



My living positively hand-book



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hello

Welcome to your book



We are very happy you are reading it. This book is about HIV and AIDS. We want to start with a little bad news, and then some good news.

There is no cure for HIV. It will live in your body for the rest of your life, until you are an old old old old woman or man.

The **good news** is: You can help to keep your body healthy and feeling strong for the rest of your life, until you are an old old old old woman or man. We call this “living positively” – with health, happiness and hope for the future.

This book was made by children, families, doctors, nurses, teachers, and counsellors. Many of us are living with HIV, just like you. We hope that our pictures and words will help you learn a lot about HIV and **living positively**.

Find a grown-up to read this book with you. They can help with the activities and answer any other questions you have. Maybe this is someone in your family or someone at your clinic.

It is OK to put marks in this book. There are no right or wrong answers, so don't worry about making mistakes.



I am Aunty

I am Sipho

I am Lucille

I am Sister Thandi

I am Doctor Themba

Hello – we are your friends. We are here to tell you about HIV and AIDS.

Look out for us as you read your book. We will help you find out many ways to live positively.

Contents



- All about me 2–3
- Who else has HIV? 4–5
- What is HIV?..... 6–15
- Sinazo’s story 16–17
- How do I get HIV? 18–19
- How do I live positively? 20–21
- What may happen to my body without help? 22–25
- Zamo’s story 26–27
- How do I feel today?..... 28–33
- Feel-good! 34–35
- My medicines 36–37
- Traditional healers 38–39
- A trickster tale 40–43
- How to take your medicines 44–45
- Babalwa’s story 46–47
- Children talk about having HIV..... 48–51
- HIV and discrimination..... 52–53
- Patient file 54–55
- My everyday colouring book 56–61
- My blood tests 62–67
- Make a book 68–71
- Other books to read 72–73
- Thankyou’s and copyright 74–77
- Notes and emergency information 78–79

**This is a book
about me!**

**I will draw
or write
about myself
in these boxes.**



Blank box for drawing or writing.

**Where do you stay?
Who stays with
you? What do
you like to do?**



I am **not** the only one with HIV!

Many adults and children in my area and all over the world are living with HIV, just like me.



We are all living positively too!





Draw or write everything you know about HIV in this box.
What does it look like? What does it do?

Understanding HIV

Here are 3 stories that can help you understand what HIV does. The stories will help you to know how to stay healthy. They are all different ways of thinking about HIV and AIDS. Read the stories and choose which one you like best.



1 Is HIV like a cattle thief?

My health is like cattle that I own.
My health is very **valuable**.
HIV is like a thief that is trying
to steal my health.

I can keep my cattle **safe** by building
a big fence around my kraal.

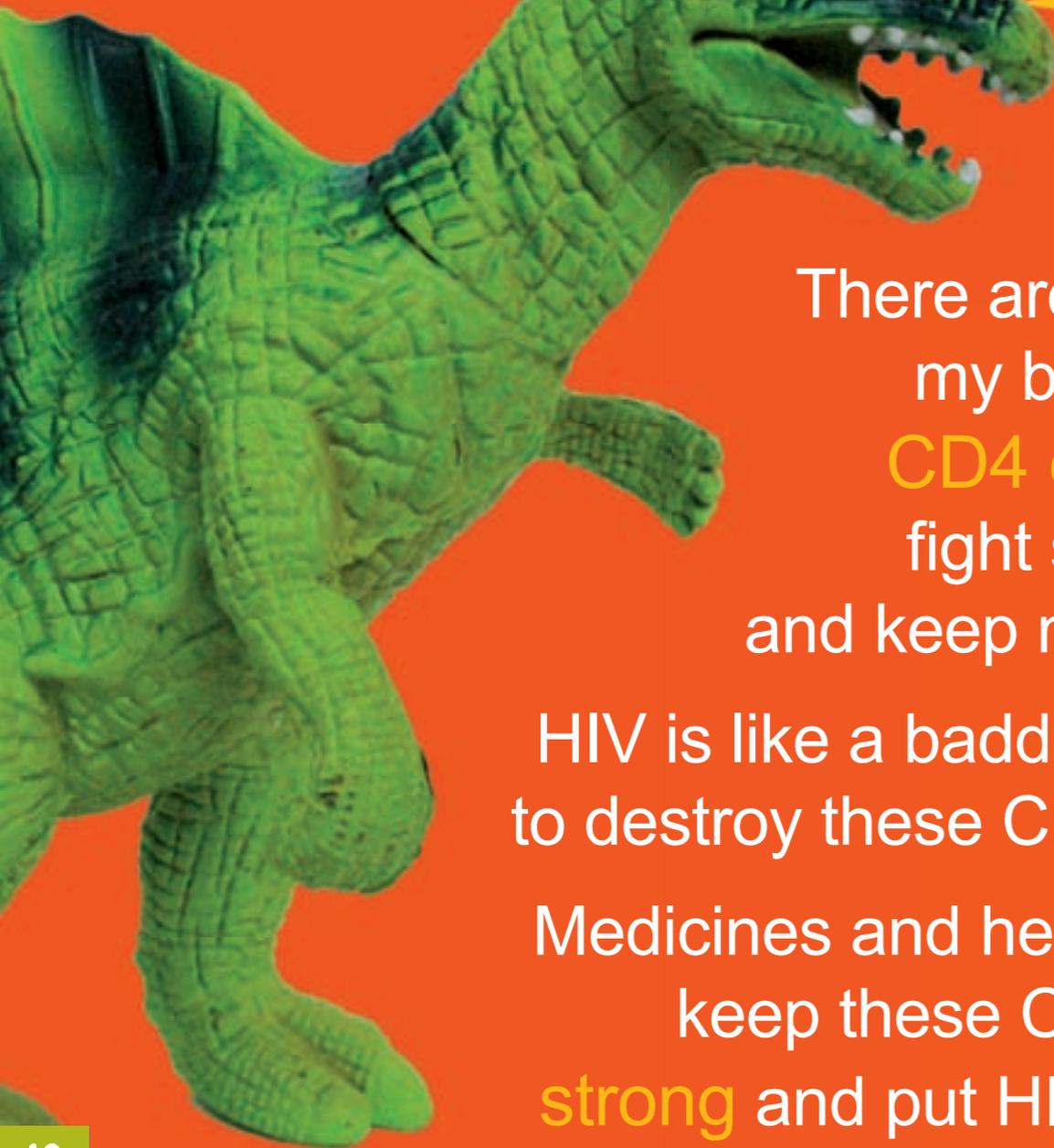
Medicines and healthy foods are like
this fence. They **protect** my health
from HIV.

