

Palliative Care at Home for Young Children in Africa

Caregiver's Toolkit







Palliative Care at Home for Young Children in Africa:

Training and Support Package







Convicts The University of Oxford and the Diego, Dringers of Weles Margariel Fund
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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 toolkit

This toolkit is called "Palliative Care at Home for Young Children in Africa: Caregiver's Toolkit".

We will begin by answering some questions you may have about this toolkit.

- What is a toolkit?
- Who is this toolkit for?
- Who will show you how to use this toolkit?
- What is this toolkit about?
- Why do you need a toolkit?

What is a toolkit?

A toolkit is a book that you can keep with you in your home and use to guide you.

Who is this toolkit for?

This toolkit is for people, like you, who care for children who are HIV positive.

We call the person who cares for a child with HIV the "caregiver".

In this toolkit we focus on caregivers who care for children with HIV who are younger than about seven years old.

If you do not know if your child is HIV positive or not, we recommend that you take your child to a clinic or hospital for a test.

In some places a special test for HIV can be carried out when the child is very young (about two months after birth).

In other places an HIV test can only be carried out when the child is about eighteen months old.

Who will show you how to use this toolkit?

Your home-based care worker will show you how to use this toolkit.

What is this toolkit about?

This toolkit is about helping you (the caregiver) to provide palliative care for a young child who has an HIV infection.

Why do you need a toolkit?

You need a toolkit because there is a lot to remember and to know about caring for a young child who has HIV.

You can look at this toolkit when you are unsure of what to do.

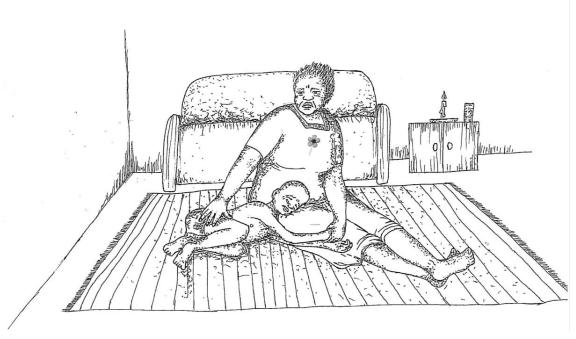
The toolkit is made up of four parts:

Part 1: Palliative care

Part 2: Caring for a child who has HIV and is not sick at the moment

Part 3: Caring for a child who has HIV and becomes sick and then gets better

Part 4: Caring for a very sick child who has HIV and may not get better



Part 1: Looking at palliative care

Telling you about Part 1

In Part 1 you and the home-based care worker will look at the following:

- What do we mean by palliative care?
- What are your child's needs?
- What are your needs?

What do we mean by palliative care?

When we talk about palliative care we mean the care of adults and children who have an illness from which they may not recover if it is not treated, like HIV and cancer.

Palliative care aims to care for the child who has HIV infection, the caregiver and the rest of the family.



What are your child's needs?

Together you and your home-based care worker will draw a picture of all your child's problems as you see them:

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What are your needs? Together you and your home-based care worker will draw a picture of all your own problems:	

What is your child's main problem today?

What is your main problem today?

We will continue to go through this toolkit and when we come to the end of the toolkit we will return and look again at a) your child's main problem and b) your main problem.

Part 2: Caring for a child with HIV infection who is well

Telling you about Part 2

In Part 2 we look at caring for a child with HIV infection who is well.

Together you and your home-based care worker will look at the following:

- How to keep your child well
- How to keep yourself well
- Telling your young child about HIV
- Supporting your young child to keep taking medicine



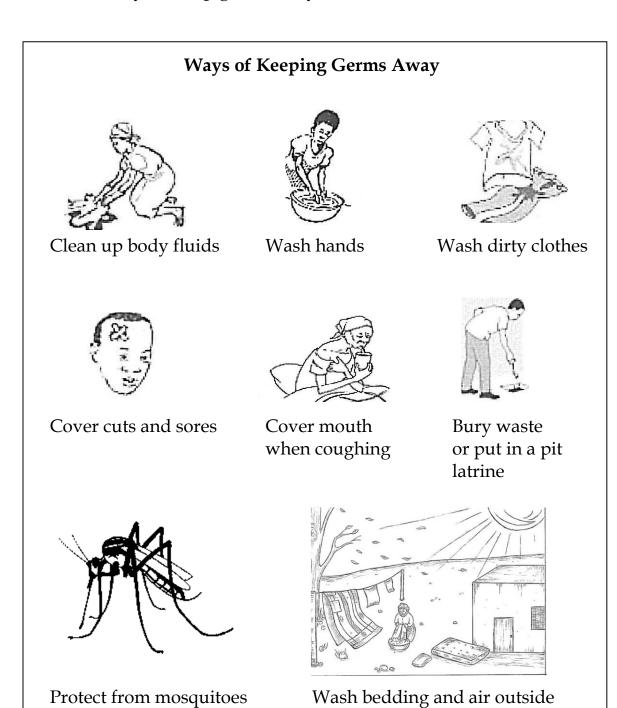
How to keep your child well

There are many ways that you can keep your child well and we will look at a few:

