

# Palliative Care at Home for Young Children in Africa

**Guide for Home-based  
Care Workers**



*Diana*

Princess of Wales Memorial Fund  
THE WORK CONTINUES



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# 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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## Telling you about this course

We will start this course by telling you a bit about the course.

We will look at the following:

- Who is the course for?
- Who will take you through the course?
- How long will the course take?
- What is this course about?
- What will you learn from this course?
- What do we mean by caregiver?
- Why is this course about supporting caregivers?

### **Who is this course for?**

This course is for people like you who have had some training in home-based care.

Before you start the course a trainer will give you a list of things that we expect you to already know about home-based care. If you are unsure of some of these things then the trainer will revise these with you.

### **Who will take you through this course?**

A trainer will take you through this course.

### **How long will the course take?**

The course will take three days to complete.

## **What is the course about?**

This course is about helping you support people who care for young children who are HIV positive. We focus on children who are less than about seven years of age and who are being cared for at home.

In clinics with the appropriate equipment, a baby can be tested for HIV infection when it is two months old. In other clinics we must wait for eighteen months before we know if the child has HIV.

If you do not know whether a young child is HIV infected or not, please encourage the caregiver to take the child for an HIV test.

The course is about palliative care for children who have HIV and we tell you more about palliative care on page 10.

The course has two books. This book is called:  
**Palliative Care at Home for Young Children: Guide for Home-based Care Workers.**

The second book is called:  
**Palliative Care at Home for Young Children: Caregiver's Toolkit.**

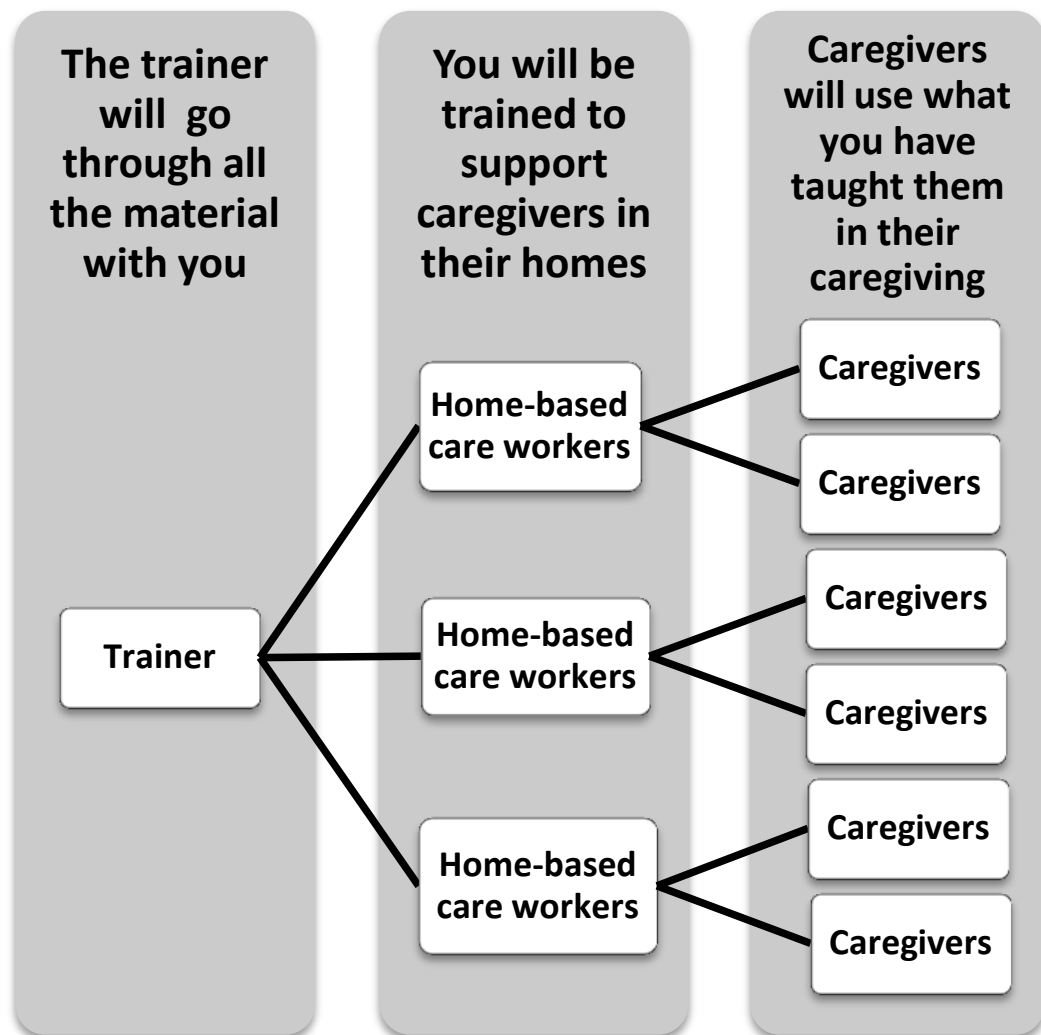
The trainer will go through both these books with you.

When you have finished the course you will keep a copy of this book "**Guide for Home-based Care Workers**" for yourself.

You will be given extra copies of the “**Caregiver’s Toolkit**”, which you will take with you into a home to give to caregivers you support.

Together you and caregivers at home will go through the Caregiver’s Toolkit so that caregivers at home can learn about palliative care for a young child with HIV.

In this diagram, we show you what will happen:



*Diagram showing how you will use your training to support caregivers at home*

At the end of the course we will spend time looking at how you will use the “**Caregiver’s Toolkit**” in the home.

### **What will you learn from this course?**

To know more about what will be covered over the next three days please look at page 105 in this book.

At the end of the course you 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.

You will practise aspects of palliative care, for example:

- Telling a young child about HIV infection.
- Supporting a caregiver to give medication to a young child.
- Supporting the caregiver to care for themselves.
- Knowing when to refer a sick child to a clinic.
- Telling a young child and family that the child is very ill and may die.
- Recognising abnormal bereavement and giving support.

### **What do we mean by a caregiver?**

In this course we use the word caregiver to mean the person who looks after the child most of the time.

We know that many different people care for young children at home including mothers, grannies, fathers, aunts and even sisters.

A granny may have to care for several young grandchildren.

Children may be cared for by men and we know that sometimes men are not acknowledged as caregivers by home-based care workers.

Young children may be cared for by older children who are still in school.

It is important for you to support whoever is a caregiver.



*Supporting a caregiver*

## **Why is this course about supporting the caregivers of young children who have HIV?**

We want you to support the caregiver of a child who has HIV as these caregivers, their children and their families all have special needs.

We know that children with HIV are often not sick, but some may become sick and some may die.

As a home-based care worker, you probably already support caregivers who look after children with HIV. As you go through this course you may realise that you already know a lot.

### **The course has four parts:**

- Part 1     Looking at palliative care for young children with HIV at home
  
- Part 2     Supporting a caregiver whose child with HIV is well
  
- Part 3     Supporting a caregiver whose child with HIV becomes sick and gets better
  
- Part 4     Supporting a caregiver whose child with HIV is very sick and may die

We will also give you nine messages that you can use in many different situations to help you care for a sick child.

These nine messages are:

1. Giving a little can mean a lot
2. Be kind to yourself
3. Ask for help
4. Listen to the child
5. Offer comfort to a distressed child
6. Prepare the child and the family
7. Prevent and treat
8. Empower
9. Remember



**Part 1: Looking at palliative care for young children with HIV at home**

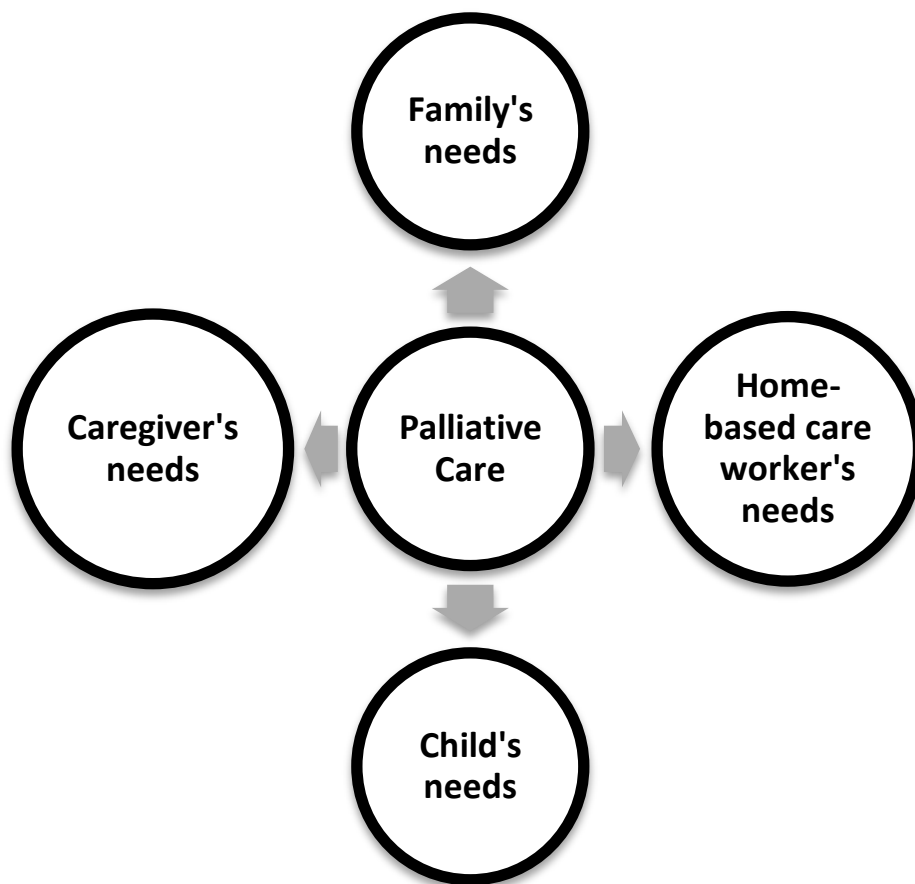


## Introducing Part 1

In Part 1 we look at the following:

- What is palliative care?
- What are the needs of a caregiver and sick child at home?
- What can you and the caregiver do to meet these needs?
- Two important points in this course:
  - Help the family help themselves.
  - Don't work alone – always ask for help.

This diagram tells you what we will look at.



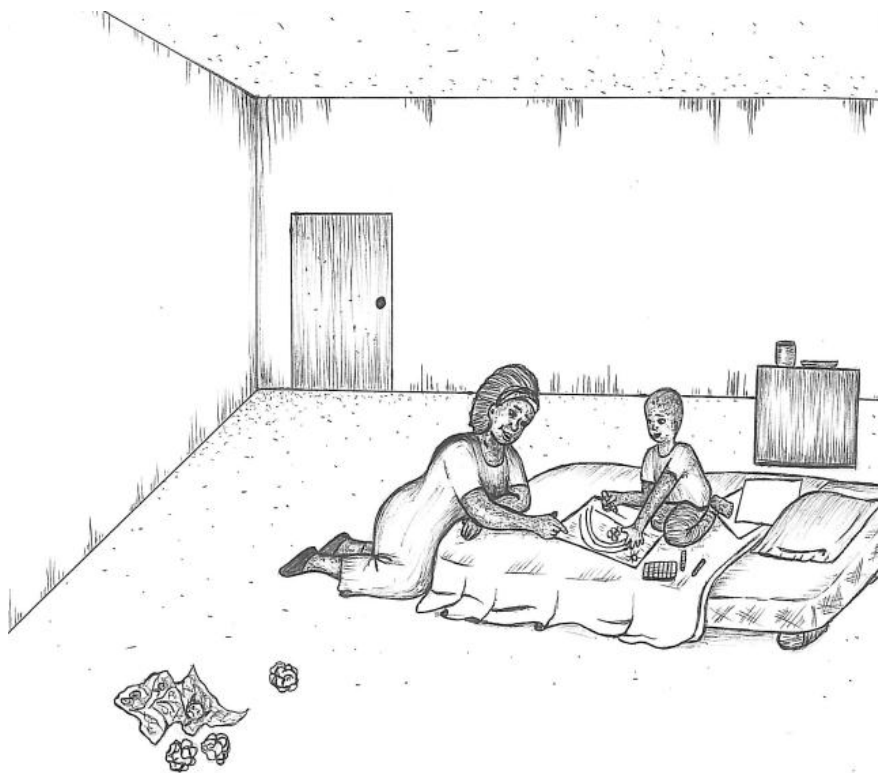
*Diagram: What we will cover in looking at palliative care*

## What is palliative care?

Palliative care is care for people who have an illness from which they may not recover. Examples of such illnesses are HIV and cancer, if it is not treated.

In this course we look at how palliative care aims to support the caregiver, the child with HIV and other relatives at home (for example grannies, mothers, aunts and older sisters).

Palliative care also aims to support you - the home-based care worker.



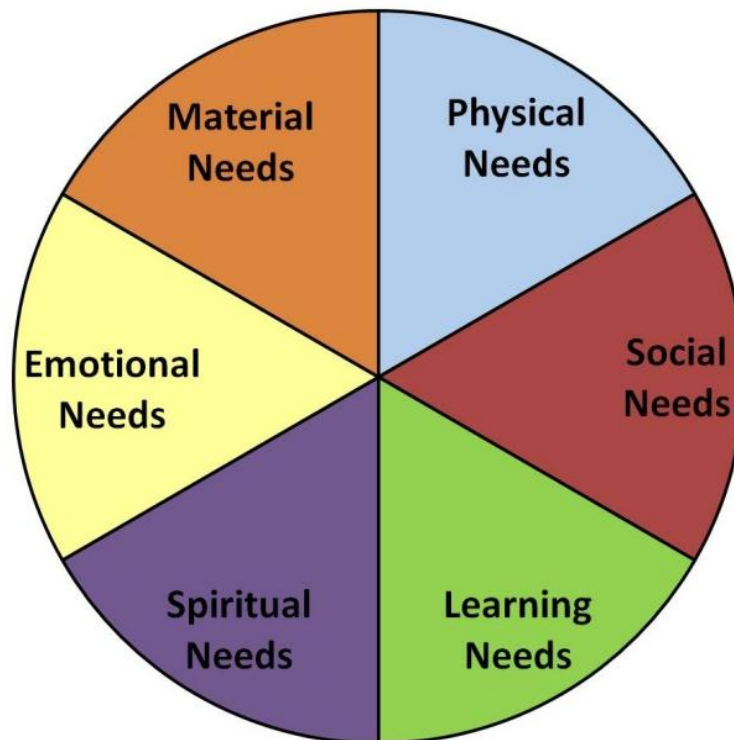
*Supporting the caregiver and young child with HIV*

Palliative care aims to support the caregiver, the child and the family for the following reasons:

- The caregiver must remain in good health.
- The child with HIV should be eased of pain or other problems in the body.
- The caregiver and their child should be content in themselves and have a clean, comfortable home.
- The caregiver and child should eat good, clean food.
- The caregiver and child must be able to tell others when they are hurt, frightened or upset.

When you are supporting the caregiver and the child you should understand all their needs.

We can think of palliative care and needs using the following diagram:



*There are many different kinds of needs*

The different needs can be:

1. *Physical needs*: When we talk about physical needs we mean problems that the child may be experiencing in the body. For example, pain, vomiting, diarrhoea and headache.

2. *Social needs*: When we talk about social needs we mean that the caregiver and child should have friends and family to support them.

3. *Emotional needs*: When we talk about emotional needs we mean that the caregiver and child should be content within themselves. If a caregiver or child is very unhappy or angry we say that they have emotional difficulties.

4. *Spiritual needs*: When we talk about spiritual needs we mean that a caregiver and child should feel a sense of peace with their life. This may involve praying or going to church or visiting a traditional healer to make peace with their ancestors.

5. *Learning needs*: Both a caregiver and child have learning needs. The caregiver may need to learn how best to care for himself/herself and for the child. The child with HIV must be encouraged to go to school. Even a sick child may be able to go to school or have books at home for learning.

6. *Material needs*: Material needs are practical things that the child, the caregiver or the family may need, such as money for transport, food and medication.

