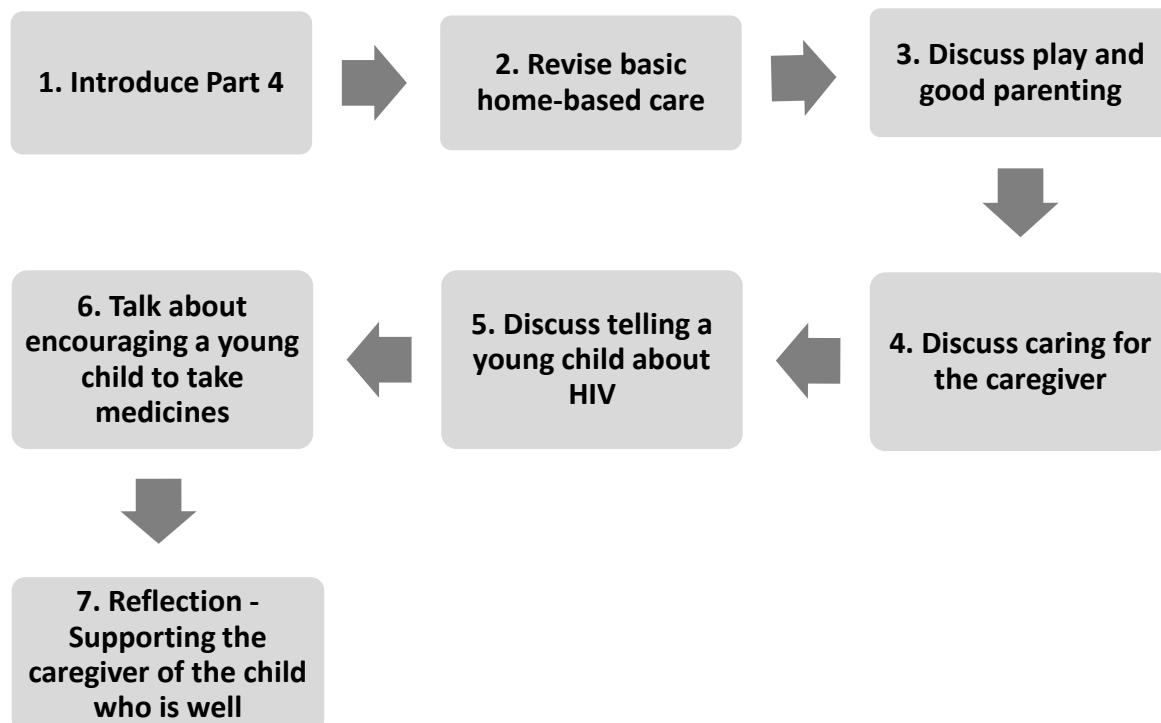
Planning Part 4 (with suggested times):

Revise universal precautions	15 minutes
Revise breastfeeding	5 minutes
Revise formula feeding	5 minutes
Revise nutrition and food hygiene	5 minutes
Look at play, storytelling and talking	10 minutes
Look at parenting skills	10 minutes
Look at checkups for caregivers	10 minutes
Look at discussing HIV status	20 minutes
Look at supporting adherence to medication	20 minutes
Reflection	20 minutes

## Materials you will need

- Guide for Home-based Care Workers
- Caregiver's Toolkit
- Flip-chart paper and pens

## Trainer's guidance





### ☀️ **Activity 1: Introducing Part 4**

Tell the participants that Part 4 is about keeping a child with HIV well.

A well child needs:

- Protection from germs
- Good nutrition
- Play and good parenting

It is important that the caregiver is supported and looks after his or her own health.

A young child should know something about HIV infection. A young child should be encouraged to adhere to medication, especially medicines for HIV, anti-retroviral therapy, ART).

Ask participants to turn to page 19 in the Guide for Home-based Care Workers and look at the diagram: *A Well Child*.

### ☀️ **Activity 2: Revision in basic home-based care**

The participants will revise basic home-based care. Give each participant a topic:

- a) Cleaning up spills
- b) Dealing with a cut or sore
- c) Disposing of waste
- d) Cough hygiene
- e) Disposing of sputum
- f) Protecting from mosquitoes
- g) Breastfeeding
- h) Formula feeding
- i) Good nutrition and food hygiene

Each participant will give a brief presentation on their topic using the handouts, the Guide for Home-based Care Workers (pages 20-22) and the flip-charts and pens.

### ☀️ **Activity 3: Looking at the importance of play and good parenting**

Ask participants to form two groups. Provide flip-charts and pens.

#### **Group 1**

Discuss:

- Why and how should a young child play?
- How important is it to talk and listen to young children?
- How important is it to tell young children stories and sing songs for them?
- How important is it to play, talk and listen to a child older than 2 years old? (page 9 in the Caregiver's Toolkit).

#### **Group 2**

Discuss:

- What does it mean to be a good parent?
- How can we be good parents?
- How important it is to show love and affection to young children?
- What can we do if the child is lonely?
- What can we do if the child is sad? (page 9 in the Caregiver's Toolkit).

Ask a representative of the group to give feedback to the whole group.  
Together read pages 23 and 24 in the Guide for Home-based Care Workers.

#### ☀️ **Activity 4: Looking at caring for the caregiver**

Ask participants to turn to page 10 of the Caregiver's Toolkit.

Go through the list of checkups for caregivers. Discuss if these checkups are available at clinics.

Ask each home-based care worker in turn to name a way that they could look after their own health.

#### ☀️ **Activity 5: Telling a young child about HIV**

Ask participants to form three groups. Provide flip-charts and pens.

**Group 1**            Discuss why it might be good to tell a young child about HIV infection.

**Group 2**            Discuss potential problems in telling a young child about HIV.

**Group 3**            Discuss how to tell a young child about HIV.

Ask a representative from each group to present their discussion to the larger group.

#### ☀️ **Activity 6: How to tell a young child about HIV**

Ask participants to look at pages 25-28 in the Guide for Home-based Care Workers and look at page 11 in the Caregiver's Toolkit.

Together read and discuss the story "John and the Sleeping Germs," in the Caregiver's Toolkit (pages 12-14). Discuss if participants feel that this story would be useful in telling a young child about HIV.

Discuss how to cope with a child's anticipated emotions if they are told about HIV infection (for example, anger, fear or crying).

Discuss questions that the child may ask:

- Why did it happen to me?
- How did I get this germ?
- What will I do if other children laugh at me?
- What will I do if other children exclude me?

Write replies to these discussions on a flip-chart.

### ☀️ **Activity 7: Supporting a caregiver to give medicines to the child**

Ask participants to form three groups. Provide flip-chart paper and pens.

**Group 1**            Discuss how to support a caregiver to give a young child medicine.

**Group 2**            Discuss how to support a caregiver if the child refuses to take medication.

**Group 3**            Discuss the medicines that a young child may have to take.

Ask a representative of each group to give feedback to the whole group.

