

BOOKLET SIX

My Daily Life and My Treatment



Why is this booklet important?

Even though living with HIV and taking ART can seem to have taken over your life, ordinary daily life goes on and you can find ways of enjoying it. You may need to also think about how being HIV positive fits with your beliefs too. This booklet will help you to think about how to fit your life and treatment together. Telling others about your HIV status, facing stigma, knowing your rights as a child, making sense (through your belief system) of why you are affected, and finding people to talk to, are all covered in this booklet.

We hope you will find ways to start thinking about important choices you may need to make about having sex, and how sexual relationships may affect your life.

Facts we must know:

- **ART is part of the daily life of a person who is taking it – even a child must have 100% adherence to their ART, meaning they should take all their pills at the right time in the right way DAILY.**
- **Daily activities can still be enjoyed when you are taking ART.**
- **Stigma and discrimination related to HIV must be stopped. They go against the Rights of the Child.**
- **Stigma means that when people find out that you are HIV positive, they think bad things about you. They discriminate against you by avoiding you and treating you unkindly.**



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Activities:

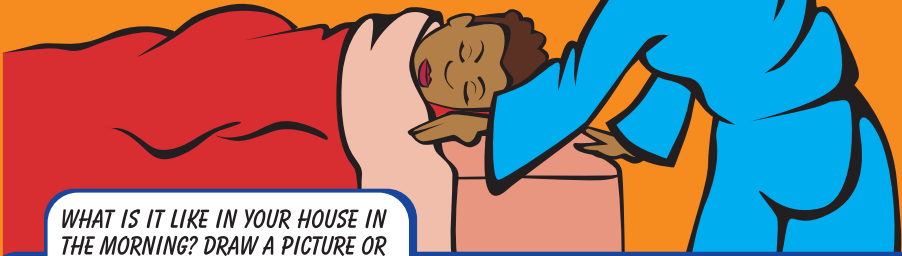
Let's have fun and share!

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Activity 1:

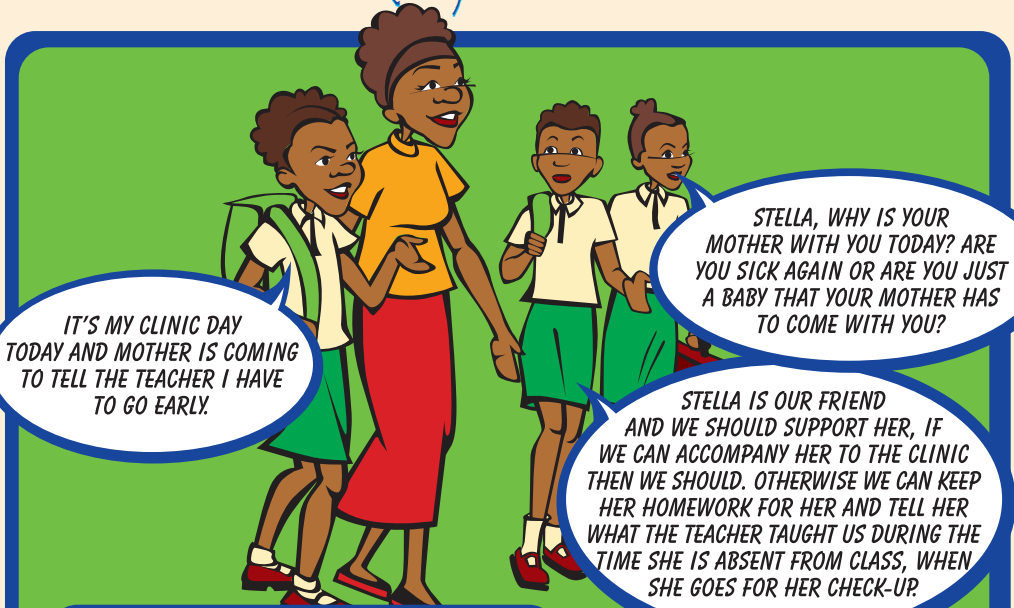
Mapping My Daily Life -
What Happens Each Day

WAKE UP STELLA. IT'S
TIME FOR SCHOOL. YOU NEED TO GET DRESSED,
WASH YOUR FACE, COMB YOUR HAIR AND
BRUSH YOUR TEETH. TELL ME WHEN YOU'VE
TAKEN YOUR TABLETS SO I CAN TICK YOUR
CALENDAR TOGETHER WITH YOU.



WHAT IS IT LIKE IN YOUR HOUSE IN
THE MORNING? DRAW A PICTURE OR
WRITE ABOUT IT BELOW.