Draw the cattle thief story here



2 Is HIV like a baddie?

Draw the CD4 guards' story here



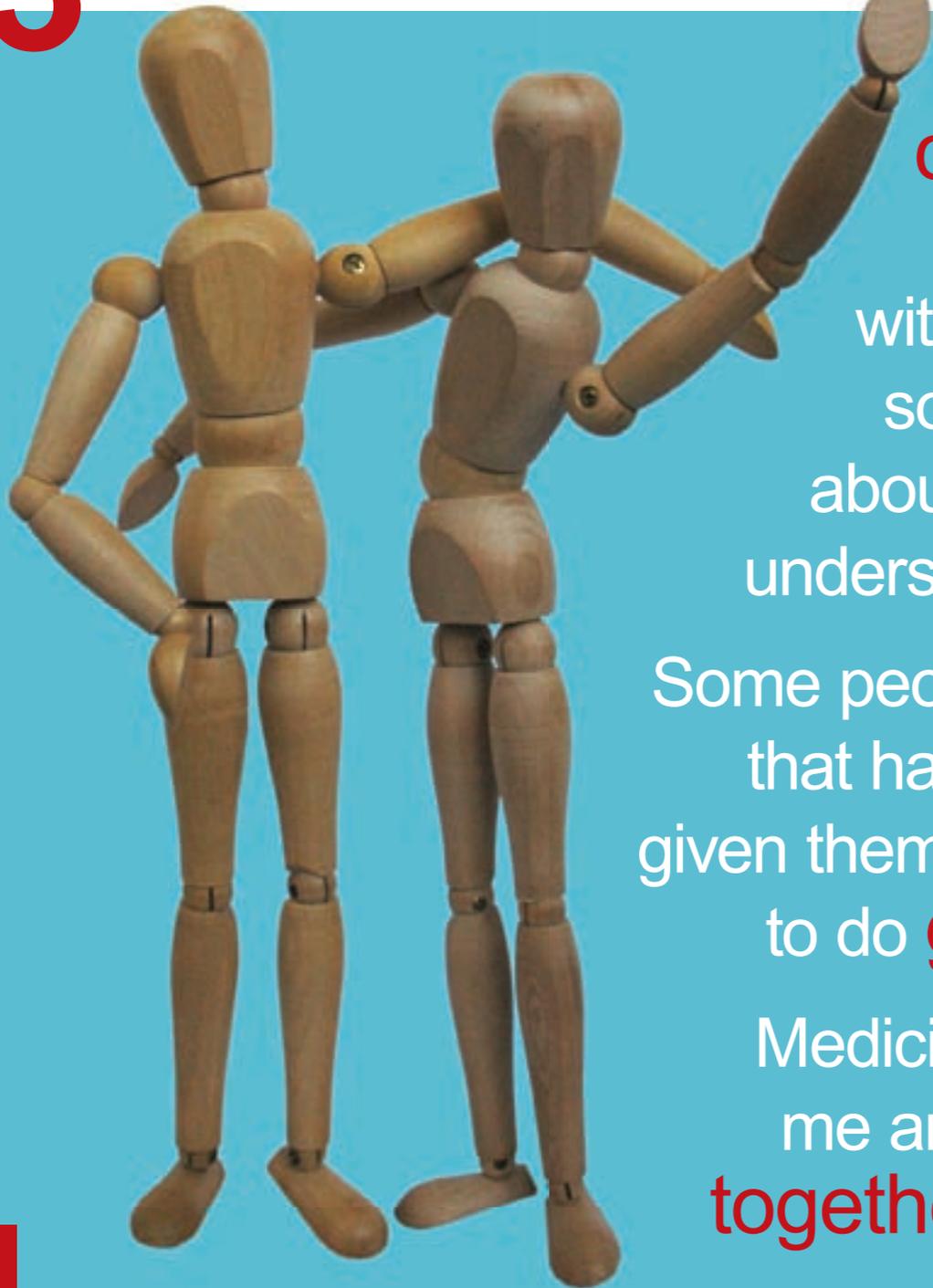
There are guards in my blood called **CD4 cells**. They fight sicknesses and keep me healthy.

HIV is like a baddie that tries to destroy these CD4 guards.

Medicines and healthy foods keep these CD4 guards **strong** and put HIV to sleep.



3 Is HIV like a friend?



I did not **choose** HIV, but it will be with me forever, so I must learn about it and try to understand it better.

Some people even say that having HIV has given them the strength to do **great** things.

Medicines can help me and HIV to live **together** all my life.

Draw the story here



What is **HIV** like?

What else
is HIV like?

A pig?

A car?

Why?

Have you heard
any other stories
about HIV?



Make up a story
about HIV and
what it does.



Write or draw your own story about HIV here



A large white rectangular area for writing or drawing a story about HIV.

SINAZO

Sinazo's story

My name is Pelogazi Mkutshwa but they call me Sinazo. My mother gave me this name, and it means lastborn. I am ten years old and I am in Grade 4. I stay in Goso Forest with my granny, my uncle, my sister Thembeke, and my cousins. I made these photos of them.

When I wake up in the morning I take my pills, eat and sweep. I go to the river to fetch fresh water. I also go to the forest to fetch wood. I walk to school, it is close. When I arrive home I wash my clothes in the river. Sometimes I help my granny in the garden, we grow mealies and beans and potatoes. I help to dig the soil. I like to cook, and my granny has taught me to make rice.

When my mother gave birth to me, it was fine. But then my mother was sick, and she was tested HIV positive and she died. After this, I started coughing and I was taken to the clinic. I was also tested HIV positive in 2004.

My granny by our house



My cousins Sipho and Nokonwaba, and our neighbours



Thembeke



How do children get HIV?

From 4 ways only!



1

Children can get HIV when the baby is growing inside the mother's body or when the baby is being born. And sometimes the baby gets HIV through the mother's milk.



2

Children can get HIV if someone with HIV has sex with them. It is wrong for anyone to have sex with children. You should tell a grown-up who can protect you.



3

Children can get HIV if the blood of a person with HIV gets into their blood. The blood can only get in through a cut or open place in the skin.



4

Children can get HIV if they are pricked with a needle or cut by a blade that has been used by someone who has HIV.

REMEMBER: You do **NOT** get HIV from: touching, playing, hugging, kissing, sharing food, sharing a toilet, witchcraft, mosquitoes, using condoms, riding in a taxi, or sitting near someone.



No matter how a child gets HIV, it is **not** his or her fault. I did not choose HIV, but I can choose to live positively: with **health, happiness** and **hope**.

- How do you live positively?
- Do you take care of your body?
- Do you use your strengths?
- Do you stand up for yourself?
- Do you share your love?

How do you live positively? Write or draw your story here.

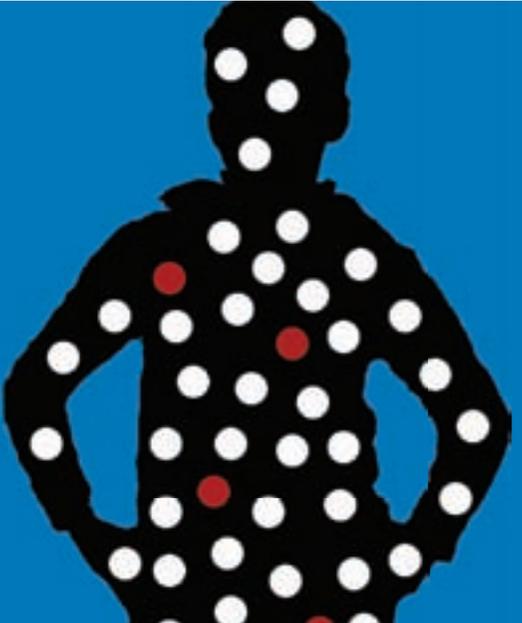
A large, empty white rectangular area intended for a child to write or draw their story. In the bottom right corner of this area, there is a small illustration of four crayons (red, green, yellow, blue) in a red container.