- Keeping your child free from germs
- Breastfeeding or formula feeding
- Giving your child good, clean food
- Taking your child to the clinic
- Playing with your child
- Being a good parent

1. Keeping your child free from germs

A child with HIV can get very sick if they are exposed to germs. Here are a few ways to keep germs away from a child.



2. Breastfeed a newborn baby

Please check with a clinic sister about breastfeeding.

It is important to breastfeed a baby for six months after birth.

A newborn baby does not need to be fed with anything except breast milk. Breast milk can help protect a baby from germs.

If you are formula feeding your baby, make sure everything is very clean.

If you are feeding a baby using a bottle and formula powder, it is very important that the bottle, water, teat and bottle tops are very clean. You must put the right amount of formula into the bottle, otherwise your baby will get sick.

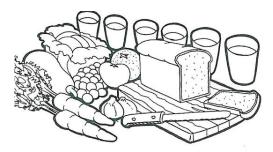
The home-based care worker will show you how to wash, sterilise and prepare a baby's bottle.

What to do when formula feeding

Step	Actions Actions
Cleaning	
Sterilising	
Preparing	

3. Give your child good, clean food

Together you and your home-based based care worker will look at the food you buy and prepare.



Together you and your home-based care worker can see if you can improve what you and your child eat and drink.

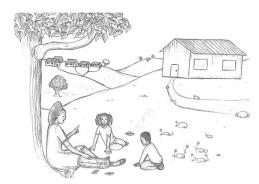
4. Take your child to the clinic for immunisation, growth checks, blood tests and medicines



Together you and your home-based care worker will check when you need to take your child to the clinic. The nurse will check your child's immunisation and growth (weight and height).

Your child may need worm medicines and other medicine to stop infections. Your child may need blood tests to check the HIV.

5. Play with your child and encourage your child to play with other children



Draw three ways that you can play with your young child.



6. Be a good parent

Draw three ways that you can be a good parent to your child.



How to keep yourself well

We will now look at how to keep yourself well.

We will discuss this further on page 27 when we look at 'being kind to yourself'.

When you take the child to the clinic you could ask the nurse to check you and here is a list of checkups that the nurse may want to think about:

Health Checkup for Caregivers

Checkup	How often	Result of tests
Weight	Every visit	
Sugar	Once a year	
Blood pressure	Once a year	
Papanicolaou test or PAP smear (women)	Check with clinic nurse	
Breast examination (women)	Once a year	
Prostate check	Check with clinic	
(men)	nurse	
HIV	Check with clinic nurse	
Cholesterol	Check with clinic nurse	
Sexually transmitted infections (STI) testing	Check with clinic nurse	
Family planning	Check with clinic nurse	

Telling your young child about HIV infection

We now look at telling your young child something about their HIV infection.

Draw or write three reasons why it may be a good thing to tell your young child something about their HIV infection:



How do you feel about telling your child something about their HIV infection?

Has your child been asking any questions about HIV or about medicines used to control HIV?



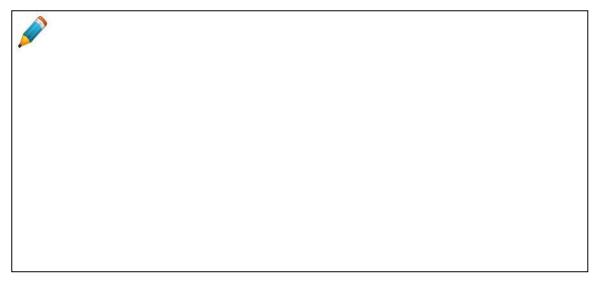
Your home-based care worker can support you if you wish to tell your child something about their HIV infection.

Together you can practise what to say before you talk to your child.

We find the following story useful to talk about HIV with a child who is older than four years of age. When you tell your child this story ask your child to draw pictures in the spaces. You can change the name in the story.

John and the Sleeping Germs

John was five years old. He was very friendly and liked to help at home. John went to a school close to his house. Ask your child to draw a picture of John.