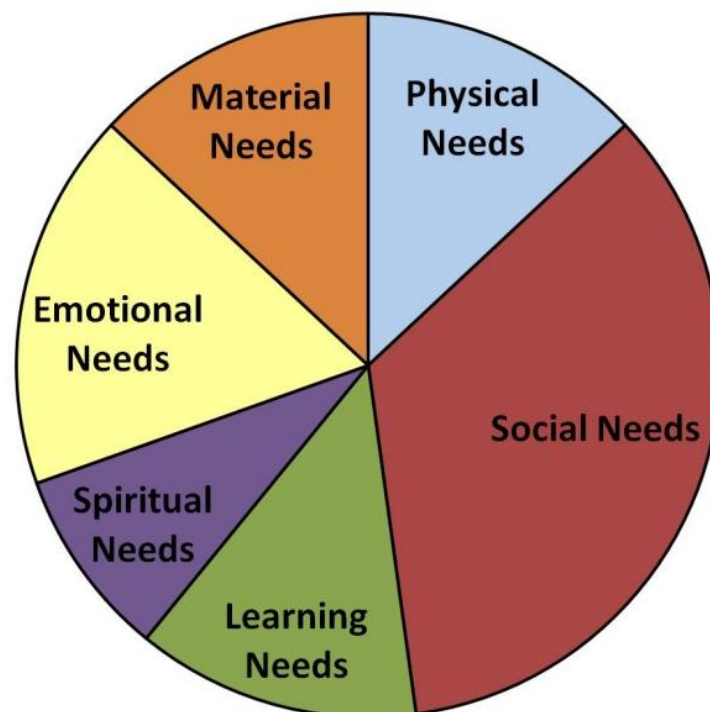
## **What can you and the caregiver do to meet the needs?**

A caregiver and a child may have many different needs at one time.

We find it useful to sit with the caregiver and child and together use the palliative care diagram to describe all their needs.

Together you and the caregiver can highlight the biggest problem they face today. For example, a granny who is caring for many children may tell you that she has lost hope and feels she cannot cope as there is no money and no one to help her.

You and the granny would draw a palliative care picture to show this biggest need:



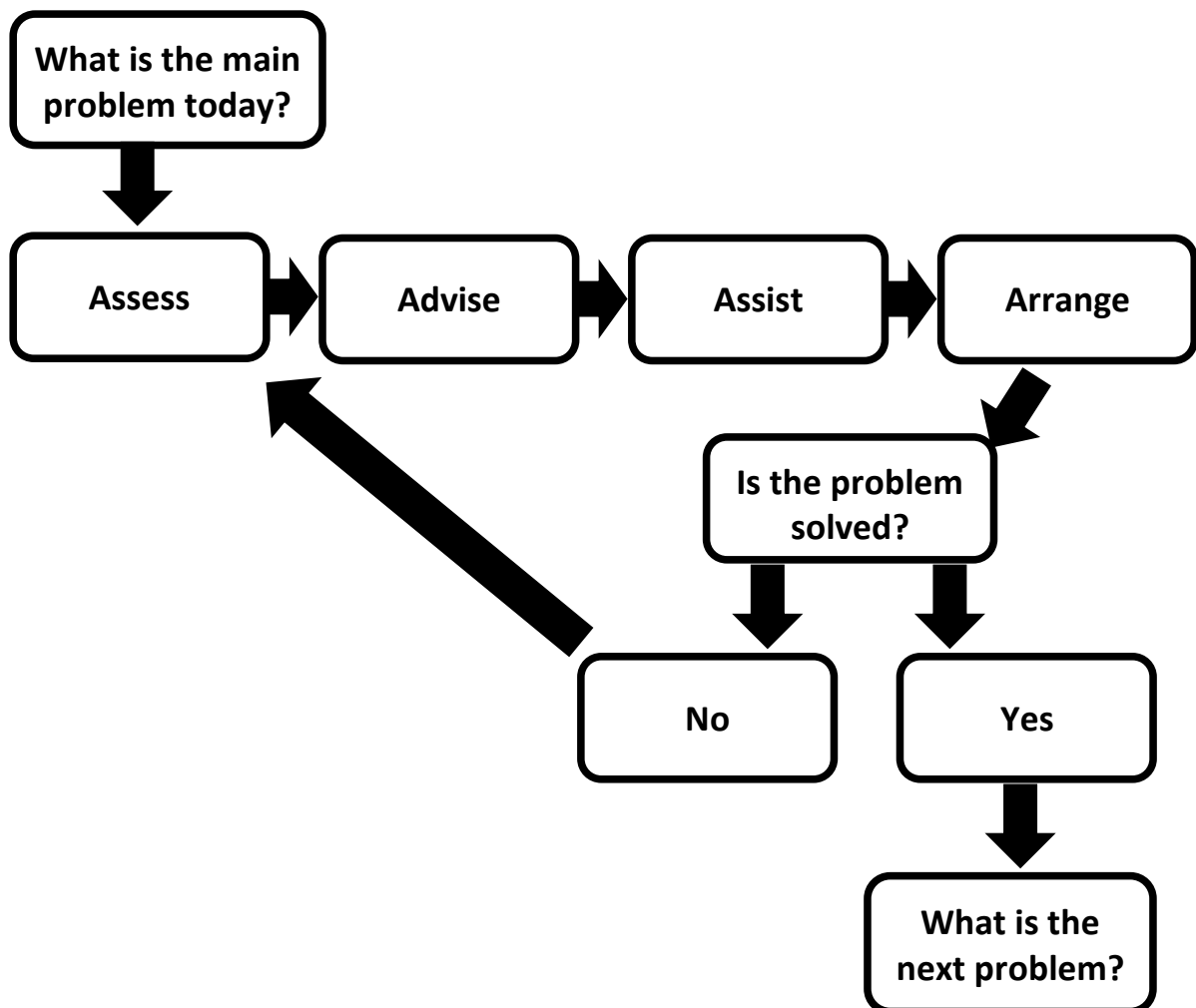
*In this diagram we can see that the biggest need is a social one*

The palliative care diagram now shows that the social need is the biggest problem for the caregiver today.

It is usually best for you and the caregiver to look at the biggest problem first.

We can do four things with a problem:

1. Assess: What is the problem? Why is it a problem?
2. Advise: What can be done about the problem?
3. Assist: What help is needed?
4. Arrange: How can that help be arranged?



*Diagram showing the process to assess, advise, assist and arrange*

Throughout this course the trainer will spend some time showing you how to decide on the main problem and to assess, advise, assist and arrange.

When the main problem seems better you can together look at the next problem.



*Try to deal with the main problem first*



## Two important points of this course

As you go through this course we want you to remember two important things:

1. Don't try to do everything for the caregiver and the child.

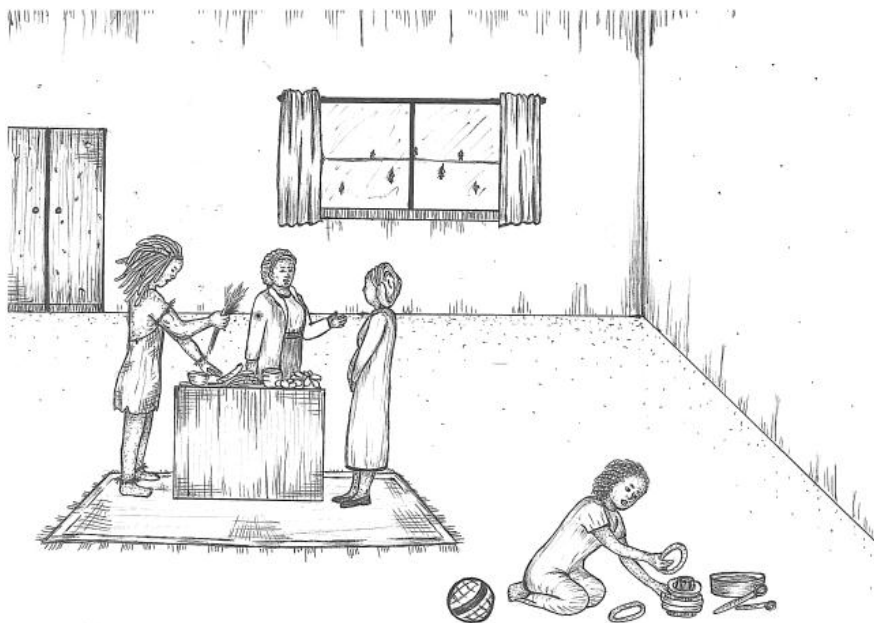
We want you to share your knowledge and experience with the caregiver so they can care for themselves and for the child when you are not available.

HELP THE FAMILY AND CHILD TO HELP THEMSELVES

2. Don't work alone.

We recommend that you always work as part of a larger team. You may have to face difficult problems and you need to ask other people for help.

DON'T WORK ALONE - ASK OTHERS FOR HELP



## Summary of Part 1

In Part 1 we looked at palliative care as a way of trying to meet the needs of a caregiver and child with HIV.

We know that there may be many needs including the following:

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

It is usually best for you, the caregiver and child to look at all the problems and then together decide which is the main problem today.

The trainer will show you how to solve that problem using the following:

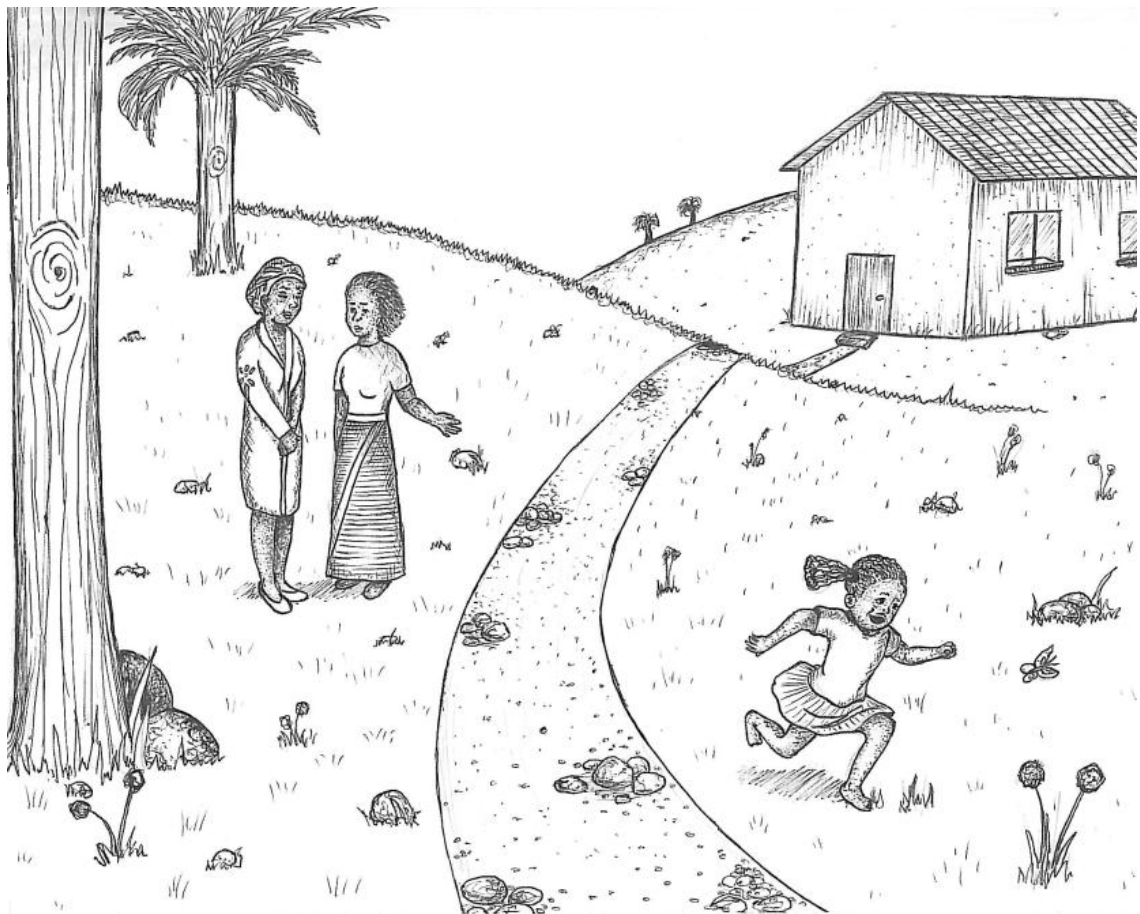
- Assess
- Advise
- Assist
- Arrange

Remember the two important points:

1. Don't try to do everything for the caregiver and the child - help them to help themselves
2. Don't work alone - ask others for help

In the rest of the course we look at supporting a caregiver and the child with HIV at home.

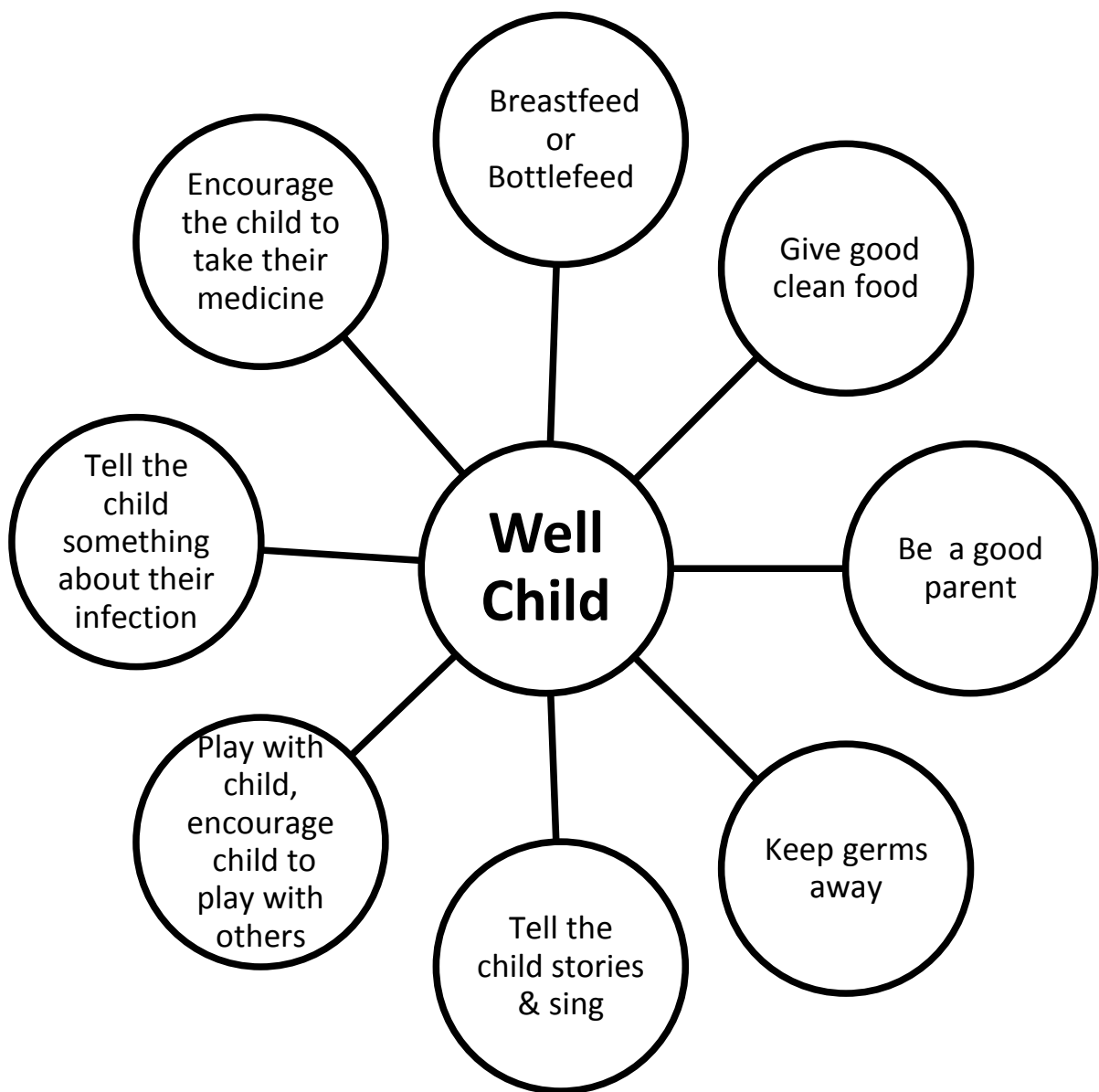
## Part 2: Supporting a caregiver whose child with HIV infection who is well



## Introducing Part 2

In Part 2 we look at how to support a caregiver who cares for a child who has HIV infection and is well.