What may happen to my body without help?

HIV has **FOUR STAGES**. Doctors decide what stage we are in by looking at our blood and our bodies. The **BLUE** box shows what is happening in our blood at each stage. It shows how many good CD4 cells (white dots) we have to keep us healthy. It shows how many HIV viruses (red dots) are causing trouble. The **YELLOW** box tells what sicknesses may come at each stage. The **GREEN** box tells us what we can do to keep our bodies strong at each stage.

You can see how there are more and more red HIV dots in your body as you move from Stage 1 to Stage 2, and then to Stage 3 and 4. The good white cells become less and less. Between Stages 3 and 4, you will need medicines called ARVs. These help to make you healthier.

1 Stage 1



● CD4 cells ● HIV

2 Stage 2



● CD4 cells ● HIV

3 Stage 3



● CD4 cells ● HIV

4 Stage 4



● CD4 cells ● HIV

AIDS is when HIV invites a lot of big sicknesses to be guests in your body. This happens only when HIV has made your body weak.

How may I feel?
You are likely to feel well, with no sicknesses.

What can I do?
You can help yourself to keep well by eating healthy food, keeping clean, exercising and having fresh air.

How may I feel?
You may start getting a few sicknesses like a rash, a cough or runny tummy.

What can I do?
You can tell someone as soon as you get sick, and ask for treatment. If you are given co-trimoxazole, you must take it every day.

How may I feel?
You may feel more sick more often. You may need to spend some time in hospital. You may get thin or feel tired.

What can I do?
You can make sure you take the medicines you are given for as long as the doctor says you must! You can eat small meals often to help you keep strong.

How may I feel?
You may get very sick without ARV medicines. Even if you feel well and are not thin, you may be given ARVs.

What can I do?
You must make sure you take your medicines every day. Are you still keeping yourself clean and eating good food? Yes, of course!

ARVs to the rescue – for life

When you are very sick with HIV, the doctors will say that you have AIDS. You will then be given ARVs. These medicines are shown as **yellow** pills in this picture. Can you see that there are now more good **white** CD4 dots and less **red** HIV dots? The ARVs do not get rid of every red dot, but they help your body to make enough CD4 cells to keep well.



ARVs help you to live a healthier life.



Soon, your body will start to feel much better. You will feel stronger and not so tired. Your sicknesses will go away. You will start to gain weight and grow taller.

You WILL have to take these ARVs at the same time every day for the rest of your life, until you are an old woman or man. You will also have to keep treating any sicknesses that you get. You will need to keep eating healthy foods to keep your body strong.



ZAMO

Zamo's story

My name is Zamokuhle Mdingwa. My name was given to me by my mother and father but I don't know what it means.

I am 10 years old and I am in Grade 3. I was born in Ethekwini but I live now in Xurana C. I stay with my granny and my cousin Ncembakazi and near to my friend Sikho. On holidays my cousin Lulu visits me and we play together.

I help my cousins with the goats and the sheep that belong to our family. I like to play with marbles and a soccer ball. My football club collected some coins for a ball but it burst.

After my mother fell sick, they took blood at the clinic and found I was HIV positive. The counsellor told me my status. I do not remember this because I was very young.

Granny and Ncembakazi



We are playing football



Lulu



How do I feel today?

My whole body feels good!