Together read pages 29-32 in the Guide for Home-based Care Workers.

Together look at page 15 in the Caregiver's Toolkit.

### ☀️ **Activity 8: Reflection**

Tell participants that Part 4 is coming to a close.

Read the story '**Supporting the caregiver of the child who is well**' to the participants.

Ask if there are any comments or questions and then discuss the story together.

## **Supporting the caregiver of the child who is well**

Today Madele is visiting a new family. When she arrives at the home, Madele makes sure she speaks to each of the family members. She meets the young child's sister and brother and checks that they are well.

Madele sits with the parents and Sizwe, the baby, and talks to them. She finds out that Sizwe is HIV positive. Once she has found out about the family and has told them a little bit about her, she knows that they are comfortable with her. She goes on to ask them how she can help them today. Both the mother and father have questions for Madele and she is happy to see that the whole family is involved in caring for little Sizwe.

Londiwe, Sizwe's mother, is worried about whether or not she should breastfeed her baby. Madele asks Londiwe what the clinic sister has advised her to do. Londiwe replies that the clinic sister has suggested that since Sizwe is on ART he should be breastfed. Madele agrees with her and explains to Londiwe that just like any other baby she should breastfeed Sizwe and begin giving him solids after 6 months.

Next Madele checks with Londiwe that Sizwe has had all the necessary immunizations. Londiwe is happy that the clinic sister has told her that she will let her know if her baby needs anything special. Madele has a look at the clinic card that Londiwe has for the baby. Londiwe has taken Sizwe for all his checkups and he seems to be growing well. Madele encourages Londiwe to keep up the good work of taking Sizwe to the clinic for regular visits. Londiwe knows that Sizwe has to have his blood tested at the clinic every few weeks and marks it on her card so that she does not forget.

Madele asks Londiwe about the food she cooks for the children. Londiwe takes Madele into her kitchen and shows her the fresh fruit and vegetables she has. She explains to Madele that she prepares porridge, fruit and vegetables every day for the children. Madele reminds Londiwe to keep uncooked and cooked food separately and to always cover all food. She explains that all food should be prepared with clean water. Madele takes a small container and puts a little bit of uncooked rice into it. She explains to Londiwe that she can make small toys like this for Sizwe to play with. The bright colours of the container and the sound of the rice will keep him interested and happy.

Bongani, Sizwe's father tells Madele that he is worried about Sizwe's little sister, Thandi, who is also HIV positive. Thandi was on ART but has stopped taking her

medication; she spits out the medication and refuses to listen to her parents. Madele explains to Londiwe and Bongani that sometimes it is difficult for young children to accept that they need to take medication, especially if no other children around them do. It would help if Thandi’s parents used a story to help her understand why it is important for her to take her medication. Madele gives them an example of what they can tell Thandi to help her take her medication:

*“Germs can make a child sick. You have some germs in your blood. There are soldiers in your blood that help put the germs to sleep. Your medicine makes the soldiers in your blood strong. You need medicine every day. If you don’t take medicine the germs can wake up.”*

Madele explains to the parents that they can also sit with Thandi and draw with her pictures of how she can be strong and well by taking her medication and how it will protect her. Madele shows both parents how they can make little containers to keep the medication in, one little container for each day. This will help them remember when to give both Thandi and Sizwe their medication. Thandi can help to make her medicine containers and to decorate them.

Both the family and Madele are satisfied with the visit. Madele leaves, promising to visit again soon.

**Key points for discussion from the story:**

What was the main problem today?

- a) Mum concerned about breastfeeding and immunisation
- b) Dad concerned that child would not take medicine

<b>Did the home-based care worker do the following:</b>	<b>YES</b>	<b>NO</b>
<b>Assess</b>		
<b>Advise</b>		
<b>Assist</b>		
<b>Arrange</b>		

In the story Madele covered the following:

- a) Exclusive breastfeeding
- b) Immunisation
- c) Monitoring growth
- d) Blood tests
- e) Good, clean food
- f) Play (home-made toys)
- g) Ways of telling a young child about HIV
- h) Ways of remembering to take medicine

Ask if there are any questions or comments.

Thank the participants for taking part in Part 4.

## **Part 5: Supporting the caregiver of a child who becomes sick and gets better**

### **Trainer's introduction**

This part is about supporting the caregiver of a child with HIV infection who becomes sick and gets better. You will look at coping with common problems and when to refer a sick, young child to a clinic or hospital. We look, in particular at possible side-effects of ART and to be aware of child abuse.

Approximate length of Part 5: **2 hours**

### **Aims of Part 5**

The aims of Part 5 are to:

- Facilitate participants in dealing with common problems in looking after a young child with HIV.
- Revise when to refer for help.
- Gain awareness of the common problems associated with ART.
- Gain awareness of recognising and dealing with child abuse.

### **Key learning outcomes**

The key learning outcomes are as follows:

- Assessing common problems.
- Advising caregivers about common problems.
- Assisting the caregiver with common problems.
- Arranging transport to the clinic or follow up.
- Revising danger signs.
- Recognising the common problems of ART.
- Recognising and referring children where abuse is suspected.



## Trainer's preparation

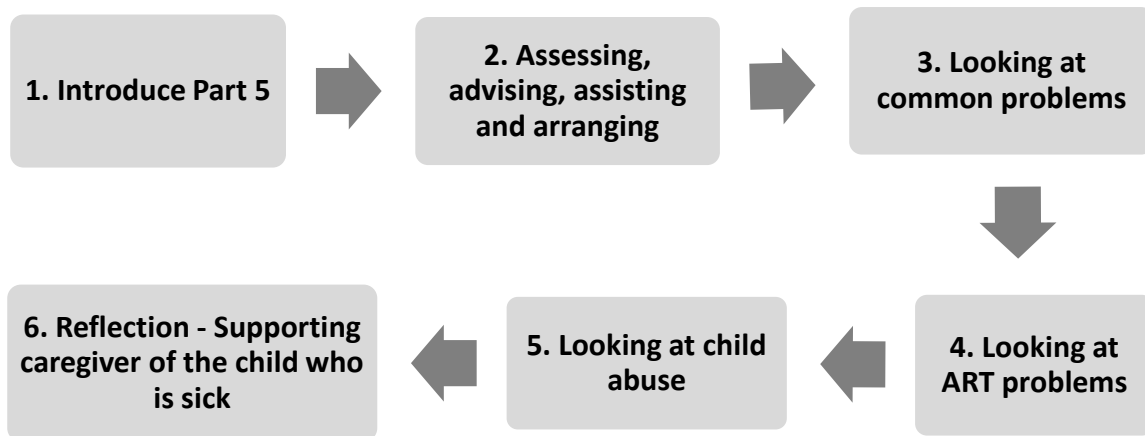
Planning Part 5 (suggested times):

Assessing, advising, assisting and arranging	10 minutes
Common problems:	
1. Active feeding	15 minutes
2. Fever	5 minutes
3. Diarrhoea	5 minutes
4. Constipation	5 minutes
5. Dry and sore mouth	5 minutes
6. Skin problems	5 minutes
7. Cough	5 minutes
Danger signs	20 minutes
ART problems	10 minutes
Child abuse	10 minutes
Reflection	25 minutes

## Materials you will need

- Guide for Home-based Care Workers
- Caregiver's Toolkit
- Flip-chart paper and pens

## Trainer's guidance



### ☀️**Activity 1: Introducing Part 5**

You will explain to participants that Part 5 is about assessing, advising, assisting and arranging with common problems.