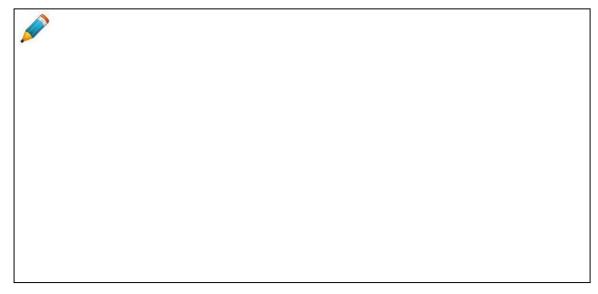


John sometimes had to miss school because he had to go to the clinic for a blood test. The nurse at the clinic said that John might need special medicine because he had a germ in his blood. Ask your child to draw a picture of John and the nurse.

John did not like missing school and he asked, "Why do I have to have my blood tested?"

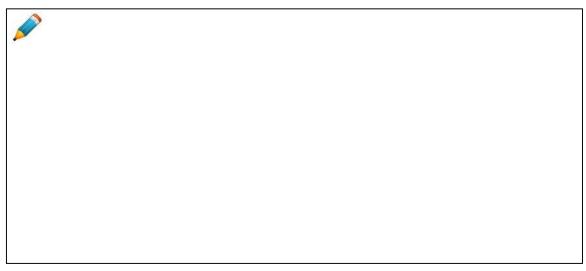
"Why do I have to take medicine?"

"Why am I different to all the other children at school?" Ask your child to draw a picture of John asking questions.



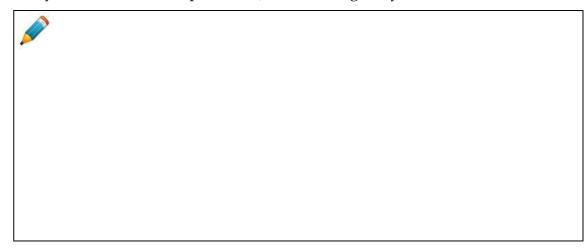
John's granny sat John on her lap. She told him that he had some germs in his blood. These germs attacked the guards in his blood and without guards he would become sick. The nurse took blood so she could see how many germs and guards he had in his blood. Ask your child to draw a picture of the guards in the blood and the germs.

John's granny told him that medicine and good, clean food keep the guards strong and put the germs to sleep. The medicine has to be taken every day. If the medicine is missed, the germs wake up. Ask your child to draw a picture of the medicine putting the germs to sleep.



John asked his granny, "Why do I have this germ?" "Have I been naughty?"

His granny smiled and hugged him tightly and answered, "No John, you have not been naughty. Many children and adults have this germ and if they take their medicine they will stay well." Ask your child to draw a picture of John and his granny.



You may want to discuss the following with your child:

- Who can your child tell about the germs in his or her blood?
- Who can your child ask for help if other children tease him or her?

Supporting your young child to keep taking medicine

We will now look at supporting your child to keep taking their medicine.

It is important that your child continues to take medicine.

Sometimes young children do not want to take their medicine.



Draw four ways that you could encourage your child to keep taking medicines.



It is very important that you know about medicines:

- ✓ How much to give
- ✓ How to give
- ✓ When to give
- ✓ How to remember to give

Your home-based care worker will help you prepare and give medicine to your child.

Part 3: Caring for a young child who becomes sick and gets better

Telling you about Part 3

In Part 3 we look at caring for your child when they become sick.



If your child becomes sick, immediately contact your home-based care worker, clinic nurse or doctor if you are concerned that it is serious.

Your home-based care worker will do the following to support you to care for your sick child:

- Find out what is causing the sickness.
- Give advice on what to do.
- Assist you to carry out tasks.
- Arrange for you to take the child to the clinic if you are concerned or arrange to visit you again soon.

We will look at important things when caring for a sick child:

- Feeding a sick child
- Treating common problems
- When to refer a sick child to the clinic
- The special problems of medicines for HIV
- The special problems of a child who has been abused

Feeding a sick child

A sick child may not want to eat or drink.

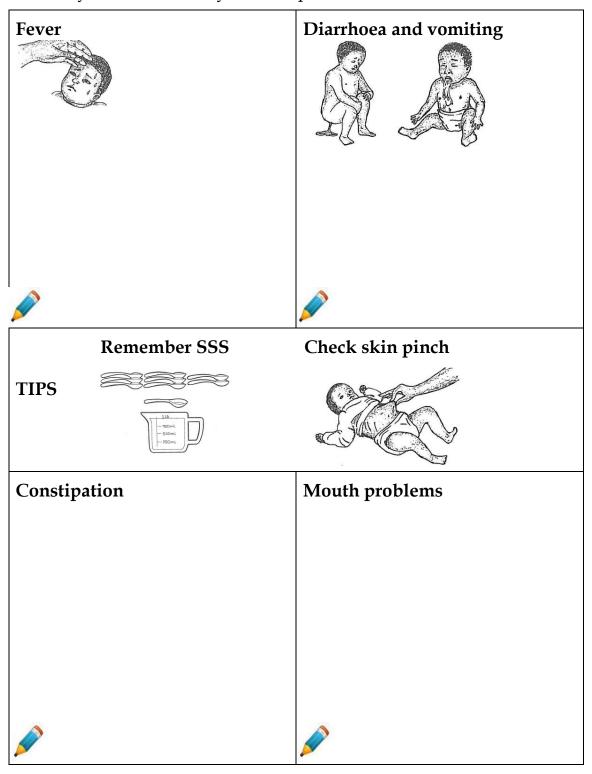
It is important that you encourage them to eat and drink a little amount of food and fluid often – at least every one or two hours.