I can't see properly



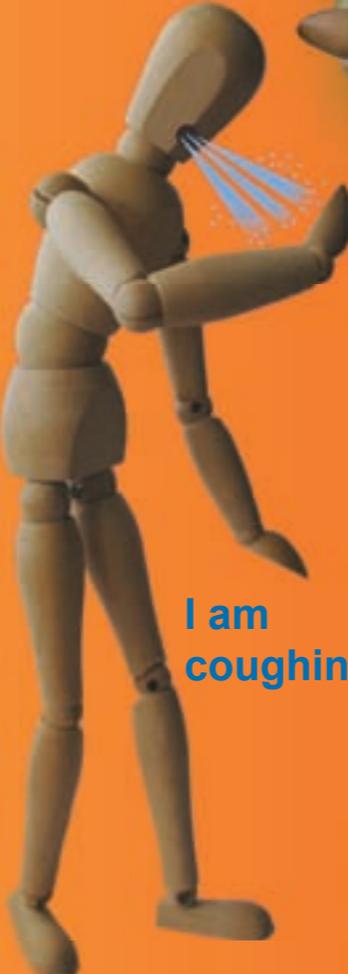
I feel dizzy



I am tired



I have nausea, vomiting, running stomach



I have a headache



I have fever and sweating day or night



My hands or feet are paining – pins and needles



Rash

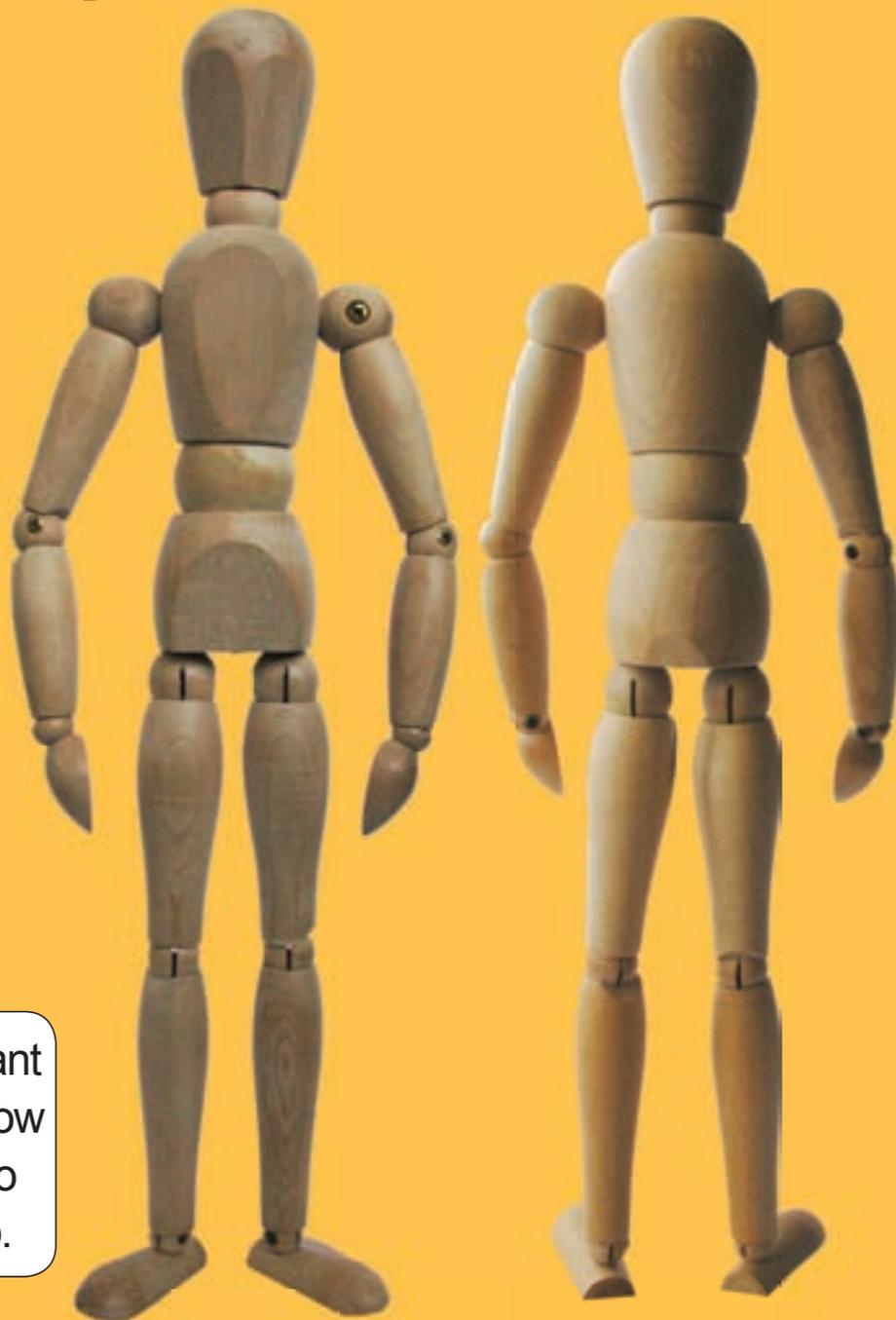


Do any other parts feel sore?

Weak?

Itchy?

Strange?



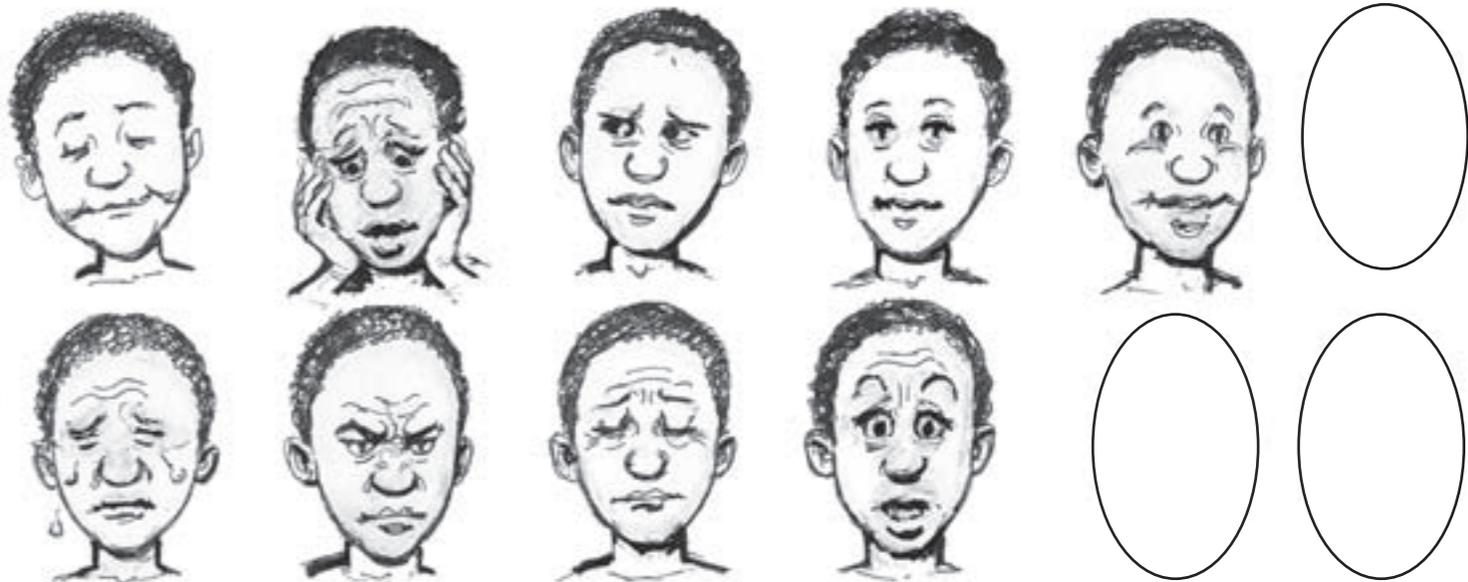
My front

My back



It is important to tell me how you feel so I can help.

Do my feelings **match** any of these faces?



Do my feelings match any of these words?

- | | | |
|---------|---------|---------------|
| proud | loving | confused |
| sad | lost | safe |
| shy | tired | confident |
| lonely | grouchy | optimistic |
| hurt | helpful | embarrassed |
| scared | strong | curious |
| silly | naughty | comfortable |
| bored | lucky | surprised |
| happy | sorry | frustrated |
| worried | playful | misunderstood |
| calm | angry | thoughtful |

My pain

These pictures help children tell others how much hurt they have.



This picture shows no hurt.



This picture shows just a little bit of hurt.



This picture shows a little more hurt.



This picture shows a lot of hurt.



This picture shows the biggest hurt you could ever have.

Can you point to the picture that shows how much hurt you have right now?

These are boxes of hurt



One is just a little hurt.



Two is a little more hurt.



Three is a lot of hurt.



Four is the most hurt you could ever have.

How many boxes of hurt do you have right now?
Count one, two, three or four?

Write or draw about your pain here:



What do you do for yourself when you're hurting?
What do you want others to do?
What helps most to take the hurt away?

Feel-good!

There are people like nurses and doctors who can help you to feel better and keep well.

You can be a good partner with them, helping to care for yourself.

What things can you do for yourself, to care for your body?

- Do you wash your hands before eating and after going to the toilet?
- Do you keep your finger-nails short and clean?
- Do you eat small meals often, even if you are not hungry?
- Do you brush your teeth after eating and before you go to sleep?
- Do you have time to play every day?



If you feel sad or cross, what things can you do for yourself?

Do you feel better if you:

- Listen to the radio or watch television?
- Talk to a friend?
- Play a game?
- Sing a song?
- Read a book?



Some children get rid of angry feelings by digging in the garden!

I feel better if I smile!



My medicines



I take 3TC, d4T, and NVP. I take them at 7 in the morning and 7 at night. I hear on the radio what the time is. My uncle is also taking his pills at 7 and 7. I take medicines because I have TB and also HIV. I have been taking them from 2004, and I will take them for the rest of my life. I forgot once to take my pills, but I do not forget anymore. When the CD4 count has gone up, I know I'm taking the tablets properly.