You will look at when to refer the sick child to a clinic. You will also discuss the special problems of ART and the danger of child abuse.

Ask participants to look at the diagram on page 35 in the Guide for Home-based Care Workers, *The Sick Child*.

### ☀️**Activity 2: Assessing, advising, assisting and arranging**

Ask participants to turn to pages 36-38 in the Guide for Home-based Care Workers and together read the section on assessing, advising, assisting and arranging.

Ask participants if they have any comments or suggestions.

### ☀️**Activity 3: Common problems we may face**

Give each participant a problem to work with:

1. Child not wanting to eat or drink
2. Fever
3. Diarrhoea
4. Constipation
5. Mouth problems
6. Skin problems
7. Cough
8. Danger signs (1-4)
9. Danger signs (5-10)

Ask the participants to read about their problem in the Guide for Home-based Care Workers (pages 39-49).

Each participant will stand in front of the group and discuss their problem, describing what they would do to:

- Assess
- Advise
- Assist
- Arrange

#### ☀️ **Activity 4: The special problems of ART**

Ask participants to turn to page 50 in the Guide for Home-based Care Workers and read this page together.

Together look at pages 17-20 in the Caregiver's Toolkit. Ask participants if they have any questions or comments.

#### ☀️ **Activity 5: Looking at the problems of child abuse**

Ask participants to form three groups. Provide flip-chart paper and pens.

**Group 1**      Discuss the different types of abuse that a child can suffer from: physical abuse, sexual abuse, emotional abuse and neglect.

**Group 2**      Discuss the signs or what would make you suspect that a child was being abused in any way.

**Group 3**      Discuss the different things you can do to help a child who is being abused in any way.

Ask a representative of each group to give feedback to the whole group.

Together read pages 51-53 in the Guide for Home-based Care Workers.

Together complete pages 21 and 22 in the Caregiver's Toolkit.

Ask the group what they would do if they suspected that a child was being abused.

It is very important that you (the trainer) know something about resources and referrals for abused children in the area so you can provide positive guidance.

### ☀️ **Activity 6: Reflection**

Read the story '**Supporting the caregiver of a child who is sick**' to the participants. This story deals with:

- a) Feeding a sick child
- b) Dealing with a distressed child

#### **Supporting the caregiver of a child who is sick**

It has been a few months since Madele began visiting Londiwe, Bongani and little Sizwe. She has visited them every second week but recently Sizwe has not been well and Madele is worried about him. She decides to visit the family. When she arrives at the home she finds that Londiwe is troubled. Sizwe has diarrhoea and he is crying.

Together Madele and Londiwe read through what needs to be done for Sizwe in the Caregiver's Toolkit. They see that there are some options for helping Sizwe. Madele explains that the most important thing is to increase the amount of fluids that Londiwe gives to Sizwe. Londiwe also needs to give Sizwe small amounts of food frequently. Together Madele and Londiwe go through the Helpful Handouts and revise on how to make Sugar Salt Solution which Londiwe can feed to Sizwe. Madele suggests that Londiwe can also give Sizwe some cornflower or custard powder mixed with a small amount of water or some peach and guava leaves crushed and boiled. Bananas are also good as well as plain yoghurt. Londiwe tells Madele that Sizwe usually likes to drink Coca Cola; Madele explains that this is fine as long as Londiwe leaves the coke to stand for a few minutes until all the bubbles have disappeared.

Madele reminds Londiwe to keep Sizwe's anal area clean by washing it gently with warm water after every loose motion. She should then pat the skin dry and gently rub aqueous cream or Vaseline.

Londiwe is a little unsure of whether or not she should take Sizwe to the clinic. Madele asks her a few questions to check. She asks Londiwe if Sizwe is passing urine, if there is any blood in his stools and if he has sunken eyes. Londiwe replies that Sizwe is passing urine normally, that there is no blood in his stools and his eyes are not sunken in. Madele then shows Londiwe how to use the skin pinch to check if Sizwe is dehydrated. Since his skin returns to normal after the skin pinch they decide that Sizwe is not dehydrated and does not need to go to the clinic. Madele suggests that Londiwe gives Sizwe lots of fluids and that she watches him carefully. Madele takes out her referral list and gives Londiwe Sister Dlamini's number and tells Londiwe to contact the sister at the clinic if she has any problems. Madele reminds Londiwe to keep all the food preparation clean, to wash her hands before and after preparing food and after cleaning Sizwe.

Madele asks Londiwe if there is anything else she needs help with. Londiwe explains to Madele that she finds it difficult to feed Sizwe when he is sick. Madele explains to Londiwe that it is very important to feed a sick child so that they can get better quickly and we have to find ways to encourage them to eat. It is important for Londiwe to pay close attention to Sizwe's eating habits, especially when he is sick. Breast milk is the best source of nutrition for any sick child and Londiwe should continue breastfeeding Sizwe. Madele explains that a child's stomach is small so they need to eat and drink often and they need to eat and drink enough of the right things to get their strength back. Londiwe should try to give Sizwe little amounts of food and drink as often as she can, even if Sizwe spits it out, Londiwe should be patient and keep trying.

Madele tells Londiwe about active feeding. She explains that active feeding is when we encourage the child to eat and keep the child interested in the food. There are many ways for Londiwe to encourage Sizwe to eat, she could talk to Sizwe and tell him how nice the food is, play games with the food, give him little amounts on a spoons and praise him when he eats. Madele explains that it is important to keep Sizwe close to her on her lap and feed him.

Londiwe tells Madele that she is concerned because she does not know why Sizwe won't eat. Madele explains that when children are sick they often lose their appetites and do not eat properly. They might not want to eat because of sickness, nausea, weakness or a sore mouth but it is important for Londiwe to continue trying to feed Sizwe small amounts of food and drink frequently.

Madele explains to Londiwe that feeding time is more than just giving a child food; it is also a time for Londiwe and Sizwe to bond. Londiwe should keep eye

contact with Sizwe, smile, talk and touch him. She should encourage him to eat and praise him when he does and be patient with him.