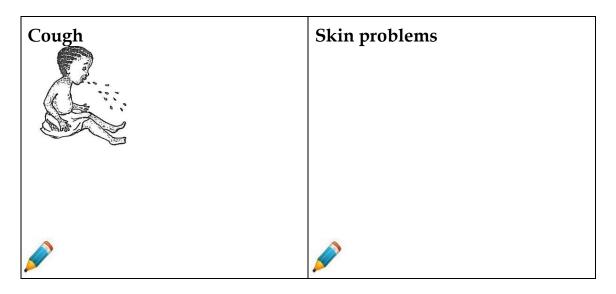
When a child is sick you must <u>actively feed</u> them. That is, hold the spoon, encourage them to swallow a bit at a time, and keep encouraging them to sip liquids and to eat a little food.

Together with your home-based care worker draw three pictures of how to actively feed a sick, young child.

Common problems faced by a young child

Together you and your home-based care worker will draw what to do if your child has any of these problems.





When and how to take your sick child to a clinic?

You should seek help if you are concerned about your sick child. Seek help if your child develops any of these problems:

Problem	Concern for today
Your child is unable to drink	
Your child vomits up everything	
Your child has fits	
Your child is very drowsy	
Your child has a cough and is breathing very fast or the chest is sinking inwards	
Your child has diarrhoea or is vomiting and the eyes are sunken in	
There is blood with diarrhoea	
Your baby is less than 2 months old and will not feed	
Your baby is less than 2 months old and has a fever	

Ask your home-based care worker to make a mark on this chart about why you and she or he are concerned. Take this toolkit with you to your clinic and show the nurse where the home-based care worker has marked.

The special problems of medicines for HIV

Your child may be taking medicines to control the HIV disease. Together, these drugs are known as antiretroviral therapy or ART.

Some children with HIV may remain well without ART. They do not yet need ART.

ART may cause some problems. Most problems are mild and disappear.

Take your child to the clinic if you notice any of the following:

- Rash
- Diarrhoea
- Vomiting
- Blistering on the mouth or skin
- Face becomes swollen
- Drowsiness
- Yellow eyes
- Tummy pain
- Breathing very fast
- Pain in the hands or feet

⊙ It is important that the child does not stop ART **⊙**

If you visit your clinic please take your child's medicine with you.

The special problems of a child who has been abused

We know that children with HIV may be abused.

The most common forms of abuse are:

- Physical
- Emotional
- Sexual
- Neglect

Your home-based care worker will discuss what to look for with each of these types of abuse. You can make notes for yourself in the table below.

Types of abuse and what to look for

Physical abuse	Emotional abuse	
Sexual abuse	Neglect	

If a child tells you that someone has abused them then you 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 will speak to someone to make sure that this does not happen again.

Reporting abuse can save a child's life.

If you suspect that your child is being abused, who can you tell?

You can make a list like the one below of people you can talk to. Write down their telephone numbers so you have them when you need them.

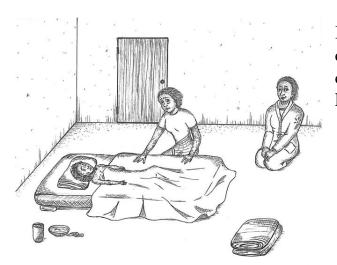
Telephone number of home-based care worker	
Telephone number of clinic sister	
Telephone number of hospital/Crisis Centre	
Telephone number of Helpline	
Telephone number of police station	

Part 4: Caring for a child who is sick and who may not get better

Telling you about Part 4

Unfortunately, we know that some children who have HIV infection may become very ill.

A few may even die.



In Part 4 we will look at caring for a very sick young child with HIV infection at home.

There are many reasons why you may want to keep a sick, young child with you at home:



Draw five reasons why you may want to keep a sick child at home with you:



In Part 4 we think of a very sick child as a flower. A 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 shade.*

The proverb tells us that a river will have parts where trees may be found which will cast shade onto the river. Therefore, 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 we can use when a caregiver 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 you look after a very sick child.