Some children with HIV may be well, but the caregiver still needs your support. Here are some ways to support the caregiver:



*Diagram looking at the child who has HIV and is well*

Some may be taking medicines to control their HIV (these drugs are called antiretroviral drugs - ART).

Other children with HIV may remain well without ART as they do not yet need it.

We will look at ART in more detail later on page 29.

We will now look at the following in supporting a caregiver:

- How you can support a caregiver to keep a child well.
- How you can support a caregiver to care for his or herself.
- How you can support a caregiver in telling a child about HIV infection.
- How you can support a caregiver to make sure that the child keeps taking medicine (including ART).

### **How can you support a caregiver to keep a child well?**

There are many ways that you can support a caregiver to keep a child with HIV from becoming sick.

We look at a few ways below:

#### *Keep the child safe from germs*

You should remind the caregiver to keep everything as clean as possible so the child is not exposed to germs.

Helpful Handout 1 shows the ways in which we can protect a child from germs.

*Encourage breastfeeding for a newborn baby*

We recommend that you ask a mother to check about breastfeeding a newborn baby with a clinic sister.

The mother should give the baby only breast milk for six months after birth.

*Keep the baby's feeding bottle clean and use right amount of formula*

If a baby is getting formula feed then it is very important to keep everything very clean.

It is very important to make sure that the right amount of formula is given to the baby.

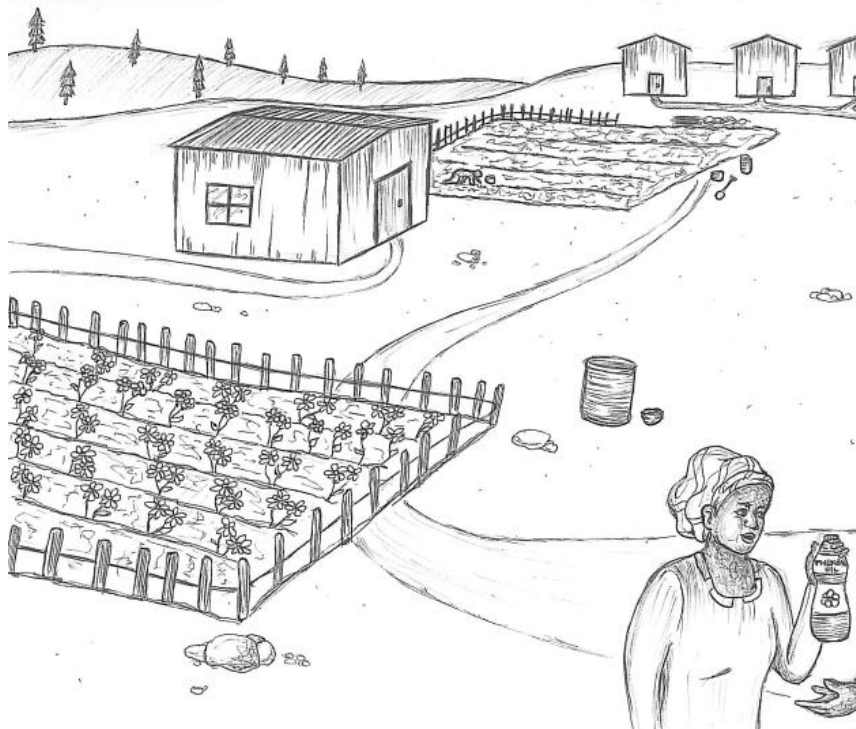
You can watch the caregiver make up the formula so she can feel supported. You can check that the water, bottle and teat are clean and that the amount of formula is right.

*A child should have good food*

From the age of about six months, a caregiver must begin to feed a baby using a clean plate and spoon.

You should encourage the mother to check with a clinic nurse before stopping breastfeeding and before giving solid food to her baby.

Together you and the caregiver could look at what food is available in the home.



*Try to give the child good, clean food*

You can support the caregiver if you see that the caregiver could make changes to what she buys and prepares for the family. For example, you can show the caregiver how to select fresh and wholesome fruit and vegetables for the family and how to keep raw foods separate from cooked foods.

*A child should be taken to the clinic for immunisation, growth monitoring and blood tests*

The child should be taken regularly to a local clinic and the clinic nurse will provide information on immunisation and growth monitoring. Children may have a “Road to Health Card” from the clinic. Together you and the caregiver can remember when the child must go to clinic for immunisation and checkups.

A child with HIV may need regular blood tests so the nurse can monitor their HIV. A child may also need medicines such as worm medicine so they do not get sick. A special medicine called Bactrim or Septrin may also help keep the child with HIV well. This medicine can stop some chest and tummy infections. The nurse may also give the child medicines such as multivitamins or vitamin A. these vitamins help the child stay healthier for longer.

*Being a good parent to the child*

Young children with HIV may have lost one or both of their parents.

Young children who have lost a close relative may find it very difficult to talk about what is upsetting them.

It is important to advise the caregiver to be patient.

It is important that the child feels secure and loved.



*The child with HIV will need special love from the caregiver*



It is important to advise the caregiver to be consistent and fair. For example, a caregiver must be kind and fair both in rewarding and in disciplining the child.

*The caregiver and family members should play with and talk to the child*

Playing and talking with a young child is very important for the following reasons:

- If a child has experienced loss or stress then play is a natural way that they can get rid of hurt and angry feelings
- Playing will encourage a child to exercise.
- Playing with other children helps the child to think of others and not just of themselves.
- Playing with others will encourage the child to talk and listen.



*Encourage the caregiver to play with the child*



*Encourage the child to play with other children*

## **How can you support the caregiver to care for themselves?**

It is very important that you support the caregiver to remain in good health.

Like the child, they should eat good, clean food.

When they take the child to clinic they should also ask the nurse to check themselves.

There is a list on page 106 of this book of health-checks that caregiver should have when they go to a clinic.

## **Supporting a caregiver in telling a child that they have HIV infection**

We find that it is usually better to tell a young child a little about their HIV infection.

We use 5 points when telling a young child about HIV infection:

1. WHY
2. WHEN
3. WHO
4. WHAT
5. HOW

You will have a chance to practice these points in the training sessions.

## 1. *Why do children need to know?*

A child may need to know about HIV infection for the following reasons:

- We find that many young children know that they have HIV even before we tell them.
- If we don't tell a child or if we tell them an untruth (for example, you are taking medicine because you have TB) then they may get confused and no longer trust us.
- The child may need to go for blood tests and take medicines and the child will ask questions about this (for example, the child may ask "Why am I different to the other children?").
- If a child knows about the infection then they will understand better why they must keep taking medicines.
- The child must know how to protect themselves from germs.
- The child must know how to protect other children from HIV infection.
- A child needs reassurance that they have not done anything wrong.

## 2. *When do children need to know?*

It is usually best to tell a child something about HIV infection when the caregiver feels ready to share this information with the child.

It is also good to tell a young child something about HIV infection when the child begins to ask questions (for

example, why do I take medicine and no one else at school does? Is it because I was naughty?).

3. *Who should tell them?*

It is usually best if the caregiver tells the child about the HIV infection.

The caregiver can ask you to help.

4. *What should a child be told?*

Sometimes a caregiver does not want to use the word "HIV" and she can tell a child something about HIV using examples of things that they know. For example she could say to the child:

"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 the blood strong. You need medicine every day.

If you don't take medicine the germs can wake up."

5. *How should they be told?*

Decide together what you and the caregiver are going to tell the child about HIV.



*Be clear about what you are going to say and practice*

Practice what you are going to say to the child about HIV.

Don't try and say everything at once or the child may become confused.

The caregiver should check that the child has understood what has been said by asking the child to repeat it.

You and the caregiver can discuss the following with the child:

- Who should the child tell about their HIV?
- How should they tell others about their HIV?
- Who can the child turn to for help if others tease them about their HIV?

We give a story in the Caregiver's Toolkit which may make it easier to tell a young child about HIV (Page 12 in the Caregiver's Toolkit).

We include a story about being different to everyone else (Page 44 of Caregiver's Toolkit)

We also include a story telling a child to face their fears (Page 45 of Caregiver's Toolkit).

### **How can you support a caregiver in making sure that a child keeps taking medicine (including ART)?**

A child who has HIV infection may need to take several types of medicines.

Some of these medicines are called ART and are used to control HIV infection.

The hospital or clinic will let the caregiver know when the child needs ART.

A child will not be started on ART until they really need it. The hospital or clinic will show the caregiver and child the following:

- That the medicine must be taken every day for the rest of the child's life.
- How much medicine to give the child.
- How to give the medicine to the child.
- When to give the medicine to the child.
- How to remember to give the medicine to the child.

**It is very important that you and the caregiver know:**

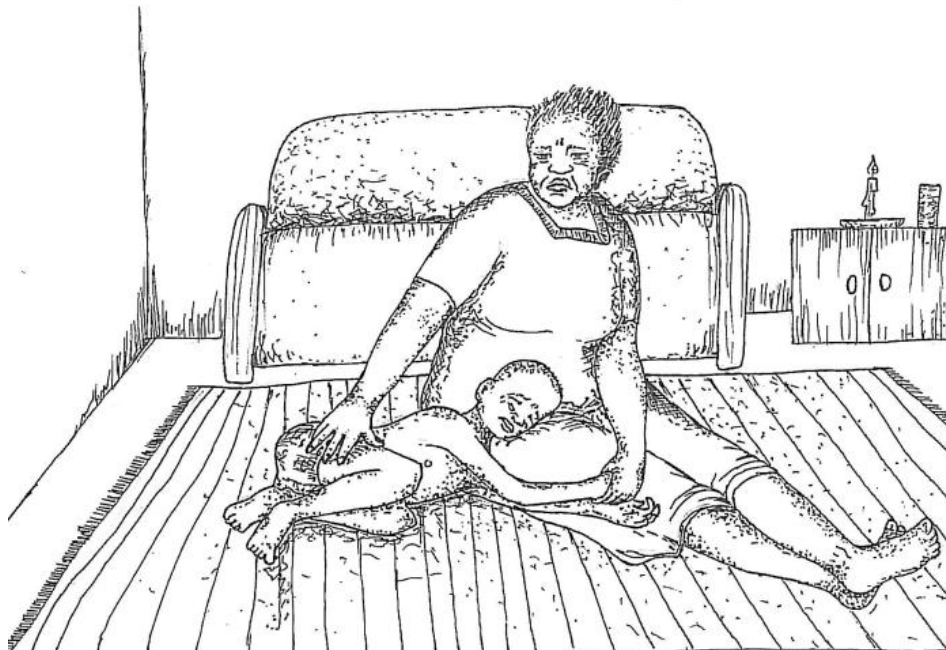
- How much to give
- How to give
- When to give
- How to remember to give the medicine

You should watch the caregiver give the medicine to the child.

Check that she is doing what the hospital or clinic asked her to do.

Sometimes a child no longer wants to take medicine.

Encouraging a young child to continue to take medicine may be difficult for the caregiver.

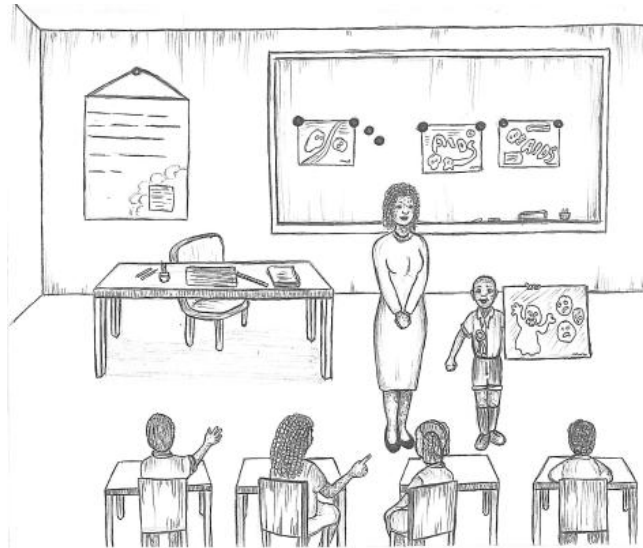


*A young child may not want to take medicine*

Here are a few suggestions on how to encourage the child to keep taking medicine:

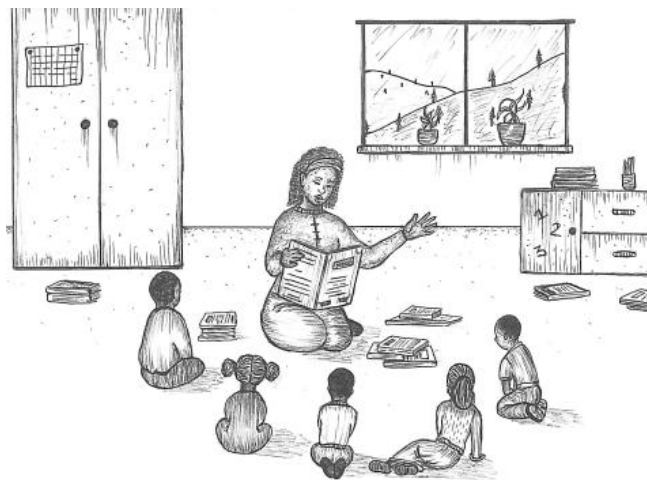
- Disguise the taste of medicine by adding it to a juice or jam or sugar on bread. Please ask the caregiver to check this with the clinic sister.
- Together with the caregiver talk to the child about the medicine and draw pictures to explain why it is important to take the medicine (for example, the medicine will help the soldiers in the blood to keep the germs asleep).
- Reward the child after they have taken the medicine (for example, some caregivers put a star or a sticker on a wall calendar to show the child that they have taken their medicine).
- Playing at also giving a doll the medicine.
- Put the medicine into a syringe and let the child suck the medicine at their own pace.
- If the caregiver is also HIV infected then they could take the ART together.





*The teacher can tell the class about HIV infection*

- Ask if there is an older child who is taking ART who could talk to the younger child.
- Ask a teacher to tell the class about HIV and the importance of taking medicine.
- We find that support groups are an excellent source of encouragement for both the caregiver and the child.



*The child could join a support group*

## Summary of Part 2

In Part 2 we looked at ways of supporting a caregiver to help a child with HIV stay well.

We looked at supporting the caregiver to look after herself

We looked at telling a young child about HIV infection.

We looked at encouraging a young child to keep taking medicine



*Looking after a child with HIV infection who is well*

**Part 3: Supporting a caregiver whose child with HIV becomes sick and gets better**



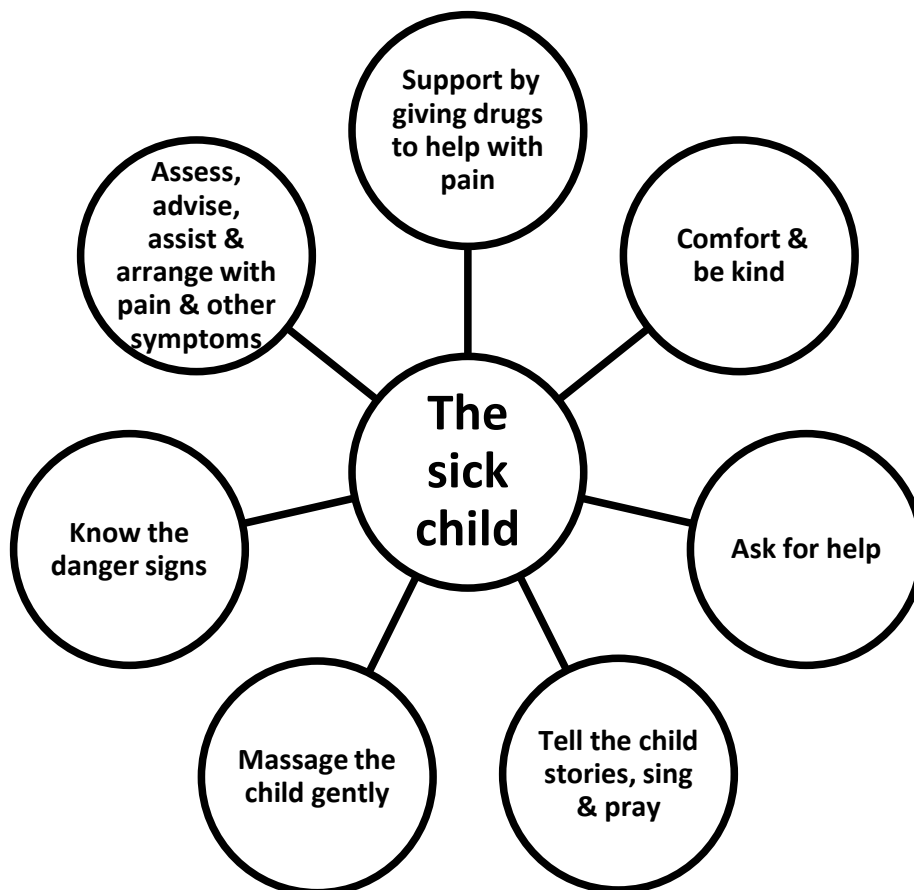
### Introducing Part 3

In Part 3 we look at supporting a caregiver whose child with HIV becomes sick and gets better.