Sizwe begins to cry again and Londiwe seems very tired. Madele knows that dealing with a sick child who is distressed can be very hard for a caregiver and she decides to encourage Londiwe. She explains to Londiwe that children are too young to explain exactly what they want so they cry for many reasons – to let us know he is unhappy or in pain or to try to get our attention to tell us he needs to be changed or fed. It is normal for Sizwe to cry, especially when he is sick, and Londiwe should always be around when Sizwe is distressed. If she cannot be there, Londiwe can ask someone else for help.

To comfort Sizwe, Madele suggests that Londiwe pick him up and hold him close to her. She can move around, rock him gently and sing to him. Madele shows Londiwe how to massage Sizwe to comfort him. Londiwe picks up a soft blanket and gives it to Sizwe. She explains to Madele that Sizwe loves this little blanket and it comforts him sometimes. Londiwe thinks it is because it smells like her. Madele agrees, this blanket has special meaning for Sizwe and can comfort him even when Londiwe is not around. Madele explains that Sizwe can even suck on this blanket, a small cloth or his fingers as this can help him manage his pain.

Before Madele leaves she tells Londiwe that she should also be patient with herself. Dealing with a child who is sick and distressed can be very hard and sometimes Londiwe will need to take a break. When Londiwe feels this way, Madele offers to help find someone close to the family, like a relative, to take care of Sizwe for a little while.

Ask participants to comment on the story.

Recap the ways to encourage feeding and to comfort a distressed child.

Remind participants that it is also important for the caregiver to take every moment to offer comfort to the child when feeding, cleaning and washing – these are all times for the caregiver and child to bond.

### **Key messages for discussion from the story:**

The child had diarrhoea. Did the home based care worker:

- Assess, advise, assist and arrange?
- Did she check for danger signs?
- Did she check food and food hygiene?

This session may be distressing as home-based care workers may experience difficulties when dealing with sick and abused children.

It is good to unwind after a session like this.

1. Explain to participants that you are going to ask them to walk around the room or walk outside. Every now and again you will ask them to stop and talk a little to the person closest to them.
2. Ask participants to slowly walk this way and that way and call, "Stop."
3. When they stand still ask them to chat briefly to the person who is standing closest to them.
4. Ask participants to talk about the session. What did they feel about it? What was important to them?

Ask if there are any questions or comments.

Thank the participants for taking part in Part 5.

## **Part 6: Supporting the caregiver of a child who is sick and may not get better**

### **Trainer's introduction**

In Part 6 we look at the difficult topic of supporting a caregiver who has been told by a doctor or nurse that their child with HIV is very ill and may not get better.

Approximate length of Part 6: **5 hours**

### **Aim of Part 6**

The aim of Part 6 is:

- To facilitate the home-based care worker to support the caregiver, the child and the family when the child is very sick and may face death.

### **Key learning outcomes**

The key learning outcomes of Part 6 are:

- To increase awareness of the need to support a caregiver of a very sick child.
- To facilitate a caregiver to care for themselves.
- To support a caregiver in seeking assistance.
- To facilitate listening to a very sick child.
- To look at coping with a distressed child.
- To review preventing and treating common problems.
- To prepare for difficult questions and difficult situations.
- To facilitate involving the caregiver and child in decision making.
- To gain awareness of memory boxes.
- To recognise and deal with abnormal bereavement.



## **Trainer's preparation**

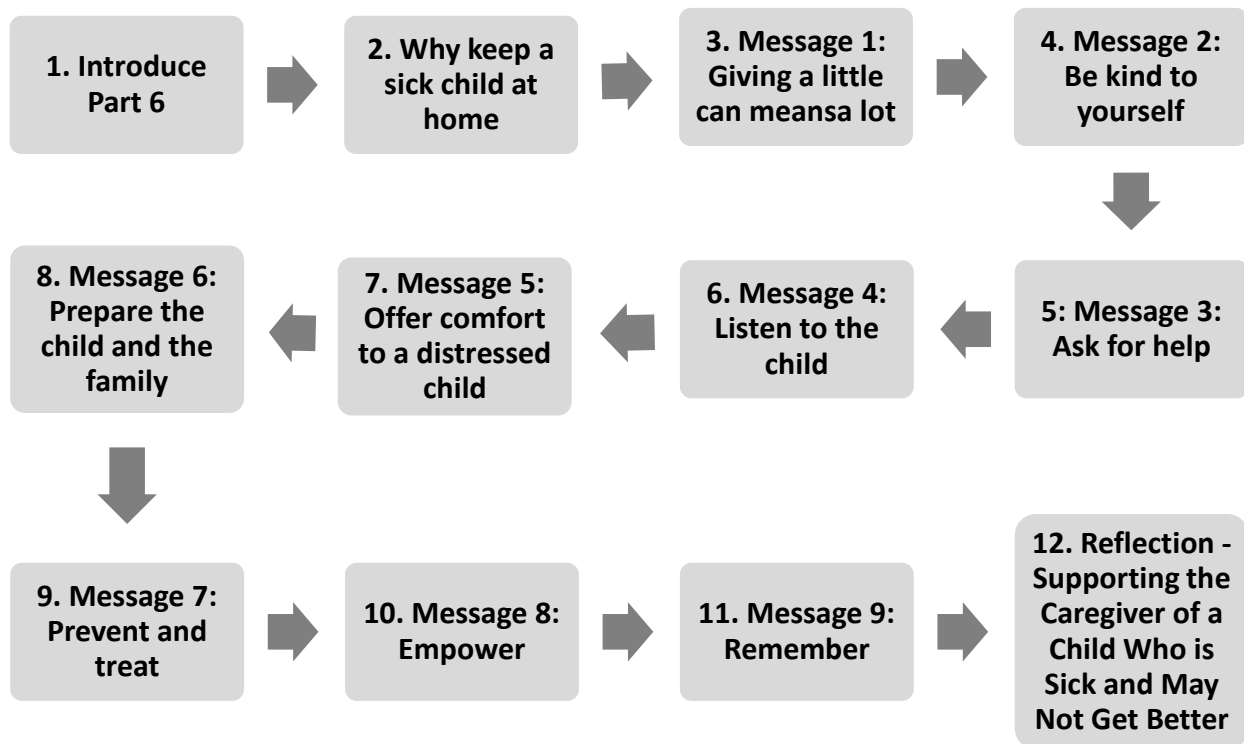
Planning Part 6 (with suggested times):

Why may it be good to care for a young, sick child at home?	10 minutes
Message 1	½ hour
Message 2	½ hour
Message 3	½ hour
Message 4	½ hour
Message 5	½ hour
Message 6	½ hour
Message 7	½ hour
Message 8	½ hour
Message 9	½ hour
Reflection	20 minutes

## **Materials you will need**

- Guide for Home-based Care Workers
- Caregiver's Toolkit
- Flip-chart paper and pens
- A ball of string

## Trainer's guidance



### ☀️ Activity 1: Introduction to Part 6

You will tell participants that Part 6 is about supporting the caregiver of a child, when the doctor or nurse has told the caregiver that the child is very ill and may not get better.