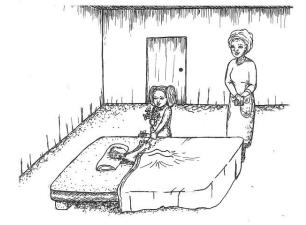
The Nine Messages

- 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

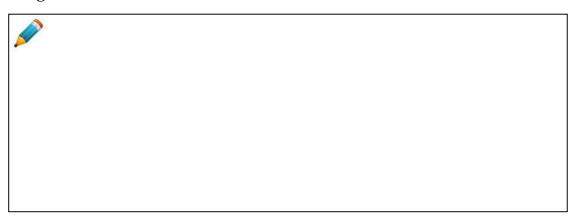
Message 1 - Giving a little can mean a lot

The home-based care worker will tell you a story called "Daisy Flowers" and you will discuss this story.

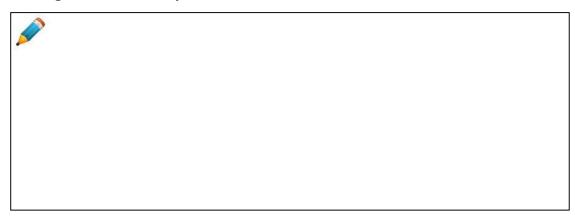
Giving a little means a lot



Draw a picture of a time when you did something small and it made a big difference to someone's life.

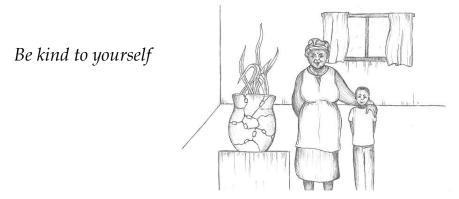


Don't give up hope. Draw one thing that you can do today if you are feeling sad and lonely.



Message 2 - Be kind to yourself

Your home-based care worker will tell you a story called "The Big Flowerpot" and you will discuss this story.



Know that you cannot be perfect. Allow others to help you. Know that things do not always turn out the way you expect them to.

We will look at the following:

- What happens if you are not kind to yourself?
- How can you be kind to yourself?

What happens if you are not kind to yourself?

If you are not kind to yourself you may become ill in your body, your mind and in your emotions.

Write down what happens to your body, mind and emotions when you are stressed?

What happens to my body?	
What happens to my mind?	
What happens to my emotions?	

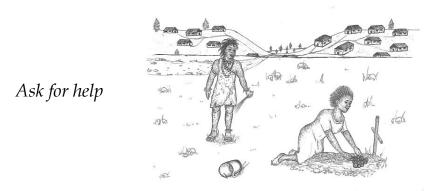
How can you be kind to yourself?

Draw three things that you can do to be kind to yourself, to rest and to look after yourself.



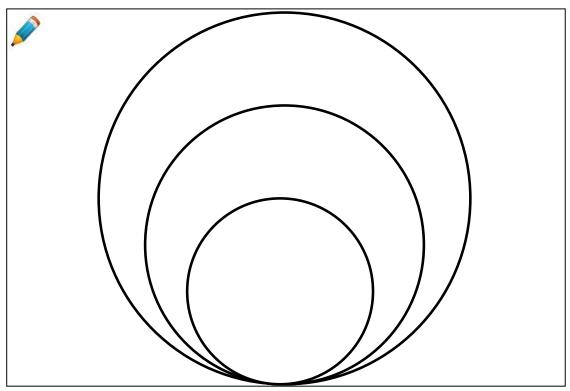
Message 3 - Ask for help

Your home-based care worker will tell you a story called "The Empty Cup" and you will discuss this story.



We will look at who you can ask for help.

Circles of Support



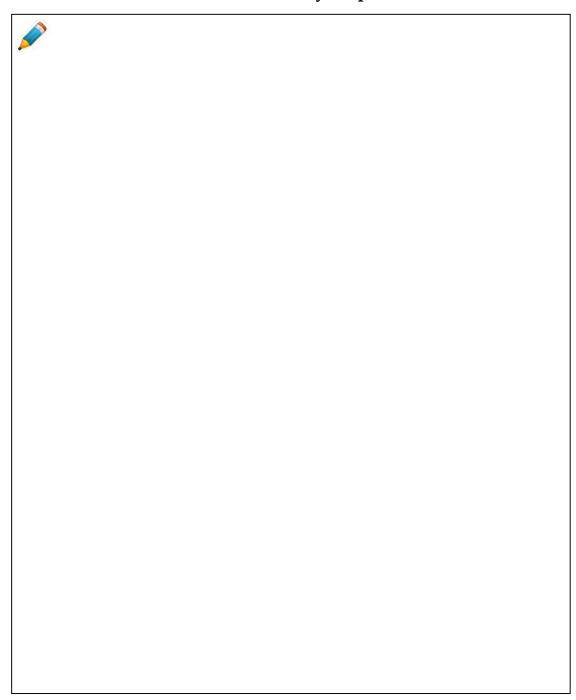
Draw yourself and a sick, young child in the small centre circle.