If a child becomes sick it is important that the caregiver is supported. You might need to visit the caregiver more often.

This can be a stressful time for the child and caregiver.

It can also be a stressful time for you. Here are some of the ways to support the caregiver:



*Diagram looking at the child who has HIV and becomes sick*

We will discuss the following:

- Finding out what is causing the sickness
- Common problems faced by a child with HIV who becomes sick
- Knowing when to refer a sick child to a clinic
- The special problems the child may face taking ART
- The special problems of abuse

### **Finding out what is causing the sickness**

As a home-based care worker you will have some training in common problems faced by children with HIV disease and in deciding what is causing a sickness. You may also know about danger signs and when to refer a sick child to a clinic. We now look at assess, advise, assist and arrange.

#### **1. ASSESS A PROBLEM**

You are looking to see if you can find a cause for the problem and if there are any **DANGER SIGNS**.

Assess the problem **by asking questions about the problem:**

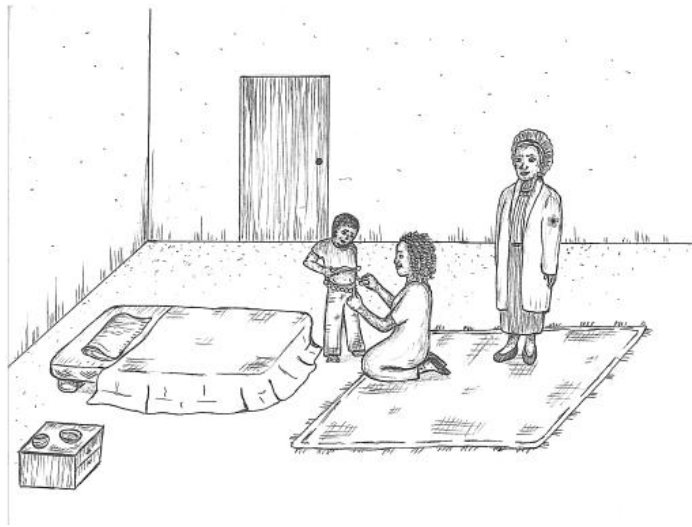
For example, how long has the child had the problem? Is the problem there all the time? Does anyone else at home have the same problem?

Assess the problem **by looking at the child:**

For example, are the eyes sunken? Is he vomiting? Is he drowsy? Is he breathing fast? Is his chest in-drawing? Is the fontanelle shrunken or bulging?

Asses the problem **by feeling the child:**

For example, does he feel hot? Is the skin pinch normal?



*Assess the sick child*

## 2. ADVISE

If you and the caregiver decide to keep the child at home, give advice.

For example, tell how to keep a child cool, how to dispose of sputum and how to use local remedies and/or medicines.



*Give advice*

### 3. ASSIST

You could assist the caregiver, for example making up Sugar Salt Solution (SSS) if the child has diarrhoea.

You could help her wash dirty bed linen.

### 4. ARRANGE

If you are concerned about the child, then arrange for the child to go to hospital or clinic.

If you feel that the caregiver can cope with the child then arrange to visit the home again soon.

Visit often to keep a close eye on the child.



*Visit often to keep an eye on the sick child*

## **Common problems faced by a child with HIV who becomes sick**

### *Crying and distress*

A sick child may cry a lot.

It can be difficult to give comfort to a crying, sick child.

We look at comforting a sick child later (page 78).

### *Pain*

A sick child may experience pain.

The pain may go away when they get better.

We look at pain later (on page 90).

### *A sick child may not feel like eating or drinking*

When a child is sick they may not feel like eating or drinking.

A caregiver must be supported to gently encourage a sick child to eat and drink.

Young children have small stomachs so they need to eat and drink often.

We must make sure they eat enough so they become well again.



When a child is sick they may not want to eat. At this time the caregiver must encourage **active feeding**.

Active feeding is when adults spend time encouraging children to eat and keep children interested in food.

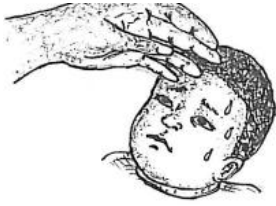
There are several ways that a caregiver can actively feed a sick child:

- Tell the child how nice the food tastes.
- Make up stories or games about the food.
- Take the child onto her lap.
- Watch the child, talk, smile and sing.
- Keep praising the child for the way they are eating.
- Allow the child to feed themselves.
- Watch the child carefully to check that they are eating.
- Give the child food when the child wants food.
- Give the child his or her favourite food.
- Tell the sick child that food and fluid will make them strong again.

When the child begins to recover they may need additional food to make up for food they missed when they were sick.

They may need an extra meal a day for up to two weeks after the sickness.

## Managing a fever



A child with HIV may get more infections than a child who does not have HIV.

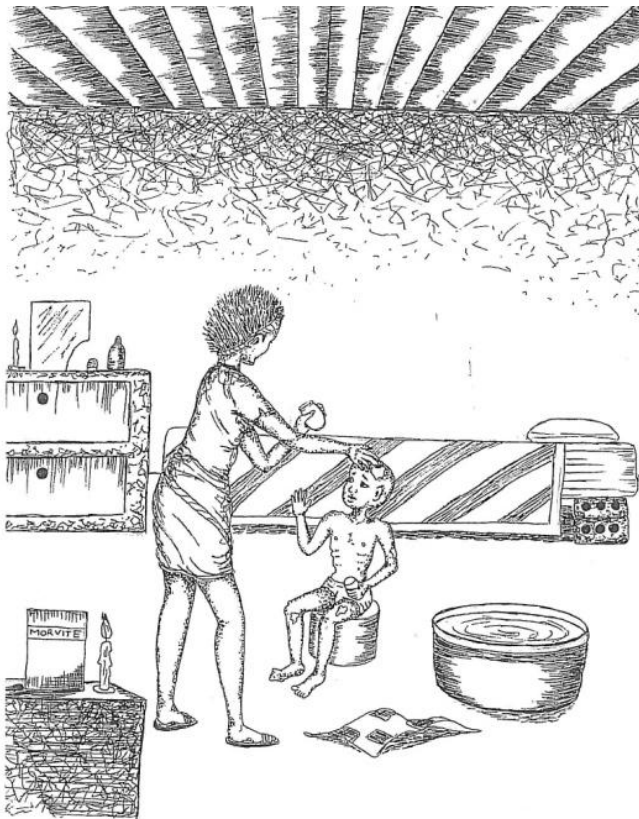
They therefore get more fevers.

### ASSESS

Can you find a cause for the fever?

### ADVISE AND ASSIST

Paracetamol is good for getting rid of fever and should be given when the child has a fever.



A hot child should be undressed and exposed to cool air.

Sponging with lukewarm water can help bring the fever down.

## ARRANGE

- Refer to clinic immediately if a child has a stiff neck or bulging fontanelle.
- Refer to the clinic if the child has a fit.
- Refer if the child is less than 2 months old.
- Refer if fever is not better in 2 days.
- If the child has no danger signs arrange to visit often.

### *Coping with a child's dry mouth*

If a child is sick then the mouth can get very dry. This may be why the child does not want to eat.

The caregiver must check the mouth often to see if it is dry.

## ASSESS

Can you find a cause for the dry mouth (think of thrush)?

## ADVISE AND ASSIST

You could support the caregiver with the following:

- Offer frequent sips of water or ice to suck.
- Swab the mouth with a moist, soft sponge on a stick.
- Give the child small pieces of pawpaw, crushed ice or chewing gum to suck or chew.
- If the child cannot suck or swallow, rub ice cubes, frozen fruit juice or pawpaw chunks on their lips.
- Some people use bicarbonate of soda to gently cleanse teeth.
- Putting Vaseline or glycerin onto the lips can help with the feeling of dryness.

## **ARRANGE**

- Arrange to visit often
- Refer if the child needs medicines.

### *Coping with sores in the mouth*

The child may not want to eat if his mouth is sore.

## **ASSESS**

Can you find a cause for the sore mouth? Does the child have thrush or mouth ulcers?

## **ADVISE AND ASSIST**

You can support the caregiver with the following:

- Offer foods such as yoghurt or porridge, depending on what the sick child likes.
- Try local remedies such as a Sour Fig Aloe that can be cut in half and the moist surface rubbed on the sores.
- Some caregivers put fresh lemon juice on the sore but this may sting.

## **ARRANGE**

Refer the child to clinic if you think they have thrush or severe mouth ulcers. Arrange to visit often.

## *Coping with nausea and vomiting*



### **ASSESS**

Can you find a cause for the vomiting?  
Has the child started any new medicine?  
Is anyone else at home vomiting? Is the feeding bottle clean?

### **ADVISE AND ASSIST**

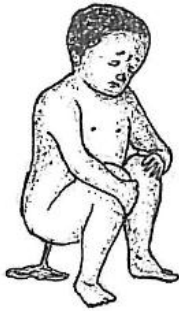
If the sick child feels like vomiting, support the caregiver to try some of the following:

- Offer small amount of foods such as mashed potatoes, rice, pap or bread.
- Offer cold food.
- Avoid greasy foods.
- Avoid strong smells that make the nausea worse.
- Let the child breathe in pleasant smells such as lemon or ginger.
- Giving small sips of cold, black tea can also help.

### **ARRANGE**

Arrange for child to go to the clinic if there are any danger signs. Arrange to visit often.

## *Coping with diarrhoea*



### **ASSESS**

Can you find a cause for the diarrhoea? Has the child started any new medicines? Is the house or food dirty? Does anyone else at home have diarrhoea.

### **ADVISE AND ASSIST**

If the child has diarrhoea, you can support the caregiver to do the following:

- Remind the caregiver to increase the amount of fluids she gives the child.
- Help the caregiver make SSS.
- The child should eat small amounts of food and drink SSS frequently and especially every time they pass a stool.
- The caregiver could offer thin porridge or rice water.
- The caregiver may also try things like cornflower or custard powder mixed with a small amount of water.
- Some caregivers try peach and guava leaves crushed, boiled and cooled for the child to sip.
- Children usually like Coca-Cola (but let it stand for a while so all the bubbles disappear).
- Bananas are good for diarrhoea.
- Remind the caregiver to keep the anal area clean by washing gently with warm water after every loose stool and pat the skin dry. Aqueous cream or Vaseline can protect the skin.
- Give advice on keeping germs away.

## **ARRANGE**

Arrange for the child to go to clinic if there are any danger signs. Arrange to visit the sick child often.

*Coping with constipation*

## **ASSESS**

Can you find a cause for the constipation? Is the child taking medicine that can make constipation worse?

## **ADVISE AND ASSIST**

Support the caregiver to do the following:

- Offer the child small sips of fluid often.
- Encourage the child to eat fruits, vegetables, porridge, locally available high-fiber foods like pawpaw and yellow bananas.
- Encourage the child to move around and exercise.
- Crush some dried pawpaw seeds and mix with a half a teaspoon full of water.
- Give the child a tablespoon of vegetable oil before breakfast (but the child may not like the taste).

## **ARRANGE**

Arrange for the child to go to clinic if constipation does not improve. Arrange to visit the sick child often.

## *Coping with itchy skin or rash*

### **ASSESS**

Can you find a cause for the itchy skin or rash? Think of thrush, think of ringworm, think of eczema, think of scabies.

### **ADVISE AND ASSIST**

You can support the caregiver by trying any of the following:

- Cut the child's nails so they are short and they can't scratch
- Avoid bathing the child in cold water, rather use lukewarm water.
- If the skin is dry then gently rub the skin with Aqueous Cream or Petroleum Jelly (Vaseline) mixed with water.
- Put one tablespoon of vegetable oil in 5 liters of water when washing the child.
- Rub the itchy skin with local remedies, like cucumber, wet tea bags, or tea leaves put in a clean piece of cloth and soaked in hot water or yoghurt.
- Keep sheets and blankets off sensitive skin.
- Make sure blankets and sheets are clean.

### **ARRANGE**

Arrange for the child to go to clinic if you think the child has thrush, ringworm, eczema or scabies. Arrange to visit the sick child often.



## *Coping with a cough*



### **ASSESS**

Can you find a cause for the cough? Are there any danger signs? Are there people in the home with a cough or TB?

### **ADVISE AND ASSIST**

Support the caregiver to try the following:

- The child can breathe in steam and the boiling water could contain soothing remedies such as honey and lemon (beware not to burn the child).
- Eucalyptus leaves or gum tree leaves are also useful in steam for inhalation.
- Help the sick child to sit in a comfortable position; use extra pillows or some back support.
- Open windows to allow in fresh air.
- Fan the child with a newspaper or clean cloth.
- Let the child sip warm water. The caregiver can add a little lemon to the water.
- Give advice on covering the mouth while coughing.
- Give advice on disposing of spit/sputum.

### **ARRANGE**

Refer to the clinic if someone in the house has TB or if the child has been coughing for more than two weeks.

Refer if the child has any danger signs. Arrange to visit the sick child often.

## **When to refer to a clinic**

Remind the caregiver to take a sick child to clinic if he or she has any of the ten danger signs.

If you are unsure of the danger signs, please ask the trainer to revise this with you.

### **The ten danger signs are:**

1. The child is unable to drink or breastfeed.
2. The child vomits everything.
3. The child has fits.
4. The child is very drowsy or unconscious.
5. The child coughs with fast breath (more than 50 breaths per minute).
6. The child is coughing and has in-drawing chest.
7. The child has diarrhoea and sunken eyes or sunken fontanelle or delayed skin pinch.
8. The child has diarrhoea with blood.
9. A child under two months old who develops a fever.
10. A child under two months old who is not feeding properly.

## **The special problems a child on ART may face**

ART, like many medicines, can have side effects.

Most side effects are not harmful and disappear with time.

It is important that the child does not stop ART.

If there are problems, the caregiver and child should go to the clinic or hospital.

The common problems when starting ART are rashes, diarrhoea and vomiting. If these occur, a child should see a nurse or a doctor.

If the child develops any of the following they should go to clinic or hospital:

- Rash
- Blistering
- Facial swelling
- Drowsiness
- Yellow eyes
- Tummy pain
- Pain in the hands or feet

When you visit the clinic, you must take the child's medicine with you.

## **The special problems of child abuse**

Unfortunately we know that children with HIV may also face abuse at home.

Dealing with a child you think might be abused is difficult for any home-based care worker.

- You know the family and you may become very upset if you see a child being abused, especially if the caregiver is responsible for the abuse.
- The family may become upset with you if you tell them or other people about your concerns.

We remind you that there are several types of abuse:

Physical abuse	For example, hitting children
Sexual abuse	For example, rape, touching genitals, exposing a child to pornography
Emotional abuse	For example, excessive shouting and telling child that they are worthless
Neglect	For example, leaving child alone without care or supervision

In the following table we list things for you to look out for:

Type of abuse	Behaviour
<b>Physical</b>	The child may seem very frightened of the caregiver. He or she could be watchful as if waiting for something bad to happen. The child may have bruises or even a broken arm or leg.
<b>Emotional</b>	The child could be very aggressive, be very demanding, use bad language, or seem to be very quiet and distant.
<b>Sexual abuse</b>	A child may have difficulty walking or sitting. He or she could wet the bed, have nightmares and may show unusual sexual behaviour.
<b>Neglect</b>	A child may beg for food or look thin and dirty.

If a child tells you that they have been abused, you should say the following to the child:

- I believe you.
- Thank you for telling me.
- I am sorry that this has happened to you.
- It is not your fault.
- I need to speak to other adults to help you and to try and make sure that this does not happen to you again.