Ask participants to look at the diagram on page 59 in the Guide for Home-based Care Workers, *The Child Who May Not Live*.

You will look at nine messages when supporting the caregiver of a very ill child.

Together read pages 57-58 in the Guide for Home-based Care Workers.

## ☀️ **Activity 2: Why it may be good to keep a young, sick child at home**

Ask participants to look at page 23 in the Caregiver's Toolkit.

Ask them to write or draw reasons why it may be good to keep a young, sick child at home.

Would anyone like to share what they have written with the whole group? Together again read page 59 in the Guide for Home-based Care Workers.

## ☀️ **Activity 3: Message 1 - Giving a little can mean a lot**

We focus on the importance of giving and of encouraging caregivers. Sometimes we may feel that we are not able to do a lot, but it is the small things we do that make a difference.

Ask participants to sit in a large circle.

Take out the ball of string. Ask everyone to hold the string in their hands so you form a "story-string". Each time you tell a story participants should hold this story-string.

Turn to pages 60-61 in the Guide for Home-based Care Workers and together read the story of *Daisy Flowers*.

Ask participants to talk together about what the story means to them. Allow them at least 10 minutes to discuss the story among themselves.

### **Key messages:**

- Caregivers can make a big difference to the lives of young, sick children by doing even a little that is kind and comforting.
- Sick children are grateful for everything that is done to make them more comfortable and to feel better.

Ask participants to turn to the Caregiver's Toolkit, page 26. Draw a picture of a time when they have done something small and made a difference to people's lives. Ask if anyone wants to share their drawing with the group.

## ☀️ **Activity 4: Message 2 - Be kind to yourself**

In this message we focus on how important it is that caregivers are kind to themselves.

Ask participants to hold the story-string. Ask participants to turn to pages 62-63 in the Guide for Home-based Care Workers and together read the story: *The Big Flowerpot*.

Ask participants to discuss the story.

Allow them at least 10 minutes to discuss the story among themselves.

### **Key messages:**

- It is important for caregivers to be kind to themselves.
- Sometimes things do not turn out the way you expect them to.

Ask participants to form three groups. Provide a flip-chart and pens.

**Group 1**            Discuss what happens to our body if we are not kind to ourselves.

**Group 2**            Discuss what happens to our emotions if we are not kind to ourselves.

**Group 3**            Discuss what happens to our thoughts if we are not kind to ourselves.

Ask a representative from each group to give feedback to the larger group.

Together read pages 64-67 in the Guide for Home-based Care Workers.

Ask participants to turn to pages 27-28 in the Caregiver's Toolkit.

Ask participants to complete the table and write down or draw at least three ways that they can be kind to themselves.

## **Breathing relaxer**

Ask participants to stand up and make a big circle.

Ask them to imagine something that is worrying them today.

Take a big breath.

All blow out. Blow the worry away.

Participants may blow softly at first, so say “Come on, I didn’t hear you.”

Encourage them to use their whole body to blow out.

## **Massage**

Ask one participant to be seated. Ask another to stand behind and gently massage their neck and hands. Participants usually love this exercise.

## **Walk**

Ask participants to go for a short walk outdoors and bring back something from nature that will remind them to be kind to themselves.

## **☀️Activity 5: Message 3 - Ask for help**

In this session we learn how important it is for caregivers to ask for help when they are unsure of what to do. They must also know who to ask for help.

Ask participants to hold the story-string. Turn to pages 68-69 in the Guide for Home-based Care Workers. Together read the story *The Empty Cup*.

Ask participants to comment on the story. Allow them at least 10 minutes to discuss the story among themselves.

### **Key messages:**

- Know when to ask for help.
- Know who to ask for help.
- You are not alone with your problems.

Ask participants to turn to pages 29 and 30 in the Caregiver’s Toolkit.

Ask participants to form two groups and provide them with flip-chart paper and pens.

**Group 1**            Ask participants to draw circles of support to represent their own situation.

**Group 2**            Ask participants to complete a community map to represent their own situation.

Ask a representative from each group to give feedback to the whole group.

**Key point for discussion:**

- You may want to discuss the traditional healer as a potential source for help and also as a potential source for harm.

Together read pages 69-71 in the Guide for Home-based Care Workers.

☀️ **Activity 6: Message 4 - Listen to the child**

This session looks at how it may be difficult to listen to babies and young children. We know that it is very important to try our best to listen to sick, young children as they may be frightened or in pain.

Ask participants to hold the story-string. Turn to pages 72-73 in the Guide for Home-based Care Workers. Together read the story of *The Snake's Ears*.

Ask participants to discuss this story.

Allow them at least 10 minutes to discuss the story among themselves.

**Key messages:**

- Listen to the child not only with your ears but also watch the child carefully.
- Listen with your heart as well as your ears.
- Repeat what the child has said so you can be sure that you understood the child properly.

- Sit close to the child – she might want to sit on your lap, or very close to you on a chair or on her bed or on a mat on the floor.
- Hold her hand, give her a hug, look into her eyes when you listen to her, and talk gently and lovingly.

Ask three participants to volunteer for a role play:

- 1 participant acts as a frightened young child
- 1 participant acts as a caregiver
- 1 participant acts as a home-based care worker

Take the participant acting as a child aside and tell them they must act as a child who is being bullied at school because of their HIV status.

The child is angry and frightened and very withdrawn.

The caregiver and home-based care worker must try to get information from the child.

The child should not give information unless the caregiver makes a big effort (sings, tells a story or asks child to draw a picture).

After the role play ask participants to turn to pages 31-32 of the Caregiver's Toolkit.

Read these pages and ask participants to complete the following:

- List three reasons why it is good to listen to a young child.
- List five ways that they could listen better to a young child.

Would anyone share what they have written with the rest of the group?

Together read pages 74-77 in the Guide for Home-based Care Workers.

### ☀️ **Activity 7: Message 5 – Offer comfort to a distressed child**

In this session we look at how to comfort and manage distress in young children. We want caregivers to understand that they can do a lot to offer comfort.

Ask participants to hold the story-string. Turn to page 78 in the Guide for Home-based Care Workers. Together read the story of the *Snow White Flower*.

Ask caregivers to discuss the story. Allow them at least 10 minutes to discuss the story among themselves.

#### **Key message:**

- You can always offer some comfort.

Ask participants to turn to page 33 of the Caregiver's Toolkit.

Ask them to draw three things they could do at home to comfort a sick, young child.

Ask if participants would like to discuss their drawings with the larger group.

Together read pages 79-80 in the Guide for Home-based Care Workers.

### ☀️ **Activity 8: Message 6 - Prepare**

In this session we look at preparing the caregiver to answer difficult questions that the sick, young child or young brothers, sisters and friends may ask. We also look at preparing the caregiver for difficult situations.