- SINAZO

When my mother told me I was HIV positive, I was happy! Because now I can drink the pills like my mother. I am taking 3TC, d4T, and NVP. They help me to feel good and have health, and if I stop I will get very sick. My mother says they will put me in the soil. Sometimes I forget when I am going to play but I remember to take them because my mother also takes them. We remind each other.

- VUYO



What ARVs do you take?

Draw or write about them here



In some communities, there are people who are **traditional healers**. These people have special training and skills that are different from clinic doctors and nurses.

It is very important to tell your clinic doctor or nurse about any traditional medicine that you take. Some traditional medicines take away the power of the ARVs. Your clinic doctor or nurse can help you decide what is safe and what is unsafe.

No one can cure HIV, it will live in your body forever. But clinic doctors and traditional healers working together can make you feel better and stronger.



Have you ever visited a traditional healer?
Draw or write about it here.



A large, empty white rectangular area intended for drawing or writing.

A trickster tale

Once there was a terrible drought.

The rivers dried up and the wells gave no water.

The animals wandered around thirsty, but there was nothing to drink. A great gathering of animals was held: elephant, giraffe, turtle, hippo, rabbit. “What can we do?” they asked each other.

One of them had an idea: “Come, let all of us go to the dry riverbed and dance, in that way we can stomp out the water.” This was a very good plan!

Everyone was happy and ready to begin right away.

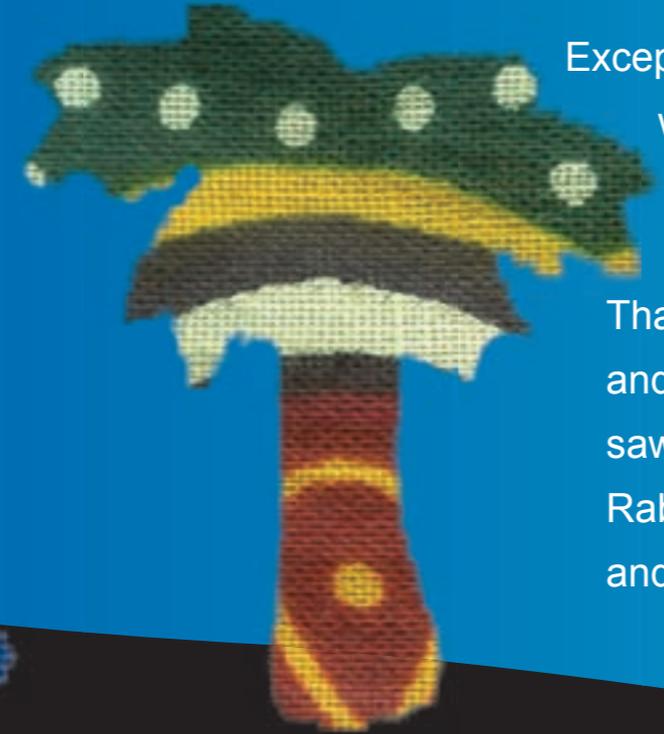
Except Rabbit, who said, “All of you are mad to try to get water from the ground by dancing. I will not go and dance.”

So the other animals danced and danced, and finally danced the water to the surface. How glad they were. Everyone drank as much as they could.

Except for Rabbit, who did not dance, and who was not allowed any water. He laughed at them: “I will find a way to drink some of your water.”

That night he went to the riverbed where the dance had been, and drank as much as he wanted. The next morning the animals saw the footprints of Rabbit in the ground.

Rabbit shouted to them: “Aha! I did have some of the water, and it was sweet and fine.”





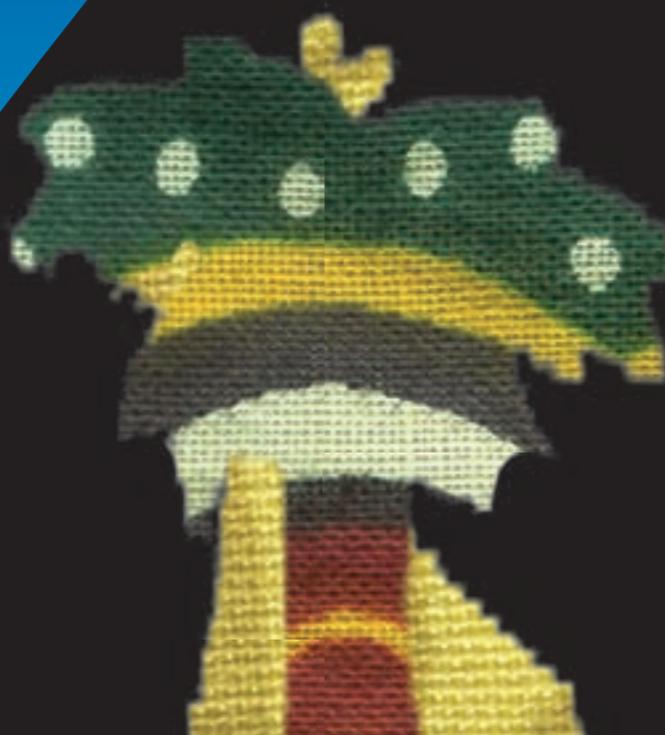
Quickly all the animals were called together. What could they do? How could they trap Rabbit to keep him from stealing more water? Turtle moved slowly forward and said, "I will catch Rabbit."

"You? How?" asked the others. Turtle answered "Rub my shell with tar, and I will go to the edge of the water and lie down. I will look like a stone, and when Rabbit steps on me his feet will stick fast."

This was a very good plan! They covered his shell with tar and slowly he moved away to the river. At the edge, close to the water, he lay down and pulled his head into his shell. Then he waited.

That night Rabbit came to get a drink. "Ha!" he laughed, "They have placed a stone here that I can stand on, so I will not wet my feet."

Rabbit stepped onto the stone, and his feet were stuck. He was caught!



We can learn many things from this story

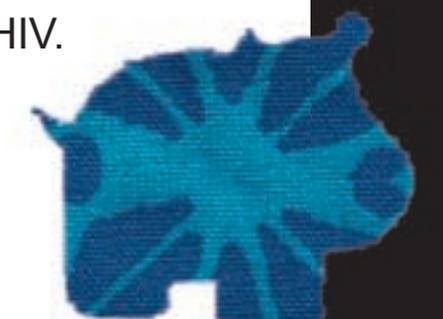
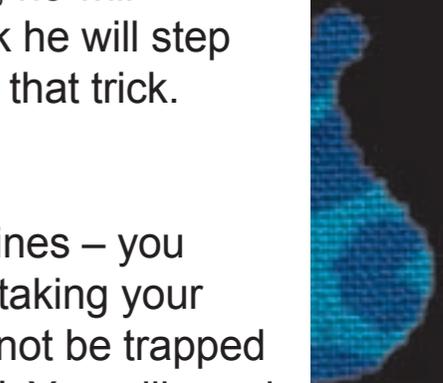
The naughty rabbit is like HIV, trying to steal your health. The clever animals are like your medicines. They play a trick on the HIV and they trap him so that he cannot steal any more health.