If you suspect that a child is being abused, and if the caregiver agrees, then it is best to take the child to the nearest clinic or hospital or crisis center, such as ChildLine.

If the caregiver does not want you to help the child, then we strongly advise that you discuss the situation with your colleagues.

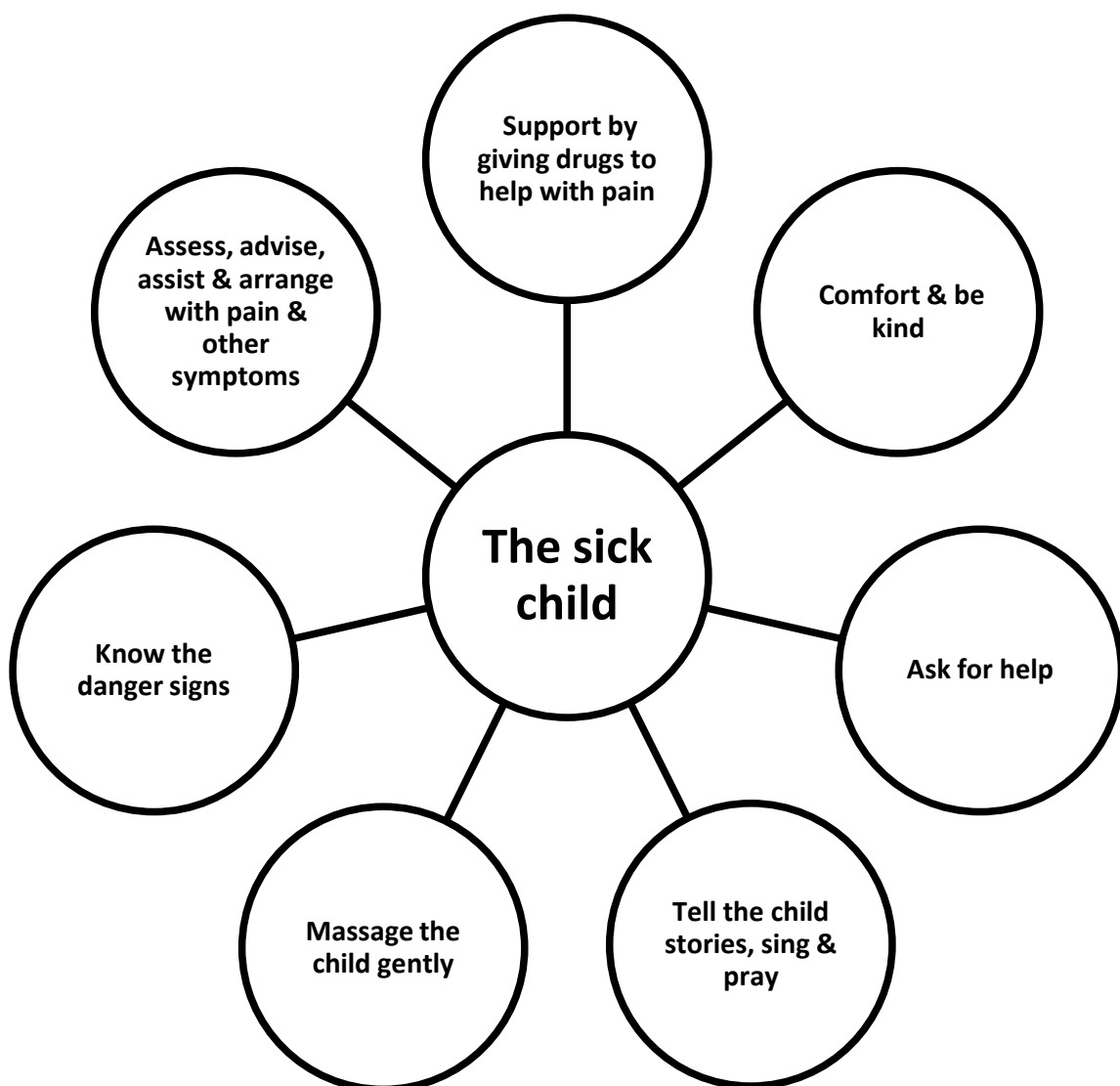
This is a very important example where you must not act alone.

You could leave the telephone number of a 'helpline for abused children' at the home.

## Summary of Part 3

In Part 3 we looked at coping with a child with HIV who becomes sick.

If the child is sick then you must be available for the caregiver and for the child more than usual. Here are some of the ways to support the caregiver:



*Diagram looking at caring for the sick child with HIV who becomes sick*

You should do the following when dealing with a sick child:

- Assess
- Advise
- Assist
- Arrange

Some sickness can be managed by the caregiver using local remedies.

The caregiver must feel supported.

Arrange for the child to go to a clinic or hospital if the child shows any of the ten danger signs (see page 49).

You now know about the possible side effects of ART.

We looked at the special problems of child abuse.

It is best to ask a colleague or supervisor for advice when you suspect that a child is being abused.



**Part 4: Supporting the caregiver of a child with HIV who gets sick and may not get better**



## Introducing Part 4

In Part 4 we look at supporting a caregiver of a child with HIV who gets sick and may not get better.

Unfortunately, we know that a very sick child with HIV may die.

There are many reasons why a caregiver may want to keep a very sick, young child with them at home, for example:

- The caregiver and child may have been to hospital or clinic many times.
- The doctor or nurse has told them that there is nothing more that can be done to help the child.
- They may be unable to afford to go to a hospital or clinic.
- The hospital or clinic may be far away.
- It is difficult to transport a very sick child.
- The caregivers, family and friends may want to spend time with the sick child.
- The sick child may want to stay at home.

In Part 4 we think of a very sick child as a flower. The flower may only be with us for a short time and will bring joy to our lives.

Those who care for a beautiful flower must themselves be cared for.

Here are two African proverbs about the death of a child and about sorrow:

Kuyoqhuma nhlamvu, ezinye ziyofekela  
(Zulu proverb).  
*Some seeds will grow and others will die.*

The proverb seems to tell us to accept that it is natural for some young children to die.

Akukho mful'ungenathunzi (Zulu proverb).  
*There is no river without a shade.*

The proverb tells us that a river will have parts where trees may be found which will cast a shade into the river.

When a person comes up against problems they should remember that there is no life without problems.

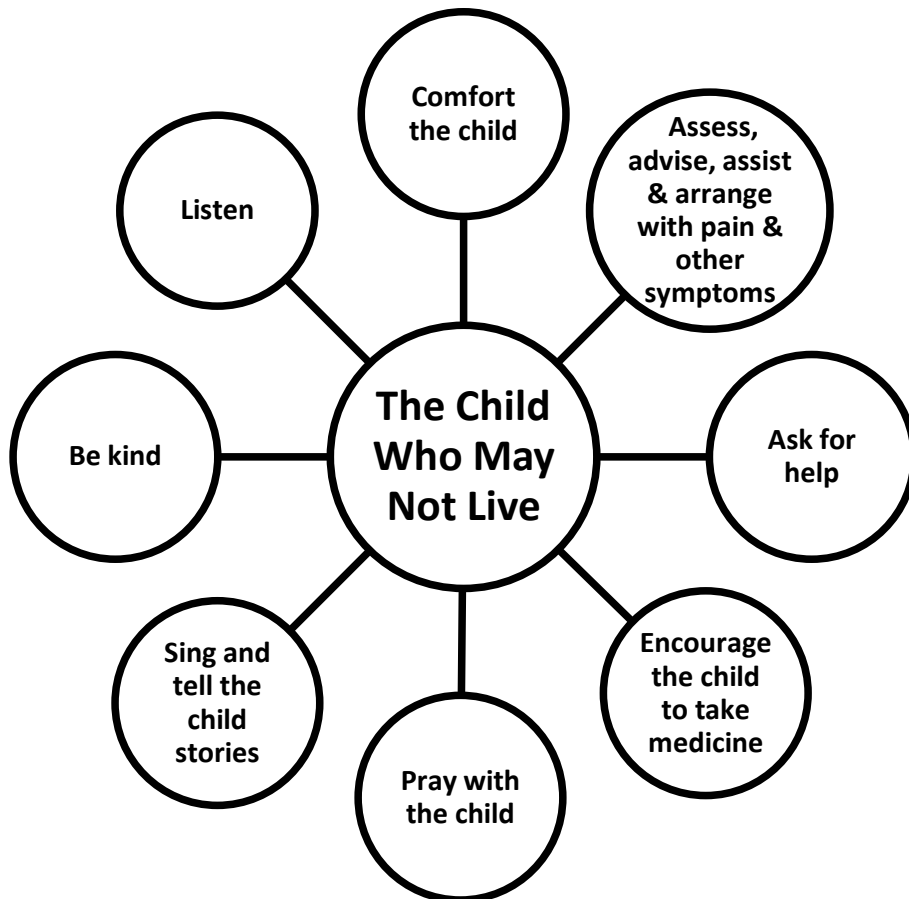
In Part 4 we look at nine messages you can use to support a caregiver who has been told by a doctor or nurse that her child is very ill and may not get better.

You may find that you can use these messages in many other situations.

We find that the messages are very important when a caregiver looks after a very sick child.

## The Nine Messages are:

1. Giving a little can mean a lot
2. Be kind to yourself
3. Ask for help
4. Listen to the child
5. Offer comfort to a distressed child
6. Prepare the child and the family
7. Prevent and treat
8. Empower
9. Remember



*Diagram looking at caring for the sick child with HIV who may not get better*

## **Message 1: Giving a little can mean a lot**

We know that caring for a very sick child is stressful for a caregiver and for you. A caregiver may feel that they are not good enough or that they are not able to do much to care for the child.

They may feel like giving up. They may feel hopeless. They may feel that everything is too much for them.

We use the first message “Giving a little can mean a lot” to tell the caregiver that they are useful and must not lose hope. We use a story “Daisy Flowers” to help you and the caregiver remember this message.

### *Daisy Flowers*

*There was a kind neighbour called Nkosazana who came to visit the house of a very sick child. She gently bathed the child, exercised all her joints and told the child stories. She gave advice to the mother and arranged to visit again soon. As she was about to leave she saw that the sick child’s younger sister was crying.*

*“Why are you crying?” Nkosazana asked kindly.*

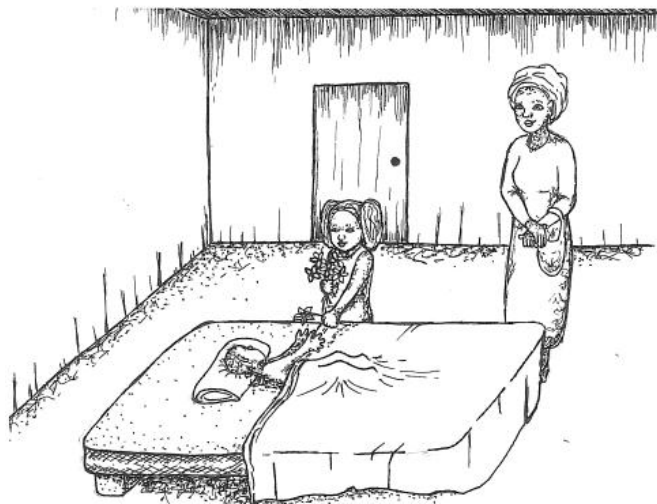
*“I’m crying because you did not greet me,” replied the young child.*

*“I’m so sorry,” said Nkosazana, “Please forgive me. What is your name?”*

*“My name is Daisy.”*

*The next day Nkosazana returned to the house and brought a big bunch of Daisy Flowers for Daisy.*

*Daisy loved the flowers and smiled and picked one out of the bunch to give to her sick sister.*



*Giving a little can mean a lot*

Both you and the caregiver can make a big difference to the care of sick children by doing even a little.

A caregiver may simply need reassurance from you that they are doing a good job.

Sometimes both you and caregivers may feel that you are not making a difference. Remember that it is often small things that we don't even notice that can make a difference to sick children's lives.

Sometimes you just need to remind a caregiver to smile as they may be so busy and care worn that they may have forgotten how to smile.

If a caregiver feels like giving up, then tell them the story of *Daisy Flowers*.

Decide together what is the main problem today. Assess, advise, assist and arrange. Try and sort out one problem at a time. Visit often and ask for help from colleagues if you are unsure how to help.

## **Message 2: Be kind to yourself**

We know that when people care for a very sick child they may spend a lot of time with the child and forget to look after their own needs.

We use the second message - "Be kind to yourself" to remind caregivers to be kind to themselves.

We use a story "The Big Flower Pot" to remind you and the caregiver that you must be kind to yourselves.

### *The Big Flowerpot*

*A woman has made a big pot out of clay. She loves her big pot greatly, places flowers in it and puts it on a very high table. She polishes the pot every day.*

*The children want to play with the pot and put flowers into it but she chases them away. She will not let them touch the pot. She allows no one else to care for it and becomes very tired as she looks after the pot without any help.*

*One day someone leaves a window open and a gust of wind comes into the room and the pot falls on the floor. It breaks into many pieces and the flowers are scattered over the floor.*

*The woman is very sad and cries because her big flowerpot is broken.*

*The next morning she gets down on her hands and knees and begins to pick up the pieces of the broken pot. She glues the pieces back together. When she cannot find the right piece she makes more pieces from her clay. She slowly builds another big pot. It is cracked but it holds water and flowers.*

*She loves her new cracked pot and places it on a low table where the children can play with the pot and help her clean it. The*

*children pick flowers to put into the cracked pot and the old woman is no longer tired.*



*Be kind to yourself*

If a caregiver is kind to herself she will feel that she is managing to do a good job in caring for a sick child.

We will now look at:

- Why it is so important to remind caregivers to be kind to themselves.
- How do caregivers know if they are caring enough for themselves.
- What a caregiver must do to be kind to herself.



*Why is it so important for caregivers to be kind to themselves?*

Caregivers must be kind to themselves for many reasons including the following:

- If we are not kind to ourselves then we can experience great stress and become sick.
- As a result of our stress we find caring for others difficult.
- If you, or a caregiver, are HIV positive then you will really understand the problems that many young children have to face and this may be very difficult for you.

*How do caregivers know if they are caring enough for themselves?*

Sometimes it is difficult for caregivers to know if they are caring enough for themselves. They may not even realize that they are stressed.

Stress describes the strain we feel when we are overburdened.

We may feel upset in our bodies, in our minds and in our emotions.

The following things happen to us when we are very stressed:

*Your body gets upset:*

- Your heart beats fast or seems to flutter.
- You may have a headache.
- You may have diarrhoea or constipation.
- Your muscles may ache.
- You may even lose your hair, get a rash, lose weight, put on weight and have high blood pressure.
- You may sleep poorly.

*Your mind gets upset:*

- Your thoughts are busy all the time.
- You may keep thinking about things that have happened in the past.
- You can't seem to focus on anything.
- You can't finish tasks.
- You find it hard to care about the children.
- You may dread going to see the children.
- You try to avoid people.

*Your emotions get upset and you may feel:*

- Irritable
- Aggressive
- Sad
- Bad
- Useless
- Angry
- Exhausted

If you, or a caregiver, feel like this then you need to ask a serious question: are you kind enough to yourself?



*How can a caregiver care enough for herself?*

Very importantly, we need to look at how both you and caregivers can care for yourselves.

Here are a few ideas on how a caregiver could be kind to herself:

- Pray or meditate.
- Rest enough.
- Have fun! Do things she enjoys (for example, go for a walk, sing or paint).
- Talk to friends.
- Join a support group.
- Spend time alone away from the house. You could help the caregiver by staying with the sick child for a while or by asking someone else to stay with the sick child while the caregiver takes a break.

Together you and the caregiver could discuss ways of reducing stress.

Visit often.

If you are worried that a caregiver seems to be very stressed we advise you to seek help from your colleagues.

You could also advise the caregiver to seek help from a clinic nurse or doctor.

### **Message 3: Ask for help**

A caregiver cannot care for a sick child without help from other people.

We use the third message “Ask for help” to remind the caregiver to seek help.

The story to remind the caregiver to seek help is called “The Empty Cup.”