Ask participants to hold the story-string. Turn to page 81 in the Guide for Home-based Care Workers. Together read the story of *Flowers from Heaven*.

Ask participants to discuss the story.

Allow them at least 10 minutes to discuss the story among themselves.



**Key messages:**

- A child may ask about illness, dying or death.
- We must be prepared to answer a child's difficult questions.
- A caregiver should be prepared to cope with difficult situations.

Ask the group to discuss why it may be difficult to talk to a young child and caregiver about dying and death.

Ask them to write their answers on a flip-chart.

Together read pages 82-83 in the Guide for Home-based Care Workers. Look at pages 34-35 in the Caregiver's Toolkit.

Ask participants to draw three reasons why it may be good to talk about dying and death.

Together look at the story on pages 36-38 of the Caregiver's Toolkit - *John and James*. Read this story and ask participants what they think about the story.

Ask participants to form two groups and provide them with flip-chart paper and pens.

**Group 1**            Discuss why it may be good to talk about dying and death.

**Group 2**            Discuss why it may **not** be good to talk about dying and death.

Ask a representative from each group to give feedback to the larger group.

Ask participants to form three groups:

**NOTE: Some groups may not want to carry out these role plays. Discuss this with the group first. If they do not feel comfortable then skip this exercise.**

**Group 1**            Role play caregiver and home-based care worker - my sick child no longer wants to eat or drink.

**Group 2**            Role play caregiver and home-based care worker - what will happen with the child immediately before death.

**Group 3**            Role play caregiver and home-based care worker – what will happen with the child immediately after death.

Together again read pages 84-86 in the Guide for Home-based Care Workers.

Ask participants to hold the story-string.

Together read the stories:

a) *The Turtle and the Eagle*, and b) *The Giant called Fear* on pages 44 and 45 of the Caregiver's Toolkit.

Ask participants to go for a ten minute walk and think about what has been discussed.

### ☀️ **Activity 9: Message 7 - Prevent and treat**

In this session we look at preventing and treating problems experienced by young children who are very ill. Caregivers should be supported to prevent problems arising and to be able to offer treatments.

Ask participants to hold the story-string. Turn to page 87 in the Guide for Home-based Care Workers. Together read the story of *The Red Moon*.

Ask participants to discuss this story.

Allow them at least 10 minutes to discuss the story among themselves.

**Key messages:**

- It is better to prevent problems before they arise.
- Treat problems that do occur.

Ask participants to form three groups and provide them with flip-chart paper and pens.

**Group 1**      Discuss how to prevent stiff joints.

**Group 2**      Discuss how to prevent bed sores.

**Group 3**      Discuss possible causes of pain in a very sick child.

Ask a representative from each group to give feedback to the whole group.

Together read pages 88-89 in the Guide for Home-based Care Workers (reading about bed sores and stiff joints).

Look at page 40 in the Caregiver's Toolkit: Draw a picture of how to prevent stiff joints.

Together read pages 90-93 in the Guide for Home-based Care Workers (reading about children's pain).

Ask participants to turn to pages 39 and 40 in the Caregiver's Toolkit. Explain about the pain-faces and the pain table (looking at pain in a young child).

Ask participants to call out the names of any medication they know for pain. Write the names on a flip-chart.

Describe a little about each of the medicines that have been listed. Add and discuss any medicines they have left out.

Ask participants to read pages 107 and 108 in the Guide for Home-based Care Workers.

**Key point for discussion:**

Pain medicine must be given as follows:

- The right medicine
- The right time
- The right way
- The right amount
- Give regularly to stop pain from coming back

☀️ **Activity 10: Message 8 - Empower**

In this session we look at why it is very important to empower young children, caregivers and their families.

Empowering others means that you help people come up with solutions to their problems and do not try to do everything for them as if they were helpless.

Ask participants to hold the story-string. Turn to pages 94-95 in the Guide for Home-based Care Workers. Together read the story *The Boy and the Flowers*.

Ask participants to discuss this story. Allow at least ten minutes for feedback about this story.

**Key messages:**

- Allow the child, caregiver and family to come up with a possible solution.
- Work out how together you can make the solution happen.

Ask participants to form two groups and provide them with flip-chart paper and pens.

**Group 1** Discuss reasons why it would be good to empower a child, caregiver and family.

**Group 2** Ask the group to provide specific examples of how they have empowered families or will empower families.

Ask a representative from each group to give feedback to the larger group. Together read pages 95-96 in the Guide for Home-based Care Workers.

Look at page 41 in the Caregiver's Toolkit.

Ask participants to quietly draw their own main problem today. Ask them to draw the main problem of a child they care for.

Draw one thing they can do to solve their own problem.

Draw one thing they can do to support a child solve a problem.

Ask if anyone would like to give feedback to the whole group.

### ☀️ **Activity 11: Message 9 - Remember**

In this session we look at the importance of remembering those who have died and discuss some ways to do this. We also look at abnormal bereavement.

Ask participants to hold the story-string. Turn to pages 97-98 in the Guide for Home-based Care Workers. Together read the story of *The Wax Child*.

Ask participants to discuss this story. Allow at least ten minutes for feedback about this story.

**Key messages:**

- People can find much comfort in remembering those who have died.
- People should be helped to remember those who have died.
- We should support caregivers and their families during bereavement.
- We should know about abnormal bereavement.

Ask participants to turn to pages 99-102 in the Guide for Home-based Care Workers. Read these pages together.

Ask caregivers to write or draw in the Caregiver's Toolkit what they think could go into a memory box (Page 42 of Caregiver's Toolkit). Everyone will be able to think of things themselves but here are some ideas:

- Stories: children, caregivers, families and friends can write or draw pictures that tell a story.
- Photographs: home-based care workers could try and get a photograph of the child with a family member. Write the date on the back of the photograph. Also write who is in the photograph.
- Familiar objects: caregivers and children can put something they have used a lot in the memory box. They could put in a cup or plate that they like.
- Drawings: adults and children could place a drawing in the box.
- Letter: an adult could write a child a letter telling her how much the child is loved. The caregiver could write a short note to tell the child about things that are important.

Ask participants to again turn to page 101 in the Guide for Home-based Care Workers. Again read the section on memory boxes.

Ask participants to form two groups and provide them with flip-chart paper and pens.

**Group 1** Discuss how adults grieve the loss of a loved one.

**Group 2** Discuss how children grieve the loss of a loved one.

Ask a representative of the group to give feedback to the whole group.

Look at page 43 in the Caregiver's Toolkit.

Ask participants to draw a picture of how they would feel if a young child dies. Ask them to draw a picture of how young children feel if someone they know dies.

Ask if anyone would like to give feedback to the larger group.

### ☀️ **Activity 12: Reflection**

Part 6 has been a long session.

Remind the participants of the nine messages and the name of each story we used when looking at the nine messages.

Read the story '**Supporting the caregiver of child who is ill, memory work and bereavement**' to the participants.