But what if they let the rabbit go? If the rabbit goes free, he will come back to the river to steal more water. Do you think he will step on the turtle and get caught again? No! He has learned that trick. He will think of another way to steal the water.

This is what happens when you stop taking your medicines – you let HIV go free to cause more trouble. Even if you start taking your medicines again, the HIV has learned the trick and will not be trapped by those medicines anymore. This is called "resistance". You will need to take new medicines that play a different trick on the HIV.

But there are not many tricks that we know to stop HIV. If HIV learns them all, you will get very sick and there will be no medicines that can help you.

That is why it is so important for you to take all of your medicines every day.



How to take your medicines

Take your drugs at the right time, in the right amounts, and exactly as your doctor or nurse says. This is called adherence.

How do YOU take your drugs? Write or draw the ways in the empty boxes.

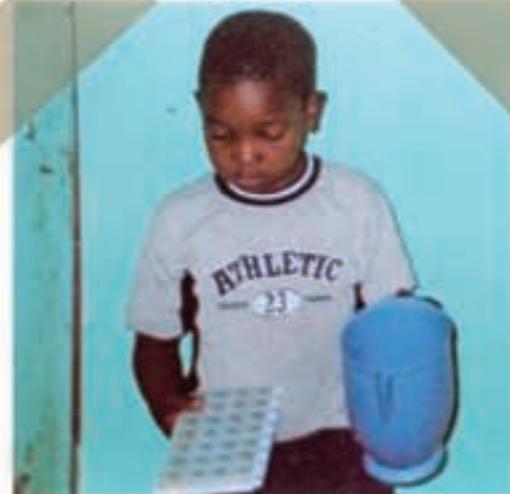


Ask a friend or family member to remind you.

Take your pills at the start of the same television or radio program each day.

Take your pills before you drive the cattle out of the kraal and after you bring them back.

Set a cell phone alarm.



BABALWA

Babalwa's story

My name is Babalwa and I stay in Khayelitsha. When I was young I was staying with my mother. Then my father passed away, and my mom got married to another guy. Then my uncle raped me and infected me with HIV.

I didn't have any information about HIV at that time. My mother passed away, and I started getting opportunistic infections. I came to the clinic regularly and I had to miss school.

I went to the Sisters of Mercy home for children and stayed there. They take good care of me. I started TB treatment, and ARVs, and joined a support group. Now I am back to school.

In 2002, I was asked to speak with Mr Mandela. I disclosed my status to him, and told him about how they treat me in my community. I was always telling myself I must not die until I meet Mr Mandela and go in an aeroplane. Mr Mandela gave me a big hug, like in all of my dreams.

Now I stay with a family and they treat me like their own.



Children talk about having HIV

I have told many people in my community about my status. Here people are well educated and there is no stigma. Many girls in my community are also HIV positive and we do things together – like dancing.

**HIV
POSITIVE**

When I disclose to people, I say that HIV is the same as the flu, or TB. You shouldn't feel like your life is finished if you have HIV.



**HIV
POSITIVE**

We love each other in my area, but they don't speak about HIV. I am not open to my friends yet. I am not ready. I have told some. My friends, they feel sorry about me. That makes me cry.

**HIV
POSITIVE**

When I learned that I had HIV, I told my sister and my cousin when I returned from the clinic. They said nothing. Now I have disclosed to everyone in my family.

**HIV
POSITIVE**

Talking about HIV? I don't think it's hard. You must first joke. After that you get to a point, ask a question, have the power to answer it. It depends how you feel.

**HIV
POSITIVE**

Sometimes my friends laugh, and I say that HIV is not a joke. It is there for us.



There are a lot of people who know my status, but I didn't tell them myself. They saw me taking pills. They haven't asked me any questions.

**HIV
POSITIVE**

If I am HIV positive, I must tell someone. If I am living with that thing on my own, I will suffer. That thing will eat me. If you can talk about it, you feel better.

**HIV
POSITIVE**

I spoke to my children about disclosure. My girl has disclosed to her friends. She tells them to get tested. My boy is shy, and does not want to disclose. I tell him that it is his choice. No one will see if you do not tell them.



Who would you like to disclose to?

A large, empty white rectangular box for writing, located on page 50.



What would you say?

A large, empty white rectangular box for writing, located on page 51.

HIV and discrimination

In some places, people with HIV are treated differently because of their status.

This is called discrimination. It is not fair and it is not right. Usually it is done by people who do not understand HIV, and this makes them afraid.

“My auntie told my friends I was HIV positive. Sometimes my uncle, he says that I am a wizard, I am spreading the disease. I am trying not to listen to him but sometimes it’s too hard.”

– Babalwa

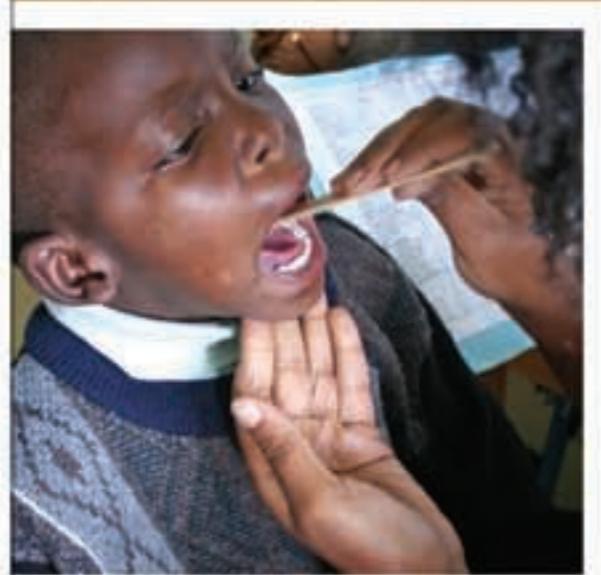
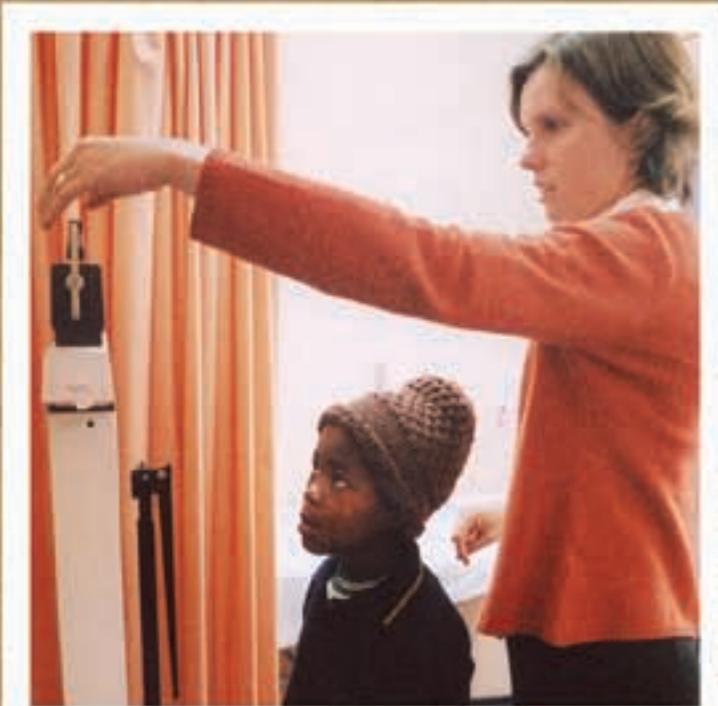
If someone treats you badly because of your status, tell your caregiver or counsellor so that they can help you.