Draw your family and friends in the next circle.

Draw other people who could help you in the biggest circle.

Together you and the home-based care worker will draw a map of your area and together you can look at where help is available.

A Community Map

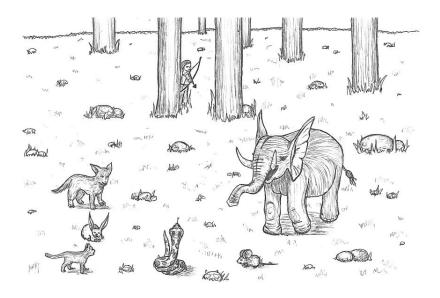


It is important that you know who to ask for help.

Message 4 - Listen to the child

Your home-based care worker will tell you a story called "The Snake's Ears" and you will discuss this story.

Listen to the child



Do not listen to your sick child with only your ears, but with your heart and understanding too.

Watch the child carefully.

Listen to children with the ears on your head and the ears in your heart.

We look at the following:

- Why is it good to listen to a young child?
- How can you listen well to your young, sick child?

Why is it good to listen to a young child?

Draw three reasons why it is good to listen to a sick, young child.					
Iow can yo	u listen well to	o your youn	ıg, sick chila	1?	

Draw five ways that you can listen well to a sick, young child.

Message 5 - Offer comfort to a distressed child

Your home-based care worker will tell you a story called "Snow White Flower" and you will discuss this story.

Offer comfort to a distressed child

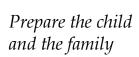


You can always offer some comfort to your distressed child.

Draw three things that you could do with a distressed young child to comfort them.

Message 6 - Prepare the child and the family

Your home-based care worker will tell you a story called "Flowers from Heaven" and you will discuss this story.





Your sick child may ask you about illness, dying or death.

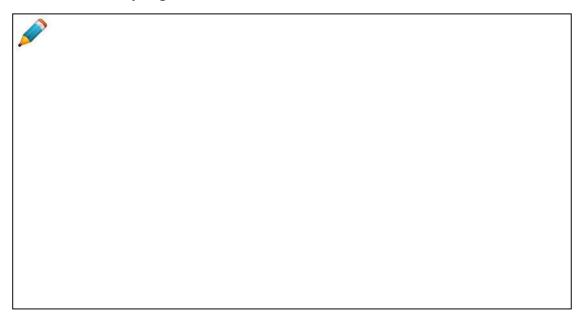
You may want to tell other children in your family about illness, dying and death.

We will look at the following:

- Why it might be good to tell children about illness, dying and death
- How to talk to young children about illness, dying and death
- What you can do if a young child does not want to eat or drink
- What happens immediately before death and after death

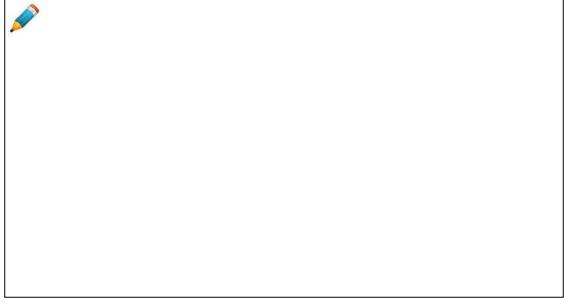
Why might it be a good thing to talk to a young, sick child about illness, dying and death?

Draw three reasons why it may be good to tell a sick, young child about illness, dying and death.



Why may it be a good thing to talk to your sick child's brothers, sisters and friends about illness, dying and death?

Draw three reasons why it might be good to talk with brothers, sisters and friends about illness, death and dying?



How to talk to young children about illness, dying and death

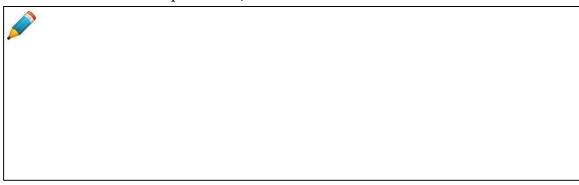
Instead of talking about dying you could tell your child a story about something that goes away and does not return.

We find the story below helps us to talk to sick young children and their brothers and sisters about illness, dying and death. You can get all the children together to share the story.