#### **Supporting the caregiver of child who is ill - memory work and bereavement**

A few weeks after Madele last visited Londiwe and Sizwe, she gets a call from Londiwe who tells Madele that the doctors have told the family that Sizwe will soon die. Madele promises to visit the family. That afternoon Madele goes to the home to find that the parents are very sad. Madele asks Bongani and Londiwe if Sizwe is still in pain. Both parents agree that Sizwe is in pain because he cries a lot. Madele takes out her Pain Faces Scale and explains to Sizwe's parents that each face shows a level of pain. She asks them to show her which face matches Sizwe's pain. They both agree on a face on the lower end of the scale, showing that Sizwe does not have a lot of pain. Madele asks Londiwe if she has any pain

medication for Sizwe. Londiwe shows her the bottle of Panado syrup that she was given at the clinic and explains that the clinic sister told her to give Sizwe half a teaspoon no more than 3 times a day whenever Sizwe is in pain. Madele shows Londiwe and Bongani how to massage Sizwe and tells them that this will also help to take away some of his pain and comfort him.

Madele asks the parents if there is anything else that is bothering them. Bongani says that they do not know whether they should tell Sizwe's brothers and sisters that he will soon die. They would like to tell them but do not know how to.

Madele suggests that they tell the children a story and let them ask questions. She reads them the story of the water insects and dragonflies which she finds on page 37 of her Caregiver's Toolkit. Bongani and Londiwe both love the story and feel comfortable sharing it with the other children.

Madele has brought her own memory box with her. She explains that she has made this memory box with her own children so that they have something to remember her by one day when she is no longer with them. Madele explains that together Bongani, Londiwe and Sizwe's brothers and sisters can make their own memory box for Sizwe and it will help them remember him when he is gone.

Madele leaves the family to work together.

Ask for questions or comment on the story.

**Key points for discussion on story:**

- Why may it be a good idea to tell the sick child's brothers and sisters about dying and death?
- Discuss the home-based care worker telling the story and the family's reaction to the story
- Did she assess the cause of pain?
- Did she advise?
- Did she assist?
- Did she arrange?
- Was the home-based care worker right in telling the caregiver to give medicine only when the child has pain?



- Do the home-based care workers in your group feel that they could make use of memory boxes?
- Who could the home-based care worker refer to if she felt that the caregiver or child was experiencing abnormal bereavement?

Tell participants that this part may be emotionally challenging.

Ask each participant to turn to the person next to them and tell that person how they are feeling.

Allow five minutes for this.

Ask for any questions or comments.

Thank everyone for taking part in this difficult Part 6.

## Part 7: A way forward

### Trainer's introduction

This part is essential. It is vital that this course closes in a way so the participants feel prepared to continue with their work and remain positive.

Approximate length of Part 7: **1 hour**

### Aims of Part 7

The aims of Part 7 are:

- To plan how home-based care workers will use the Caregiver's Toolkit with caregivers at home.
- To allow participants to debrief.
- To get feedback on the course.

### Key learning outcomes

The key learning outcomes of Part 7 are:

- Participants have a plan of how to support the delivery of palliative care in the home.
- Participants experience a positive end to the course.
- To say goodbye to the group.
- To make appropriate links for the future.

### Trainer's preparation

Planning Part 7 (with suggested times):

Planning how to deliver palliative care using Caregiver's Toolkits	30 minutes
Reflecting on the course	20 minutes
Closing the course	10 minutes

## Materials you will need

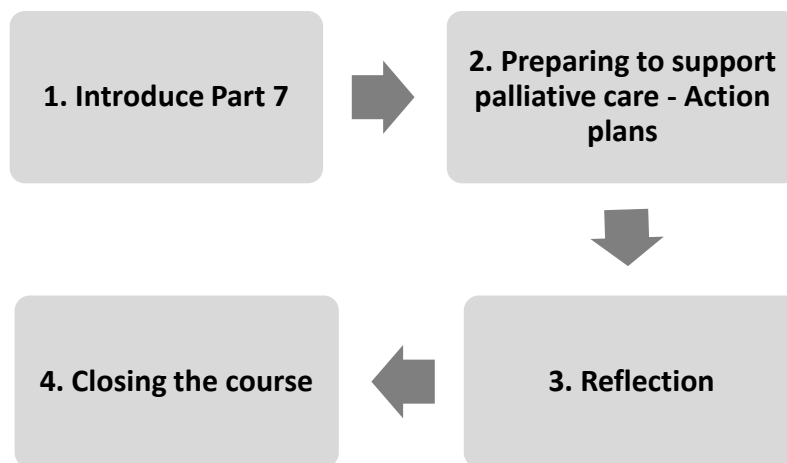
Paper and pens so participants can get each other's contact details.

Flip-chart paper and pens.

Scissors to cut story-sting

Signed certificates

## Trainer's guidance



### ☀️Activity 1: Introducing Part 7

Say that the group has worked well together. It is important to acknowledge all their hard work.

Part 7 is about preparing to deliver palliative care and about saying goodbye.

### ☀️Activity 2: Preparing to deliver palliative care

Ask participants to form three groups and provide them with flip-chart paper and pens.

Give participants 15 minutes to discuss caregivers they already support.

How do they plan to use this course and the Caregiver's Toolkit in caregiver homes?

Participants must give specific details of their plan.

You may want to ask them to make up an action plan like the one below.

<b>ACTION</b>	<b>Caregiver Name</b>	<b>Caregiver Name</b>	<b>Caregiver Name</b>
<b>Talk about palliative care</b>			
<b>Look at needs</b>			
<b>Discuss caring for well child</b>			
<b>Discuss caring for sick child</b>			
<b>Discuss checkups for caregiver</b>			
<b>Look at discussing HIV status</b>			
<b>Look at adhering to medicine</b>			
<b>Look at caring for child who may not get better</b>			
<b>Make a memory box</b>			

Ask each person to give individual feedback to the whole group.

Ask the group for comments, suggestions and questions.

### ☀️ **Activity 3: Reflecting on the course**

Ask participants to form three groups and provide them with flip-chart paper and pens.

Ask each group to reflect on the following:

- a) What are the most important things you learned during this course?
- b) What would you like to spend more time on?

- c) What skills have you developed?
- d) What strengths have you identified: in yourself, among participants, in your families, in your community?
- e) What support is available to take forward ideas from this course?
- f) What have you most enjoyed about this course?
- g) If you have a chance to attend another course, what would you change next time?

Bring the groups back together.

Ask volunteers to report back on their group's discussion.

Read the story '**Andiswa and Sindy**' to the participants.

Tell the participants to pay special attention because you are going to ask them to decide what to do at the end of the story.

### **Andiswa and Sindy**

During a very busy week Madele decides to pay a quick visit to Andiswa, the new mother. Andiswa's mother has passed away and she is left alone to care for little Sindy. When Madele enters the home she notices that the house is dirty, there is a pot of open food on the stove and there are clothes lying around the floor.