#### *The Empty Cup*

*A woman's baby has died and she is so sad that she cannot bury the child. She ties him on to her back and goes to the sangoma\* (traditional healer) for help.*

*“I can bring your baby back to life,” says the sangoma, and the woman is happy.*

*“But before I bring him back to life I want you to go to the village with this empty cup and get me some sugar,” says the sangoma.*

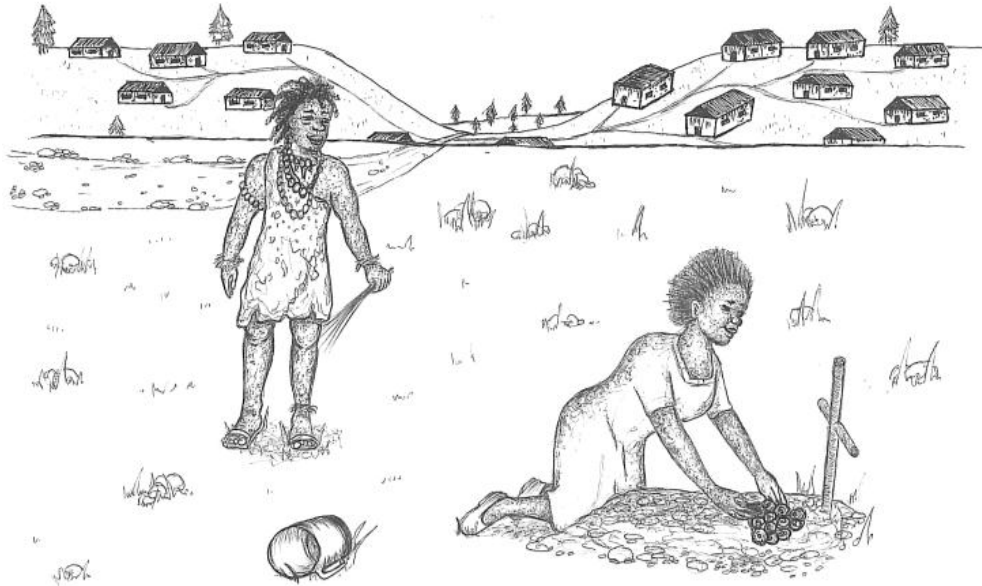
*The lady takes the cup and heads towards the door of the sangoma's hut.*

*“But,” says the sangoma, “you must bring me the sugar from a hut that has not known hardship, suffering or grief.”*

*And so the lady goes to the village and returns with an empty cup. She says to the sangoma, “Give me my child so that I can bury him. I could not fill the cup; everyone has known grief and sorrow.”*

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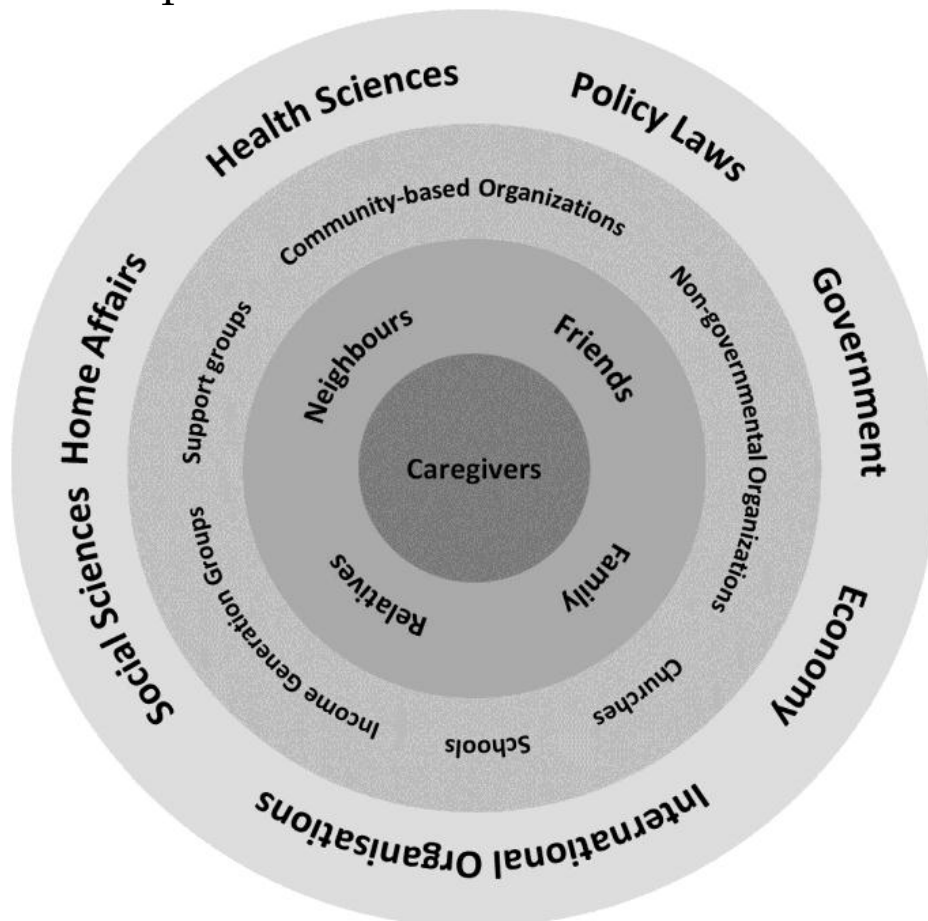
\* In South Africa, *sangoma* is the name used for a traditional healer



*Ask for help*

Who can a caregiver ask for help? We look at two ways in which a caregiver can decide who to ask for help.

The first is called the *Circles of Support*. The diagram below is an example.



There are three circles of support.

The first circle is made up of the people closest to the caregiver and the child. The caregiver may ask for help from the following people:

- Relatives
- A home-based care worker

The second circle of support is the community, especially people in the community who are close to the caregiver. The caregivers could ask for help from:

- Neighbours
- Friends
- Support groups

The third circle is made up of organizations such as churches, non-governmental organizations and the government. Together you and the caregiver should look for the following in your area for help:

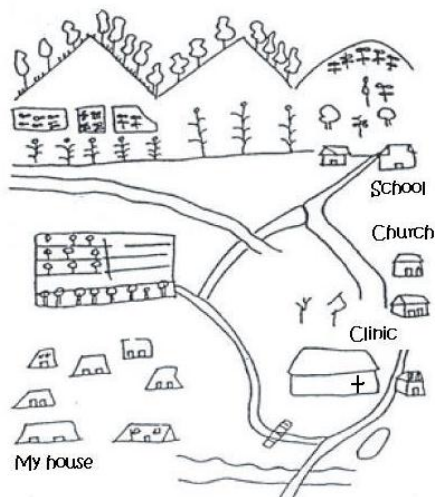
- Hospices
- Church groups that care for the sick
- Local business that may give out food and clothing
- Women's groups
- Granny groups
- Clinics and hospitals
- Teachers
- Social workers
- The police

- Traditional leaders and local leaders\*

The second way of deciding who to ask for help is called a *Community Map*

You and the caregiver could draw the caregiver's house and draw all the churches, clinics, schools in the area. The caregiver may learn about resources from you that she did not know about.

You could give the caregiver a list of telephone numbers of people she could contact for help and we look at this list on page 22 of the Caregiver's Toolkit.



*Example of a community map*

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\* People often visit traditional healers and traditional healers can offer much comfort. We recommend that a caregiver check with a clinic nurse before giving a child any traditional medicine as traditional medicine can sometimes interfere with ART.

We know that some traditional healers also say that they can cure HIV and AIDS. There is no cure for HIV and the child must keep taking ART.



## **Message 4: Listen to the child**

When a child is very ill, it is important that we carefully listen to them and watch them to try to understand everything they are trying to tell us.

It may be difficult to listen to sick, young children, but it is very important that you and caregivers try as hard as you can.

Remember that even the cries of a tiny baby are an attempt to “tell us” something.

Here is a story to help you remember that both you and caregivers must listen to the children. The story is called “The Snake’s Ears.”

### *The Snake’s Ears*

*The animals of Africa had a competition to see which animal had the best hearing. Elephant arrived with his big ears. Rabbit arrived with his long ears. The African Dog came with his pointed ears. Even Hippo arrived with his very small ears. Snake also arrived.*

*The other animals laughed at Snake, “You have no ears. Go away.”*

*But Snake said, “Let me hear what I can hear.”*

*Lion said, “Let Snake take part in the competition. Let Snake go first.”*

*Snake lay on the ground. “I can hear the Leopard crawling far in the distance.”*

*“Not bad,” said the Elephant “I can hear that too.”*

*Snake raised its body into the air. "I can hear the wind in the distant forest uprooting the trees."*

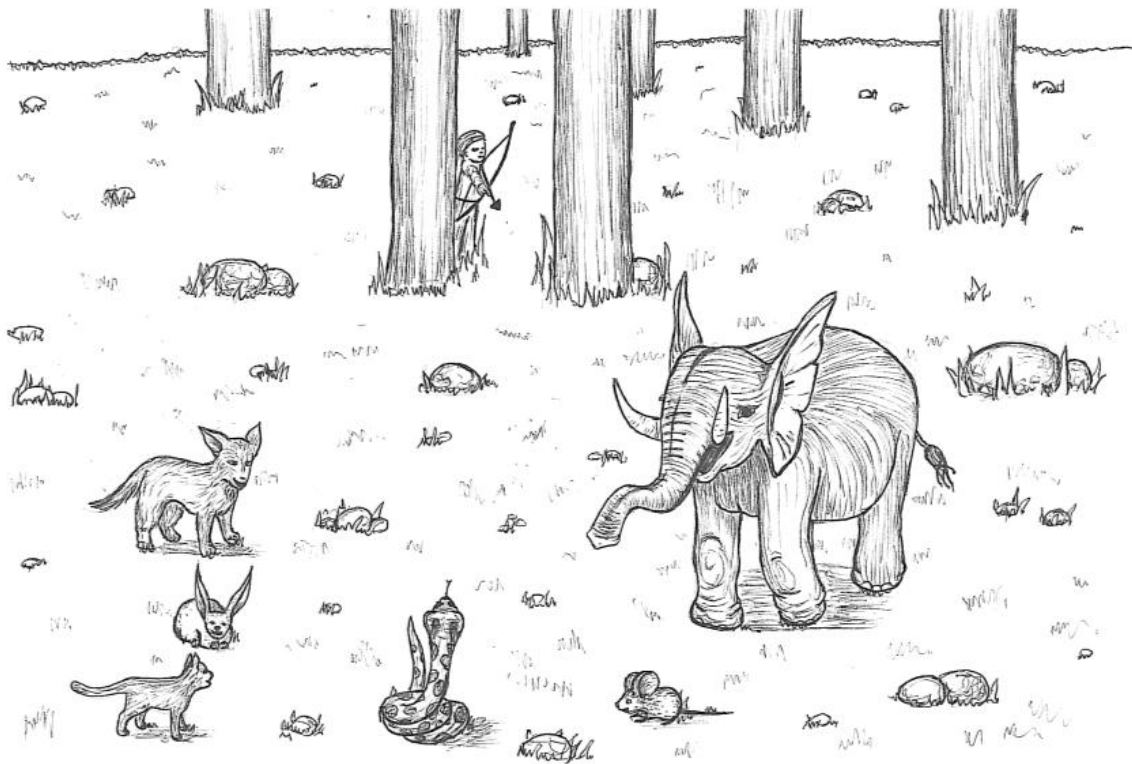
*Impressive," barked the Dog. "I can hear that too."*

*The animals were so busy watching Snake that they forgot to look around.*

*Suddenly Snake spoke," There is a hunter behind that tree. I can hear him putting an arrow into his bow. Now I hear him on the ground moving his feet."*

*Sure enough, a second later a man appeared with an arrow and a bow. All the animals ran away and Snake disappeared into the ground. The hunter's arrow flew into the empty air.*

*From that day on all the animals respected Snake for his hearing even though he had no ears.*



*Listen to the child*

*What do you and caregivers need to know about listening to children?*

It is important that caregivers listen to children for many reasons including the following:

- Caregivers can really make a difference to the lives of sick children by simply listening to them.
- Sometimes the child may feel ashamed or frightened.
- Some young children may want to ask questions about their illness and about dying and death.

You need to know about a young child's understanding of illness, dying a death.

*Looking at a young child's understanding of illness, dying and death*

The most important factor affecting a child's understanding of their sickness, dying and death is his or her own past experiences.

African children may have seen many sick people and may be familiar with death as a close relative may have died.

The table on the next page explains how children of different ages may think about death and why it is therefore very important to listen to the sick, young child as they may have misunderstandings about illness and about death.

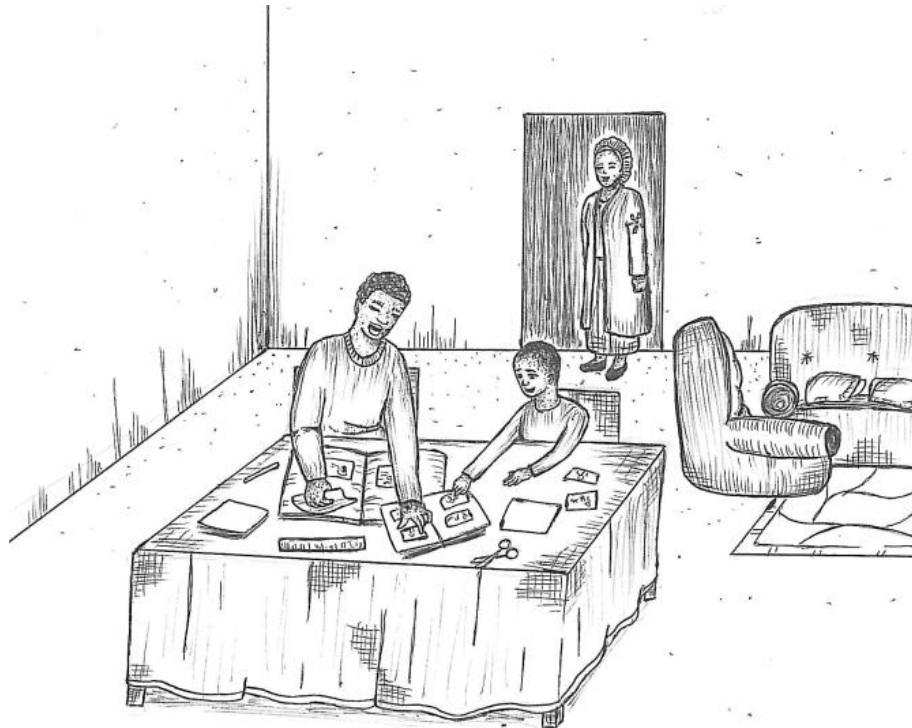
Age	The child's understanding of dying and death
<p><b>Age 1-3</b></p>	<p>The child may think that a dead person is asleep and may expect the person to wake up.</p> <p>Things that people say might confuse a child. For example, "resting with God" or "resting in peace and having eternal rest" may be confusing.</p> <p>They could have been told that the dead person has "gone away" or "gone to heaven". They may then worry when their mother goes away shopping that she won't return. They can be very frightened if they think they will be separated from their parent or caregiver.</p>
<p><b>Age 3-4</b></p>	<p>The child may think they caused a death. They could believe that if they wish hard enough the dead person may come back.</p>
<p><b>Age 5-8</b></p>	<p>Children of this age begin to accept death as permanent. They could begin to worry about their own death and they may have nightmares about skeletons and things associated with death (darkness, worms and coffins).</p> <p>They could become interested in the details of death such as coffins and burials.</p>

*How can you support the caregiver to best listen to the concerns of a child?*

Children's actions often tell us more about them than their words. A child may run away when ashamed or frightened or sad.

You and the caregiver can do simple things to listen well to the child:

- Sit down or kneel down to be close to the child.
- Look at the child.
- Listening requires that you be quiet so you can hear.
- Listen with your feelings and your eyes, not just your ears.



*Ask the child to make a drawing of what is bothering them*

Show older children pictures of faces (happy, angry, scared and sad) and ask them to talk about the pictures.

There are pictures in the Caregiver's Toolkit which may help the caregiver ask about the child's feelings (page 39 of the Caregiver's Toolkit). The caregiver can show the child these pictures and ask him or her to talk about the picture.

Together you and the caregiver could assess, advise, assist and arrange.

If you or the caregiver are concerned about a child's strong feelings then we advise that you seek help from a colleague or refer to a clinic nurse or doctor for an opinion.