John and James

John had a special friend and his name was James. They played together at school. Sometimes John got sick and could not go to school. Sometimes he felt angry and sad because he had to stay in bed. Sometimes he felt scared because he knew he had a germ in his blood.

Ask one child to draw a picture of John.



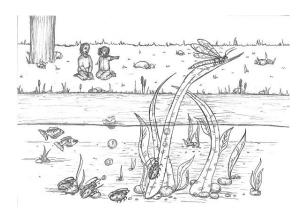
John had to go to hospital and the doctors and the nurses at the hospital were kind. John missed his friend James.

Ask another child to draw a picture of John at hospital.

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One day the doctor told John that he would not get better. John was very scared. He cried a lot and he told James all about what the doctor had said. John's granny told them a story called water-insects and dragonflies.

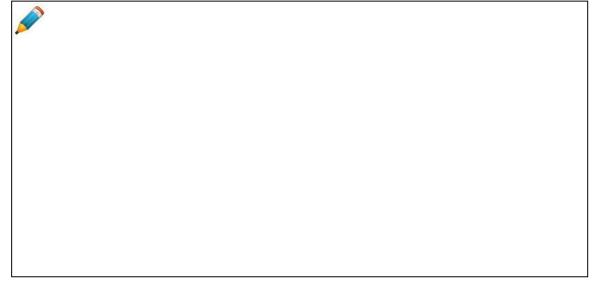
Water-insects are tiny creatures that live under the water. Sometimes the water-insects watch as one of their friends climbs up a large plant and disappears above the surface of the water. The friend does not return to them and they never see their friend again. The water-insects wonder what happened to their friend.



People that live on the land look at the water-insect as it climbs up the large plant and out of the water. They see it sit in the bright sunlight. They see it slowly change. It develops shining wings and becomes a beautiful dragonfly. It flies off happily to meet other dragonflies. Sometimes it remembers its friends below the surface but it cannot go back to them.

James said to John "I understand that the dragonfly cannot return to visit his friends. I will never forget you." Together they drew a picture of themselves.

Ask one child to draw a picture of John and James.



A few months later John died. His brothers and sisters and his friend, James, were very sad. They cried for a long time. James looked at the picture that he and John had drawn. He smiled and said, "I love you John".

Ask one child to draw a picture of James.



Your home-based care worker will support you if you wish to discuss illness, dying and death with your young children.

What can you do if a very sick child does not want to drink or eat?

A very sick child, who is close to dying, does not need much fluid or food.

Your caregiver will tell you about the Aloe Flower.

Sometimes nature tells us not to give too much fluid or food.



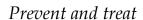
What happens immediately before death and after death?

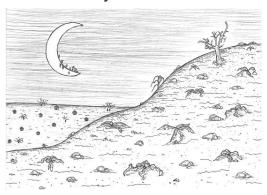
These things may be difficult to talk about. If you would like to talk about them please tell your home-based care worker and she will cover these topics with you.

If you don't want to talk about this, don't worry. Your home-based care worker will respect what you want to do.

Message 7 - Prevent and treat

Your home-based care worker will tell you a story called "The Red Moon" and you will discuss this story.





It is better to prevent problems before they arise. Then, treat problems that do occur.

We will look at the following:

- Pain in a young, sick child
- Preventing and treating pressure sores
- *Preventing stiff joints*

Looking at pain in a sick, young child

If your child is more than 4 years old you can use these pictures. Ask your child to point to which picture best shows their pain.

Wong-Baker FACES™ Pain Rating Scale



Face 0 Is a happy face because your child has no pain.

Face 2 to Face 4 Your child has pain that hurts just a little bit.

Face 6 to Face 8 Your child has pain that is upsetting.

Face 10 Your child has very severe pain that is very upsetting.

Together you and your home-based care worker will look at what is causing the pain and what to do about the pain.

If your child is younger than 4 years, you and the home-based care worker need to watch the child carefully and see if there is pain or not.

Here is what you must watch for and the home-based care worker will help you with this.

Looking for Pain in a Young Child

What to look at:	No pain	A little pain	Lots of pain
Look at the face			
Look at the legs			
Look at how the child lies			
Listen to the child's cry			
Can the child be comforted			

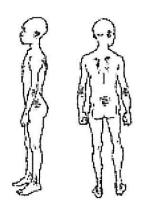
Preventing and treating pressure sores

Together you and the home-based care worker will also look at preventing and treating pressure sores.

Preventing stiff joints

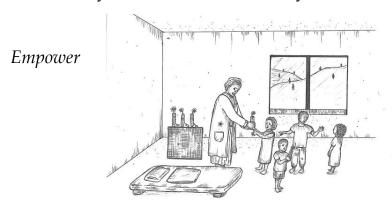
The home-based care worker will also discuss how you can deal with stiffness.