Andiswa seems overwhelmed and Sindy is crying. Andiswa shows Madele the bed that Sindy sleeps in, it is stained because Sindy has diarrhoea. Andiswa tells Madele that Sindy cries often and she suspects she is in pain because of something on her upper thigh. Madele asks Andiswa if she has been to the clinic. Andiswa tells Madele that she has been to the clinic, the medication she received from the clinic is finished and she has no money to get more medication.

Madele has a look at Sindy and notices that Sindy's face, arms, legs and tummy are all swollen. Andiswa tells Madele that Sindy is almost 1 and half years old but does not walk; Sindy does not want to stand up either. Andiswa seems to be having a hard time caring for Sindy on her own and Madele knows that she has to pay special attention to this family and provide extra care and support.

## Key points for discussion from the story:

What were the child's problems?
<ul style="list-style-type: none"><li>• Diarrhoea</li><li>• Pain</li><li>• Not walking</li><li>• Distressed</li><li>• Rash</li><li>• Kwashiorkor</li></ul>
What were the caregiver's problems?
<ul style="list-style-type: none"><li>• No money</li><li>• Not coping</li></ul>
What were the family's problems?
<ul style="list-style-type: none"><li>• No food</li><li>• Dirty house</li></ul>

- How would you assess the cause of diarrhoea - what are the possible causes?
- How would you assess for pain - what were the possible causes?
- How would you assess why Sindy is not walking?
- What advice would you give Andiswa e.g.:
  - SSS
  - Hygiene (food and home)
  - Danger signs
  - Pain medication
  - Referral

Problems that need attention a) diarrhoea b) hygiene c) pain and d) referral to find out why the child is not walking.

#### ☀️ **Activity 4: Closing the course**

Thank the groups for their feedback.

Say that you hope they have learned a lot from this course and that they will carry on the good work they have started.

Also say that their feedback will help you improve the course for other participants.

Please be aware the participants may feel a sense of loss. This is because they have covered sensitive topics with each other and have worked hard.

For some participants this may be the first time that they have had an opportunity to discuss sensitive things around illness, dying and death. These people may experience a strong sense of loss.

Explain that the aim of this last activity is to bring the time of working together as a group to an end. Say that because people may have strong emotions that it is necessary to “close” the group.

Cut the story-string into nine pieces and give each participant a piece of the string as a memento of this course.

Give each participant a signed copy of the certificate “Palliative Care for Young Children at Home in Africa: Home-based Care Workers”

Remind participants of confidentiality. Say that it is important that private information shared within the group is not shared with other people.

Remind everyone of the action plans they have written. Encourage the group to take these action plans forward.

Finish by thanking the group for their contributions and their hard work.

Say that you have enjoyed working with them.

Wish them well.

Finish with a song and a prayer if this suits your group.

At the end of the course you will discuss the participant feedback with your co-trainers and supervisors.



## Palliative Care at Home for Young Children in Africa: Knowledge and Practical Competencies

### Information for Managers and Administrators

By the end of the course: “Palliative Care at Home for Young Children in Africa: Training and Support Package” we expect your home-based care workers to have knowledge and skills in the following key areas:

### Knowledge and Skills Competencies

<b>Knowledge and skills on palliative care</b>	An understanding of palliative care? How to prioritise problems using the ‘assess, advise, assist and arrange’ method.
<b>Keeping a child well</b>	How to protect a child from germs. Know about breastfeeding, bottle/formula feeding and preparing good, clean food. Knowing about the importance of play and good parenting. How to support caregivers to care for themselves. Telling a young child age-specific messages on HIV. Encouraging a young child to take medicine.
<b>Caring for the sick child who gets better</b>	Finding out what is causing an illness. ASSESS ADVISE ASSIST ARRANGE Common problems faced by a child with HIV* Knowing the “danger signs” and when to refer. Knowing about the special problems of ART. Knowing about the special problems of child abuse.
<b>Caring for the sick child who may not get better</b>	Why might it be good to care for a child at home. Delivering the nine messages in caring for very sick children at home.
<b>*Common problems</b>	Pain, not eating, fever, vomiting, diarrhoea, constipation, skin problems, mouth problems and cough.

### Knowing about medicines used in caring for sick, young children at home

1. The child should take the right amount of medicine - the medicine container usually tells you how much to give. Do not give too much. Do not give too little.
2. The child should take the medicine at the right time - the times to take the medicine are usually written on the medicine container or in the child’s clinic/hospital records.
3. The child should finish all the medicine.
4. With ART the child must take the medicine every day.

**Palliative Care at Home for Young Children in Africa: Knowledge and Practical Competencies**

**Evaluation of Basic Competencies**

Topic	Competency	Yes	No
<b>Part 1: Palliative care</b>	A good understanding of palliative care.		
	Being able to prioritise problems and assess, assist, advise and arrange.		
<b>Part 2: Keeping a child well and preventing germs from spreading</b>	Cleaning up body fluids		
	How to hand wash		
	Dealing with cuts and sores		
	Cough hygiene and disposing of sputum		
	Protecting from mosquitoes		
<b>Feeding</b>	Know about breastfeeding		
	Knowing about bottle/formula feeding		
	Knowing about preparing good, clean food		
<b>Playing and parenting</b>	Knowing about the importance of play and giving advice on playing.		
	Knowing about good parenting and giving advice on parenting		
	Knowing how support caregivers to care for themselves		
<b>Telling a young child about their HIV infection</b>	<b>Knowing:</b>		
	WHY		
	WHEN		
	WHO		
	WHAT		
	HOW		
<b>Encouraging adherence to medicines</b>	How much medicine to give		
	How to give the medicine		
	When to give the medicine		
	How to remember to give the medicine		

**Palliative Care at Home for Young Children in Africa: Knowledge and Practical Competencies**

**Evaluation of Basic Competencies**

<b>Topic</b>	<b>Competency</b>	<b>Yes</b>	<b>No</b>
	How to encourage taking medicine		
<b>Part 3: Caring for a sick child</b>	<b>Dealing with:</b>		
	Poor feeding		
	Fever		
	Diarrhoea		
	Vomiting		
	Constipation		
	Mouth problems		
	Skin problems		
	Cough		
<b>Danger signs</b>	Recognising danger signs and knowing when to refer for help.		
<b>ART</b>	Knowing the side effects of ART		
<b>Child abuse</b>	Recognising child abuse and knowing what to do and who to ask for help.		
<b>Part 4: Caring for the child who may not get better</b>	Dealing with pain		
	Dealing with distress		
	Dealing with a child who no longer wants to eat		
<b>Talking about dying and death</b>	Assisting a caregiver to discuss dying and death with very sick young child and siblings.		
<b>Memory boxes</b>	Knowing when and how to use memory boxes		
<b>Bereavement</b>	Recognising abnormal bereavement and knowing where to get help.		