## Message 5: Offer comfort to a distressed child

It is very important that you support a caregiver to give comfort to a sick child in whatever way they can.

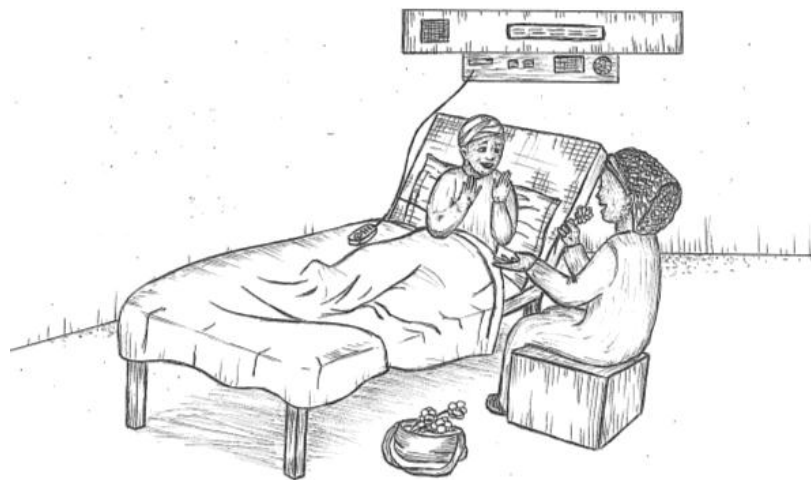
Here is a story to remind you and caregivers to give comfort; the story is called "Snow White Flower."

### *Snow White Flower*

*A young boy named John was running with his friends. He ran so fast that he tripped and hit his head on a rock. There was a lot of blood and the child had to go to a hospital.*

*In hospital the doctor made the bleeding stop and put a big bandage around John's head. His head was sore and he started to cry.*

*His mother stroked his hand and told him a story of a beautiful flower named Snow White Flower. The flower had magic powers. The child was so excited about the story and the Snow White Flower that he forgot completely about his sore head and felt no pain.*



*Comfort the child*

A young child's crying and distress can be a great challenge to caregivers.

You need to help a caregiver understand why the child is distressed.

You must help them deal with the distress.

*Why does a child become distressed?*

A sick child may become distressed and cry for many reasons.

A child may cry to let us know that he is unhappy or is in pain.

You must check and see if there is any problem causing the child to be distressed (for example sores, rash or constipation).

The child may cry to get attention as he is hungry, lonely or needs to have a nappy change.

*How can you support the caregiver to comfort a sick child?*

You can support a caregiver to comfort a distressed, sick child by doing some of the following things:

- Simply pick up a young child.
- Hold them close.
- Gently rock the child.
- Sing.



- Speak softly.
- Make up a song with the child and sing together.
- Reassure the caregiver that crying is normal when a child is sick.
- Encourage the child to suck. Sucking helps calm him, helps him to stop crying and may help him go to sleep. The child could suck on the mother's breast, the teat of a bottle or on their fingers. A child could also suck on a clean blanket or towel.
- Gently stroke a child's arms, legs, back and tummy.
- Use a toy or a puppet to distract the child from crying.
- Tell the child a story or ask the older child to tell a story.
- Pray with the child.
- Give the child an item of clothing or a small towel as a "comfort cloth".

If a child is distressed, you must visit often and aim to give the caregiver a break.

If you are concerned about a distressed child please ask your colleagues for advice or refer the child to the clinic.

## **Message 6: Prepare the child and the family**

A sick child may ask difficult questions and you need to prepare the caregiver for such difficult questions.

This message is about being prepared to answer difficult questions. The story we use to remind us of the message is called "Flowers from Heaven."

### *Flowers from Heaven*

*A young woman, named Florence, is dying and a kind neighbour visits the home each day. She plays with the children who are called Isabelle, Josephine, David and Ben. She tells them stories and asks them to draw pictures. Ben draws a picture of a young boy crying.*

*"Why is the little boy crying?" asks the kind neighbour.*

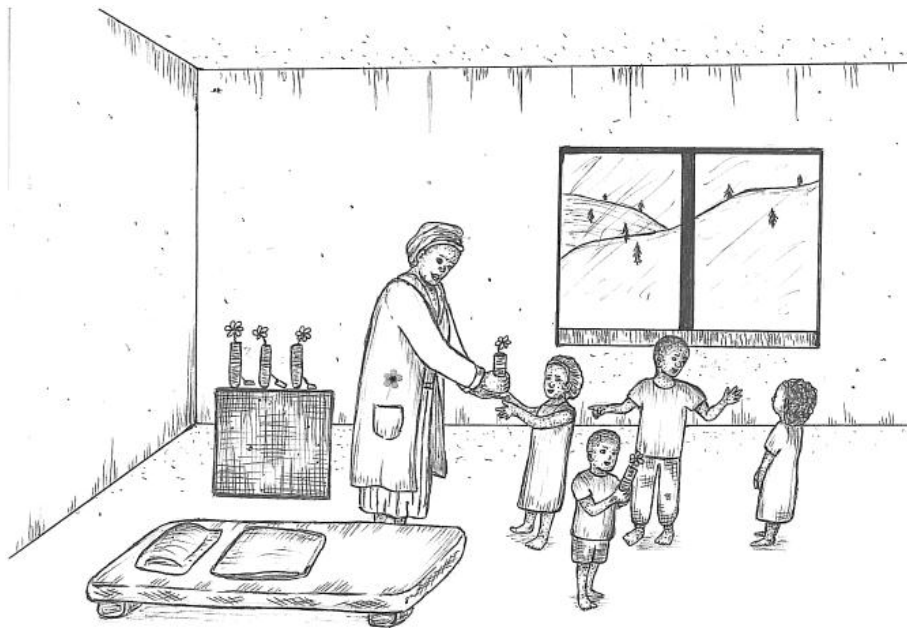
*"Because he is sad" replied Ben.*

*"Why is he so sad?"*

*"Because his mum is going to heaven and the boy is worried that his mum may get lost and be sad. How will the boy know that his mother is in heaven?"*

*The neighbour discussed Ben's question with Florence. Florence called the children to her and said, "When I die I will send you all flowers so you know that I have arrived safely in heaven."*

*A few days later Florence died while the children were at school. Before the children arrived home the kind neighbour picked a bunch of flowers from her garden, tied each bunch with a red ribbon and attached a card with each child's name onto the ribbon. When the children returned home they saw the big bunches of flowers and were comforted as they knew their mother had found her way to heaven.*



### *Be prepared*

Most caregivers find it hard to discuss difficult things such as sickness, dying and death.

Here are some reasons why people may not want to discuss dying and death:

- Some feel that talking about death may hasten death.
- Some believe that discussing death with a person means that you do not care about that person.
- In some cultures, people don't usually discuss dying and death.
- You may be afraid of your own strong emotions; for example, you could be afraid that you will cry.
- You may be scared of other people's strong emotions as they may become angry with you, cry or get depressed.
- You could be reminded of the death of someone close to you.
- You may feel that you have failed.
- You could become worried about your own death.

### *How to prepare for difficult questions*

If a sick child, his sisters, brothers or friends ask about dying and death you should be prepared to answer their questions.

Here are a few ways you could answer their questions:

- If a child asks you a difficult question you can be prepared to say: "I don't know the answer to your question. I will get help to answer it." Then go get help and return to answer the question.
- If you need to talk to a young child about dying and death it may be easier to explain death to a young child in terms of things that are absent. For example, when people die they do not breathe, eat, talk, think or feel anymore. Dead flowers do not bloom.

We use a story called John and James and a story called Water-insects and Dragonflies. These are useful in talking to young children about dying and death (pages 36-38 of the Caregiver's Toolkit).

We explain to the children that the Water-insect disappears from his family and friends but turns into something better that we cannot see.

### *How to prepare for difficult situations*

In some cultures, the beginning of the dying process is marked by dreams and people can begin to prepare for death after they have had a dream.

In other cultures a traditional healer will tell the relatives that a child will die soon.

You may want to prepare the family by discussing the following:

- How a very sick child may behave before death.
- What to expect immediately before death.
- What to expect after death.

A very sick child may no longer want to eat or drink and young babies may not be able to suck at the breast properly.

It is important that they not be forced to eat or drink as this might make them feel sick or uncomfortable.

You may need to tell relatives that a very sick child may not want to eat or drink.

We advise you to discuss this with a colleague.

We always want to offer food and drink to the ones we love.

It may be difficult not to do this.

It is a big step to accept that the child is very sick and no longer requires food or fluid.

It is important that a very sick child only be given the medicines that are going to help with the symptoms, such as pain medicines.

Other medicines may need to be stopped.

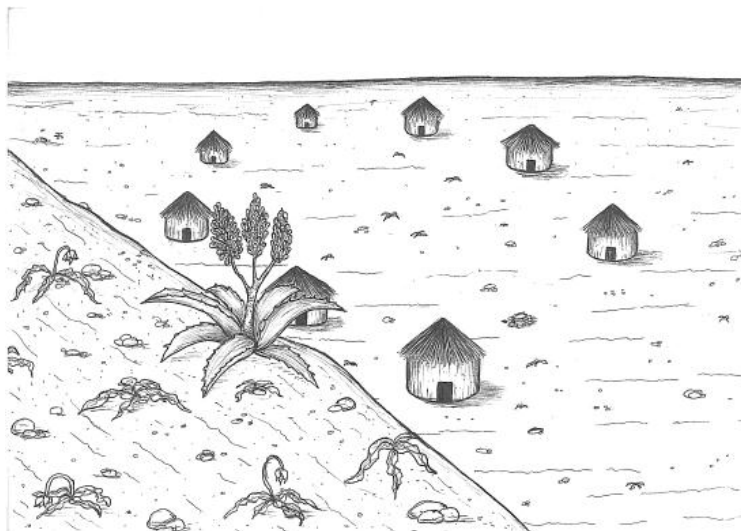
We suggest that before you stop any medicines you ask for advice from a colleague or nurse or doctor.

Perhaps this story may help you explain to relatives that the very sick child does not need food or water to be comfortable:

### *The Aloe*

*Zanele loved her garden and grew beautiful flowers. It did not rain much in her village and she drew water from the river to water her garden.*

*One year the rains did not come and the river dried up. All the flowers died except one little plant called an aloe. Zanele saw that the aloe flower did not need too much water.*



*Nature sometimes tells us not to give food and water*

Immediately before death the caregiver may notice the following:

- The child may not be interested in his surroundings.
- He does not eat or drink.
- There is no urine produced.
- He sleeps a lot.
- His breath is very shallow and there are long pauses between breaths.
- He feels cold.
- His skin may change colour.

You may want to prepare yourself and the family for what happens immediately after the child has died.

- What relatives and family do immediately after death depends on their cultural and religious beliefs.
- There are many beliefs about what happens to the child after death. You must find out what the family believes and respect this belief.
- You must be able to advise the family that they need a death certificate. Who provides this? Where must they go to get it?
- The body must be buried. What is the normal means of burial in your area?

It is difficult dealing with a very ill child who may die. It is very important that you look after yourself.

## Message 7: Prevent and treat

We look at preventing problems and treating problems that arise.

Here is a story to help you to remember about preventing and treating problems. The story is called "The Red Moon."

### *The Red Moon*

*There was once a village that was very sad. The people living there hadn't looked after it. They had thrown rubbish all over the place so there were no plants or animals left.*

*One day a little boy was walking close by the village when he passed a cave and noticed a small red flower inside. The flower was very sick - almost dying. The boy carefully dug up the flower, with roots, soil and everything. Then, he started looking for a place where he could look after it. He searched all over the village but everywhere was so dirty that there was no place where the flower could possibly live.*

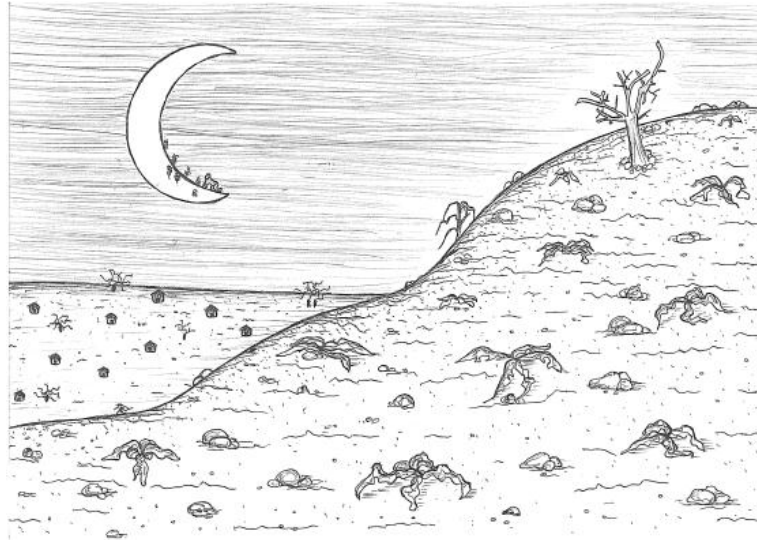
*Then he looked up at the sky and noticed the moon. It seemed to the boy that maybe the flower could survive there.*

*He put the little red flower in his pocket, and off they went to the moon. Far away from all that rubbish and with the boy visiting it every day, the flower started to grow.*

*The flower soon blossomed and before long the whole moon was completely covered with flowers.*

*That's why, whenever the little boy's flowers open up the moon takes on a soft red glow, like a warning light. Maybe it's telling us that if you don't look after your planet, a day will come when flowers will only be able to grow on the moon. In the same way we can prevent problems in our homes.*





### *Prevent problems*

Both you and caregivers can help to prevent problems from happening.

If problems do occur, then you can take immediate action to treat them and prevent them from becoming worse.

Below are a few examples of how to prevent and treat problems in a sick child.

### *Prevent stiffness*

If a sick child remains in bed all day and night, then he or she can suffer with stiff joints and muscle tiredness.

- Encourage the sick child to move in bed or get out of bed (if possible).
- Massage the sick child with petroleum jelly (Vaseline) or oil.
- Encourage exercise twice daily and help with gentle movement of ankles, knees, hips, wrists, elbows, shoulders and neck.

### *Prevent sores*

If a child lies on a mattress in bed all day, sores will develop where his skin has contact with the mattress. We call these sores “bedsores”.

- If possible, help the older child sit up in a chair from time to time. Prop up a younger child on a rolled up blanket.
- Lift the sick child to change position in bed. Do not drag the sick child, as this breaks the skin.
- Encourage the sick child to move his or her body in bed whenever possible.
- Look for damaged skin (change of colour) on the back, shoulders and hips every day.
- Put extra soft material, such as a soft cotton towel, under the sick child.
- Keep the bed clothes clean and remove all wet clothes and wet bed sheets.

If sores do develop, then:

- Clean sores very gently with salty water and allow to dry. Add the leaves of an aloe tree to your washing water as an antiseptic. Leave the sore open to air.
- Apply ripe pawpaw or papaya flesh or honey.
- If painful, give pain killers such as Paracetamol syrup to ease the pain

If problems do arise, you need to know something about treating the problem.

## *Treating pain*

Knowing about pain is very important. Some people think that children do not really experience pain. This is not true.

Children feel pain in the same way as adults.

Some people think that a child will not remember if he or she has had pain. This is not true.

A child remembers pain.

Pain is very common in children who are very sick.

Sick children (especially children who have HIV infection) can have pain in many places in their body at the same time.

A caregiver must remember to assess, advise, assist and arrange.

## **ASSESS**

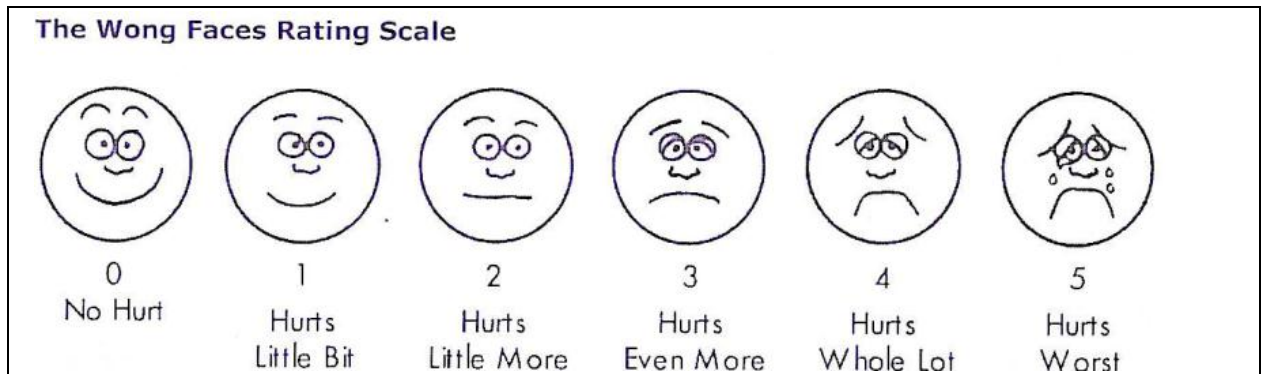
Ask both the caregiver and the young child about pain.