Draw a picture of how to prevent stiff joints.



Message 8 - Empower

Your home-based care worker will tell you a story called "The Boy and the Flowers" and you will discuss this story.



Even your sick child can come up with a possible solution to problems. Work out how you can make the solution happen. Earlier we looked at your child's main problem and your main problem.

Draw one thing you can do about your child's problem.

Draw one thing you can do about your own problem.

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Message 9 - Remember

Your home-based care worker will tell you a story called "The Wax Child" and you will discuss this story.



You can find much comfort in remembering those who died.

You can prepare for the death of a loved one.

We will look at the following:

- A memory box
- You grieving the loss of your young child
- Other children grieving

A memory box

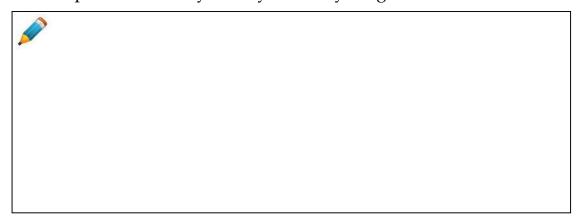
Your home-based care worker will discuss the idea of a memory box with you.

Draw a picture of what your memory box would look like.



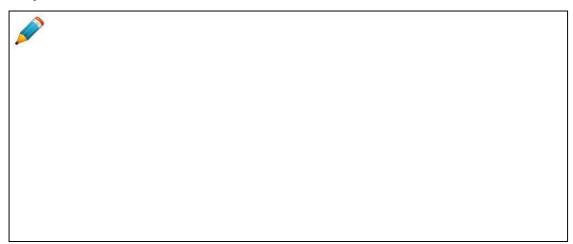
You grieving the loss of your young child

Draw a picture of how you may feel if a young child dies.



Other children grieving

Draw a picture of how young children at home may feel if someone they know dies.



We may need to ask a nurse or doctor for help if we notice any of the following in a young grieving child:

- The older child begins to use baby talk, sucks their thumb, and has incontinence of urine
- Has severe nightmares
- Harms himself or others
- Becomes very quiet
- Will not eat
- Cries most of the time

The end of this toolkit

We have written this toolkit to help you care for your young child who has HIV.

We hope that you found it useful.

We hope that you can also use these messages to care for other children who do not have HIV.

Remember that you are doing an important job. It is difficult and you are doing the best you can.

You are already providing palliative care.

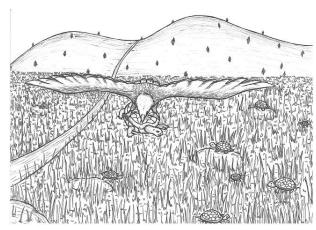
Here are a few more stories you may want to tell your children.

The Turtle and the Eagle

It is OK to be different to other children

There was a small turtle who lived with his family and friends by a small waterhole. Every day he walked slowly around the waterhole and looked up towards the sky. He could not see far beyond the waterhole because the weeds grew high.

He asked his friends and family, "Are there other waterholes and other turtles?"



"No, there are no other waterholes and there are no other turtles," replied his family and friends.

One day an eagle heard the small turtle and, without saying a word, the eagle swooped down and lifted the small turtle gently in his claws.

Together they flew high into the sky and the waterhole became smaller and smaller. From the sky the small turtle could see that there were many other waterholes and many other turtles.

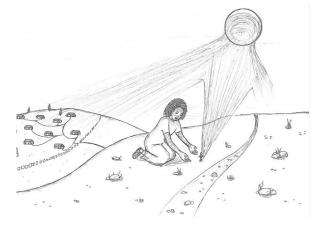
The eagle gently placed the small turtle back down by his waterhole and the turtle told the others what he had seen. Most of his friends did not believe him and said, "There are no other waterholes and there are no other turtles". However, one friend stood up and said, "Can I also fly like you? I want to be different like you. I want to see the other waterholes and turtles".

The Giant Called Fear

Don't be afraid

The villagers lived happily, planting their crops and watching the seasons go by. Then, one day they noticed that the sun was not so bright any more. They looked towards it and saw the shadow of a giant who blocked out the sun.

The villagers were scared of what the giant might do to



them. A young girl called Thembisile set out to confront the giant. The elders warned her not to go. But she said, "I must see for myself". So Thembisile set off.

As she got nearer and nearer a strange thing happened. The giant became smaller and smaller. Eventually Thembisile reached the giant. She had to stoop down to talk to him. By now he was so small she could hold him in her hand.

Thembisile asked the giant, "What is your name? The giant said, "My name is Fear".