Has anyone ever treated you differently because of HIV?



What advice would you give Babalwa?
Who can she ask for help?



patient file

CONFIDENTIAL

My Clinic: _____

My Doctor: _____

My Nurse: _____

My Counsellor: _____

This part of the book can help me remember important information about **my health**.

I can ask a grown-up at home or at the clinic to **help me** fill in this file.

My everyday colouring book



Every day I will make a mark when I take my pills.

		S	M	T	W	T	F	S
		S	M	T	W	T	F	S
draw your pills here								
how do you feel today?								

Every day I will colour the doll to match how my body is feeling.

One week might look like this:

		✓	✓	✓	✓	✓	✓	✓
		✓	✓	X	✓	✓	✓	✓
draw your pills here								
how do you feel today?								

She forgot her tablets once.

When?

She had a running stomach.

When?

She had fever & sweating.

What day was the worst?

Tuesday she played ball.

Draw it!

Month: _____ Regimen: _____

		S	M	T	W	T	F	S
		S	M	T	W	T	F	S
<p>Draw your pills here </p> <p>How do you feel today? </p>								

		S	M	T	W	T	F	S
		S	M	T	W	T	F	S
<p>Draw your pills here </p> <p>How do you feel today? </p>								

Actual/expected = %compliance: / = %
(your nurse or doctor will fill this in)

		S	M	T	W	T	F	S
		S	M	T	W	T	F	S
<p>Draw your pills here </p> <p>How do you feel today? </p>								

		S	M	T	W	T	F	S
		S	M	T	W	T	F	S
<p>Draw your pills here </p> <p>How do you feel today? </p>								

Month: _____ Regimen: _____

		S	M	T	W	T	F	S
		S	M	T	W	T	F	S
Draw your pills here ↑								
How do you feel today? →								

		S	M	T	W	T	F	S
		S	M	T	W	T	F	S
Draw your pills here ↑								
How do you feel today? →								

Actual/expected = %compliance: / = %
(your nurse or doctor will fill this in)

		S	M	T	W	T	F	S
		S	M	T	W	T	F	S
Draw your pills here ↑								
How do you feel today? →								

		S	M	T	W	T	F	S
		S	M	T	W	T	F	S
Draw your pills here ↑								
How do you feel today? →								

My blood tests

When the nurse takes your blood, it is tested to find out how your body and HIV are acting. We call these tests “labs”.

Two very important labs are CD4 count and viral load count.



We want a **CD4** number that is getting **biggerbiggerbiggerbigger**

This means your body is getting stronger.

date									
CD4									

We want a **viral load** number that is getting

smallersmaller smaller smaller

This means HIV is getting weaker.

date									
viral load									

Viral load undetectable, or **LDL**, means all the HIV in your body is sleeping.

Great job!



Be a Star!

Adherence percentage (or %) is a measure of how often you take all of your medicines.

100 per cent (%) means you took all of your medicines every day.

For 10 per cent (%), colour in one box.

For 70 per cent (%), colour in 7 boxes.

For 100 per cent (%), colour in all the boxes and the star.

You are a star!

100%

90%

80%

70%

60%

50%

40%

30%

20%

10%

Months:

1

2

3

4

5

6

7

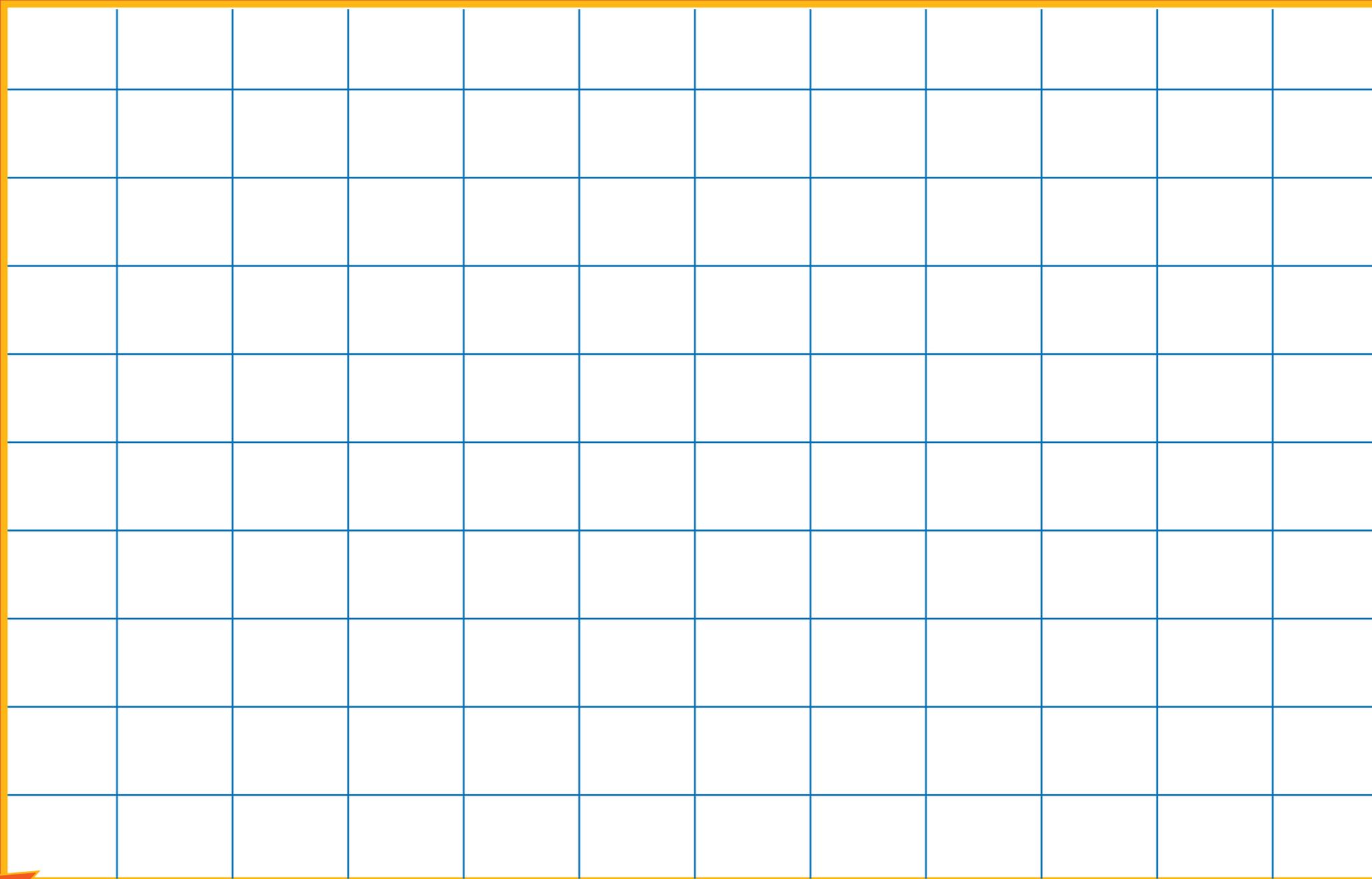
8

9

10

11

12



How many months of stars do you have?