Children with pain do not always cry.

Sometimes they lie very still because if they move the pain gets worse.

A caregiver is generally good at recognizing if their child has pain or not.

We find the following picture useful in allowing a sick, young child who is older than about four years to tell us if they have pain or not.



Explain to the caregiver and child that each face is for a child who has no pain or a lot of pain.

- Face 0 is a happy face because the child has no pain.
- Face 1 the child has pain that hurts just a little bit.
- Face 2 to face 4 tells us that the child has pain that is upsetting for them.
- Face 5 tells us that the child has very severe pain which is upsetting the child a lot.

If the child is younger than four years, you and the caregiver need to look carefully at the child to assess if they have pain or not.

We use the following table to remind us what to look for:

<b>What to look at:</b>	<b>0</b>	<b>1</b>	<b>2</b>
<b>Look at the face</b>	The child smiles	The child frowns sometimes	The child frowns often and the jaw may be clenched
<b>Look at the legs</b>	The legs are relaxed	The legs are restless and moving about	The legs are kicking a lot or drawn up towards the body
<b>Look at how the child lies</b>	The child lies quietly	The child shifts back and forth	The child's back is arched. The child is rigid or jerking
<b>Listen to the child's cry</b>	The child does not cry a lot	The child moans a lot	The child cries often and loudly or sobs
<b>Can the child be comforted</b>	The child is content	The child can be comforted by hugging, singing and so on	The child cannot be consoled.

Look at the child carefully to see if you can find a cause for the pain.

## **ADVISE AND ASSIST**

Support the caregiver to use the same methods we discussed in Message 4 “Offer comfort to a distressed child” to deal with pain.

You can assist the caregiver in distracting the child by reading stories, singing, massaging.

You can check that the caregiver is giving the pain medicine as directed by the nurse or doctor.

You can find out more about medicines on pages 107-108.

## **ARRANGE**

If you are concerned about pain then arrange for the child to attend a clinic or hospital.

If you and the caregiver feel that you can cope then arrange to visit the home as often as possible.

The caregiver and child will require your support.

## Message 8: Empower

We look at why it is very important to empower sick children and their caregivers.

Earlier we discussed “helping others to help themselves”.

By “empowering” we mean that you must encourage people to do things for themselves if they can.

Here is a story about empowering. The story is called “The Boy and the Flowers.”

### *The Boy and the Flowers*

*There was a young boy called Sizwe who was very sick. He lay in bed all day with the curtains drawn and the room was very dark. No one talked to the child about his sickness. He cried a lot.*

*A kind lady named Maboyi came into the room and opened up the curtain so the light could come into the room. She gave the little boy some paper and a few crayons and asked him to draw a picture. He drew a picture of a little boy crying in a dark place.*

*“Why is the little boy crying and why is the place so very dark?” asked Maboyi.*

*“I am crying because I am frightened of the dark,” Sizwe replied.*

*“Can I do anything to help?” asked Maboyi.*

*“Yes,” replied the little boy, “You can bring me a little flower seed that I can put near the window.*

*The flower will make the room bright. You can also bring me a candle so that I can make this dark place bright at night.”*

*And Maboyi brought him a flower and a candle and they put it near the window. The flower made the room seem happy.*

*Sizwe lit the candle at night and was happy because the room was bright.*



*Empower*

We will look at:

- Why should you empower?
- How do you empower?

*Why should you empower?*

Here are a few reasons why you should empower the caregiver and the child:

- You will not always be in the house so you must show others, especially caregivers, how to care properly for the sick child.
- If you show a family how to care for a sick child then they, in turn, may be able to help other sick children in their neighbourhood.
- It feels good when we can solve our own problems.



*How can you empower?*

You can empower a caregiver and child by doing some of the following:

- Remind the caregiver that even very sick children have strengths that need to be nurtured.
- You, and the caregiver, must be aware of resources in your community which families could contact for help, for example churches, support groups and granny groups.
- You should check if the caregiver and the sick child have identity documents (such as birth certificates).
- You must know if government grants are available to help children and families. People can get these grants by going to government departments like the Department of Social Welfare.

Is there a social worker in your area who could assist the caregiver?

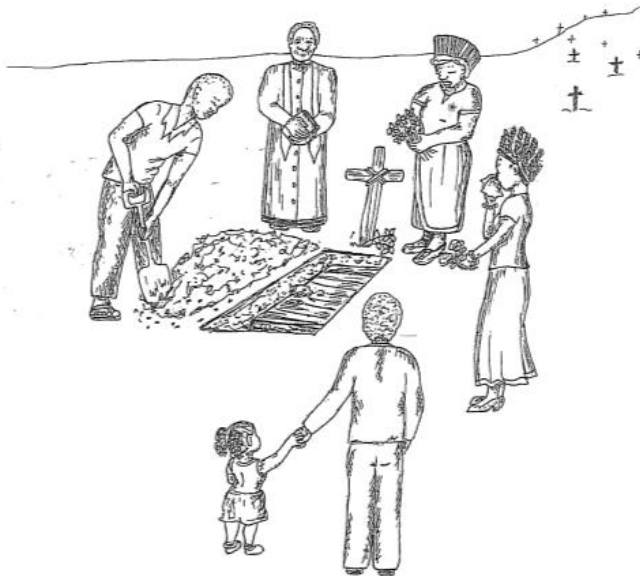
For example in South Africa, there are four types of social grants that can assist families:

- Child Support Grant
- Care Dependency Grant
- Foster Care Grant
- Grant-in-Aid Relief – this is for emergencies

## Message 9: Remember

The last message is often the most difficult.

We look at ways of supporting a caregiver and family to remember the child with HIV when he or she dies.



We look at why it is important to support caregivers who have experienced the death of a young child.

Here is a story about supporting the caregivers and family of a young child who has died. The story is called “The Wax Child”.

### *The Wax Child*

*A couple lives in a very warm place and earns a living by making candles. Their names are Mary and Simon. There is no electricity so they make candles for churches, homes and schools. They long to have a child but they have no children.*

*One day Mary sees a bird build a nest and care for the young chicks. “I wish I had a young child to care for”, thought Mary.*

Soon afterwards she gives birth and the child is like every other boy in the village except that the child is made of wax. His name is Peter. Mary and Simon love Peter and protect him from the sun so he will not melt.

Peter grows and lives in the dark inside the hut. He looks out the window and sees the birds in the sky and sees the other children playing. He wants to play. One day, without his parents knowing, he sneaks outside and plays and watches the birds. He goes back into his house before the sun gets too hot. The next day he does the same but he forgets the time and stays out longer. The following morning he is enjoying himself so much that he stays out in the hot sun and melts.

Mary and Simon see the pile of melted wax that used to be Peter and cry.

"He loved birds" Mary said, "let us shape this piece of wax into the shape of a bird". And Simon moulded the melted wax into the shape of a bird and he found feathers from every bird in the area and put them onto the wax bird. When the sun came out the wax bird did not melt as the feathers protected it.

The wax-bird became alive and flew into the sky. It circled the hut three times before it disappeared. Every day, just before the sun rose, the bird would come and circle the hut three times and Mary and Simon were comforted because they could remember Peter.

Remember



We will discuss:

- What is bereavement?
- How you can support a bereaved person?
- When to ask for help with bereavement?

*What is bereavement?*

Bereavement is mourning the death of someone close.

People react to the death of a loved one in differing ways.

People from differing cultures mourn those who have passed in different ways.

People may for example:

- Deny that the death has occurred.
- Feel numb.
- Become angry.
- Become very quiet.
- Feel guilty that they caused the death or did not do enough for the child.
- Blame others (including you) for the death of the child.
- Be relieved that the pain and suffering of their loved one is over.

If children in the family are grieving the loss of their younger brother or sister then they also need support.

It is important to remember the following about children who are mourning:

- Adults may not know how sad a child really is after the death of someone close.
- Children can grieve greatly and can grieve for a long time.
- Sometimes a child may appear to be very sad, yet soon after they may laugh and be happy.
- Sometimes they behave as if they are younger than they are.

*How can you support a bereaved person?*

If a young child is very sick, then you, and the caregiver, may want to consider if the child should spend time with sisters, brothers and young friends.

You and the caregiver could tell the sick child and other children a story about a child that gets sick and dies (see Caregiver's Toolkit, page 36).

After the death of the young child, you and the caregiver may want to think about these questions:

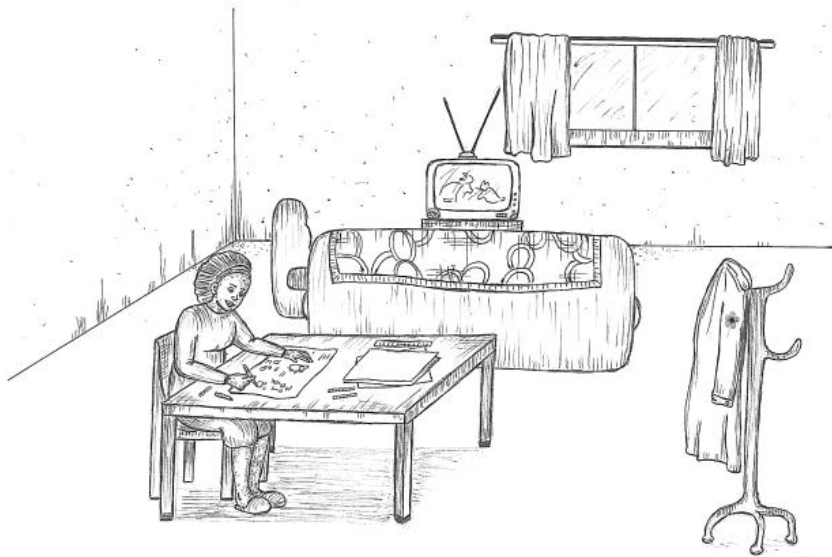
- Should the child's brothers, sisters and friends see the dead body?
- Should the child's brothers, sisters and friends attend the funeral?

In some cultures, young children are not encouraged to view the deceased person or attend funerals. You must discuss what is right for this family.

We use “Memory boxes” to help people prepare for the death of a young child and to help the young sick child.

A memory box is a special box that sick children, caregivers and families can decorate themselves.

The box is also useful because it helps the child, the caregiver and the family store photographs, letters, poems, drawings and other things which they like.



*A caregiver can use the memory box during bereavement*

*When do you need to ask for help?*

Sometimes an adult’s bereavement lasts longer than usual.

The adult becomes very affected by the death, for example:

- The adult may fail to care for themselves and their family.
- They may use too much alcohol or other drugs such as marijuana.
- They may want to harm themselves or harm other people.

Such grief may require professional help.

With children it is difficult to know when grief is too much for the child to cope with.

You must ask for advice if a child shows any of the following behaviours:

- The older child begins to use baby talk, sucks his or her thumb or becomes incontinent for urine. This behavior may mean that the child wants to return to a time when he or she felt protected and secure.
- Has severe nightmares.
- Harms himself or others.
- Becomes very quiet.
- Will not eat.
- Cries most of the time.

It is important that you ask for advice and that you visit the child regularly and accept the child even if he or she seems to behave badly.

## Summary of Part 4

We covered a lot in Part 4.

We remind you of the nine messages in supporting the caregiver of a young child who may die:

- Giving a little can mean a lot
- Be kind to yourself
- Ask for help
- Listen to the child
- Offer comfort to a distressed child
- Prepare the child and the family
- Prevent and treat
- Empower
- Remember

Remember that you are doing a difficult job. Always be kind to yourself.

Try and deal with one problem at a time.

- Assess
- Advise
- Assist
- Arrange

Help others to help themselves.

Do not work alone.



## Basic Home-based Care

The trainer will revise these aspects of basic home-based care with you before you start the course:

Topic	What will be covered
<b>Keeping germs away from a child with HIV</b>	<p>How to dispose of body fluids: (urine, faeces, blood and sputum)</p> <ul style="list-style-type: none"> <li>• Washing hands</li> <li>• Cleaning clothes</li> <li>• Disposing of waste</li> <li>• Cough hygiene</li> <li>• Protection from mosquitoes</li> </ul>
<b>Preventing dehydration</b>	Preparing and giving Sugar Salt Solution (SSS).
<b>Breastfeeding</b>	When to start and stop breastfeeding a baby.
<b>Formula feeding</b>	How to make up a baby's bottle.
<b>Feeding</b>	What foods are good for growth and keeping food clean.
<b>Danger signs in young children</b>	How to recognize danger signs.
<b>Changing nappy</b>	How to change a nappy.
<b>Caring for the mouth</b>	How to clean a mouth and what is thrush and mouth ulcers.
<b>Caring for the skin</b>	How to recognize thrush, dermatitis, ulcers, ringworm and scabies.

## Outline of the course

<b>Introduction</b>	<p>Introducing participants          Looking at the Guide for Home-based Care Workers and Caregiver's Toolkit          What is the course about          What will you learn          Who are caregivers          Why focus on caregivers of children with HIV</p>
<b>Part 1</b>	<p>Looking at palliative care          Looking at the needs of children          Looking at the needs of caregivers          What to do about these needs          Two important points in the course</p>
<b>Part 2</b>	<p>How to protect a child from germs          How to keep the child well          How to support the caregivers to care for themselves          Telling a young child that they have HIV          Encouraging a young child to take medicine</p>
<b>Part 3</b>	<p>Finding out what is causing an illness          ASSESS, ADVISE, ASSIST &amp; ARRANGE          Common problems faced by a child with HIV          When to refer          The special problems of ART          The special problems of child abuse</p>
<b>Part 4</b>	<p>Why care for a child at home          Nine messages in caring for very sick children at home</p>

## List of Health Checkups

### List of health checkups that a caregiver can request at a clinic

Checkup	How often
Weight	Every visit
Sugar	Once a year
Blood pressure	Once a year
PAP smear (women)	Check with clinic nurse
Breast examination (women)	Once a year
Prostate check (men)	Check with clinic nurse
HIV	Check with clinic nurse
Cholesterol	Check with clinic nurse
STI testing	Check with clinic nurse
Family Planning	Check with clinic nurse

## Medicines used in caring for sick, young children at home

A nurse or doctor may give medicines for the sick, young child.

You can know some useful things about the medicines:

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.

On the next page is a list of medicines that you may come across.

We have included a few things that you may find useful to know about these medicines.

<b>Name of medicine</b>	<b>What is it used for?</b>	<b>What do you need to know about this medicine?</b>
<b>Amitriptyline</b>	Pain in hands and feet	It can cause sleepiness
<b>Brufen/Ibuprofen</b>	Used for pain	It can cause tummy upset
<b>Carbenzapine (Tegretol)</b>	It is used for painful hands and feet	
<b>Coedine phosphate</b>	It is used for diarrhoea and for pain	It can cause constipation
<b>Co-trimoxazole (Bactrim, Septrin)</b>	It is used in children with HIV infection. It prevents some sicknesses such as chest infection (pneumonia)	
<b>Hyosine (Buscopan)</b>	It is used for pains in the tummy	
<b>Liquid paraffin/lactulose</b>	Used for constipation	Do not give too much of this medicine
<b>Lopermide Immodium</b>	It is used for diarrhoea	Do not give too much of this medicine
<b>Nystatin</b>	It is used for thrush (white spots - thrush) in the mouth	Try and keep it in the mouth for as long as possible.
<b>Morphine</b>	It is a very strong painkiller	It can cause confusion, drowsiness, nausea, vomiting and constipation.
<b>Paracetamol</b>	It is used for pain	Do not give more than the nurse or doctors say. It is dangerous to give too much.
<b>Pyridoxine Vitamin B6</b>	It is used for painful hands and feet	