Keep a record of clinic visits:



date	height	weight	notes and instructions	next visit



date	height	weight	notes and instructions	next visit





Your life is **big** but this book is **small**.

It does not have space to hold all of your words, drawings, ideas and information.

Don't worry!
When this book gets filled up, you can make another book.

CLINIC BOOK

Draw a new adherence calendar. Keep a list of your labs. Write down questions you have for your clinic doctors and nurses. Write down their instructions.

JOURNAL

What have you done today? What have you thought about? What have you remembered? What have you imagined?

FUN BOOK

Draw pictures. Make up stories or comics. Write poems or songs. Play games, write notes or scribble.

Follow the steps on the next 2 pages to put your books together. You won't need to buy any materials, but you will need to find them.



Look out for paper that only has printing or writing on one side.

Find posters or magazines, string, rubber bands, and small sticks.



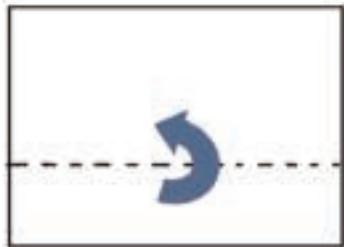
How to make **your** book

Follow the steps on **THIS SIDE** first. They will teach you how to make the inside part of the book.

1

Then choose how you will bind (or hold) your pages together: by sewing or by a stick and rubber band. Follow those instructions on the **NEXT PAGE**.

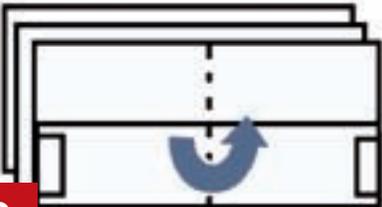
2



If you want pockets in your book, it is best to make them from a tough piece of paper, such as pages from a calendar, a poster, a magazine cover. Fold the bottom edge up, but not all the way to the top.



Paste or tape the sides closed (a spoonful of flour and two spoonfuls of water makes a good paste).



Make a paper pile. You can use all plain paper or all pockets or some of both. All the pages must be the same size. Fold the pages in half sideways.

sewing binding

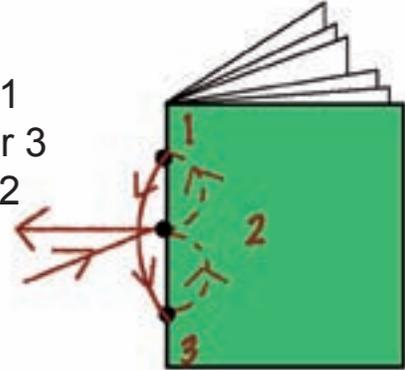
You will need:
needle and string
or wool

Make 3 holes in your pages, exactly on the middle fold line. Thread your needle.



Sew your pages together:

- in through number 2
- up and out through number 1
- down and in through number 3
- up and out through number 2



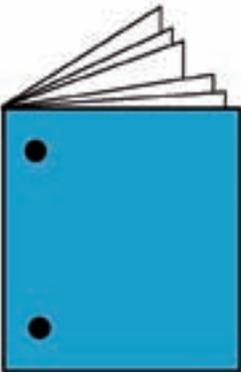
Tie the two ends of the string together.

stick and rubber band binding

You will need:
1 stick as tall as the book;
1 rubber band

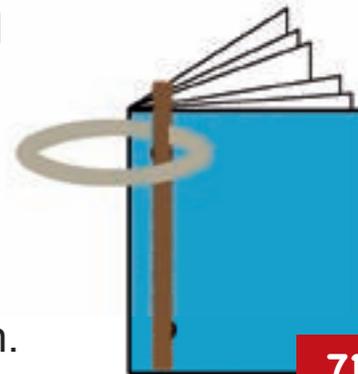
Make two holes in the pages:

- 2 fingers in from the fold.
- 2 fingers away from the top and bottom edges.



Place the stick on top of the holes:

- Wrap the rubber band around the stick.
- Poke the rubber band through the top hole.
- Pull it out through the bottom hole.
- Wrap it around the stick again.



We hope you have enjoyed your book.

If you would like to read more about living with HIV, try these books:

“Brenda Has a Dragon in Her Blood” by Hijltje Vink published by Garamond Publishers / RKWO

Soul Buddyz – a series of books for children

“You and Your Child with HIV – Living Positively” by Children’s Rights Centre

Look in your local library for children’s books on health.



go well

REMEMBER

Knowledge is power. *Never* stop learning.



thank you

There will never be enough words to show our admiration and gratitude to the young people and their families who opened their lives, their homes, and their stories to us. We can only say that we are proud to know them, and give thanks for their honesty, generosity, and strength.

The Thabalaza family
The Tshwayo Family
The Bam Family
The Ngqamba Family
The Dlomo Family
The Ngcingolo Family
The Ntsiyana Family
The Poni Family

The Mgecwa Family
The Ncinci Family
The Nonguzela Family
The Mdingwa Family
The Mfolozi Family
The Mkutsha Family
The Faniso Family

The Mphambamiso Family
The Them bani Family
The Ngxoli Family
The Ncethani Family
The Dyanti Family
The Ngemtu Family
The Mpangena Family

And all the other families living positively across South Africa.

Tying these words and images together, and producing a book lovely enough to hold them, has been a work of creativity, commitment and love on the part of the following people:

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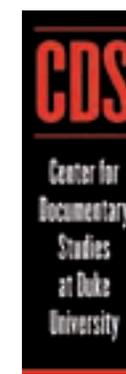
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Save the Children Sweden www.rb.se/eng

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The 10 Million Memory Project, especially Jonathan Morgan & family www.uct.ac.za/depts/cgc/Jonathan

Treatment Action Campaign staff, Khayelitsha and Lusikisiki www.tac.org.za





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We hope that you will be in touch with any questions, comments, suggestions and stories:



CHILDREN'S RIGHTS CENTRE

Children's Rights Centre
1st Floor, 480 Smith Street, Durban, South Africa 4001
Tel: (031) 307-6075; Fax: (031) 307-6074
Email: info@crc-sa.co.za
Web: www.crc-sa.co.za