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IT'S MY CLINIC DAY
TODAY AND MOTHER IS COMING
TO TELL THE TEACHER I HAVE
TO GO EARLY.

STELLA, WHY IS YOUR
MOTHER WITH YOU TODAY? ARE
YOU SICK AGAIN OR ARE YOU JUST
A BABY THAT YOUR MOTHER HAS
TO COME WITH YOU?

STELLA IS OUR FRIEND
AND WE SHOULD SUPPORT HER, IF
WE CAN ACCOMPANY HER TO THE CLINIC
THEN WE SHOULD. OTHERWISE WE CAN KEEP
HER HOMEWORK FOR HER AND TELL HER
WHAT THE TEACHER TAUGHT US DURING THE
TIME SHE IS ABSENT FROM CLASS, WHEN
SHE GOES FOR HER CHECK-UP.

NOT EVERYONE IS NICE WHEN YOU TELL THEM YOUR
HIV STATUS. CHOOSE CAREFULLY WHO NEEDS TO KNOW.
YOUR TREATMENT RELATED ACTIVITIES ARE NOW
PART OF YOUR DAILY LIFE.

LIST SOME OF THESE ACTIVITIES BELOW:
(ONE EXAMPLE IS YOUR REGULAR CHECKUPS TO THE
DOCTOR OR HEALTH CARE CENTRE).

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Activity 2:

Getting Rid of Stigma and Discrimination - I Don't Let it Get Me Down

SOME CHILDREN WHO ARE ON ART ARE TALKING ABOUT FEELINGS ABOUT STIGMA.

LOOK AT HER
UGLY THIN HAIR

HE IS THAT ONE
WHOSE FATHER HAS
BEEN WITH MANY
WOMEN

SHE IS ALWAYS
SICK AND CANNOT RUN
FAST ANYMORE, AND
IS ALWAYS MISSING
CLASSES

DON'T SPEAK TO
HER - YOU MIGHT CATCH
THAT ILLNESS

NO IT IS NOT NICE
TO BE CRUEL - THEY ARE OUR PEERS,
CHILDREN JUST LIKE US, IT IS
NOT THEIR FAULT

RED IS FOR THE BAD THINGS
THAT PEOPLE MAY SAY...
GREEN IS FOR THE GOOD THINGS
THAT WE MUST SAY AS WE
PREVENT STIGMATISATION OF HIV
POSITIVE CHILDREN

I DO NOT LIKE
IT WHEN PEOPLE POINT AT
ME AND MAKE FUN

DO YOU REALLY THINK SO?

BE STRONG AND KEEP
TAKING YOUR ART. YOU WILL SOON
BE HEALTHY AND THEN THEY'LL SEE
THAT THERE IS NOTHING WRONG
WITH BEING ON ART. THEY'LL SEE
THAT YOU CAN STILL GET GOOD
MARKS IN CLASS AND WIN
IN OUR GAMES

YES OF COURSE, I SAY
THIS BECAUSE THIS IS WHAT IT
HAS DONE FOR ME

IMAGINE IF IT WAS YOU
WHO IS BEING MADE FUN OF, WOULD
YOU LIKE IT? NO. SO LET'S BE NICE
AND KIND, THE WAY WE WOULD WANT
OTHERS TO BE TO US WHEN WE ARE
SICK AND UNWELL

REMEMBER THIS CAN
HAPPEN TO ANY OF US

I WILL TELL TEACHER.
SHE TOLD US NOT TO USE THOSE KINDS
OF WORDS. EVERY CHILD HAS A RIGHT
TO ENJOY LIFE -WHETHER THEY ARE SICK
OR NOT, WHETHER THEY ARE WEARING
NICE CLOTHES OR NOT

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Do these kinds of things happen at your school too? You can help educate your school mates. How about suggesting to your teacher that you perform some dramas, song or poem about this? Share your suggestion for the drama, poem or song here...



Suggest 3 scenes similar to the ones at Stella's school but with your own ideas too. Do role plays on these scenes and swap roles – some actors will play the role of :

- A 'stigmatising' child who is saying bad things about the one who is acting as HIV positive
- A child who is HIV positive and hears the;
 1. bad things being said to them or about them, and then;
 2. also gets to hear the good / supportive things being said about them and to them
- A 'supportive' child who is saying good and supportive things about the person who is HIV positive

Now swap roles, so that after a few role plays each of you has been in one of the three different characters – this way you will feel what it is like in the different situations.

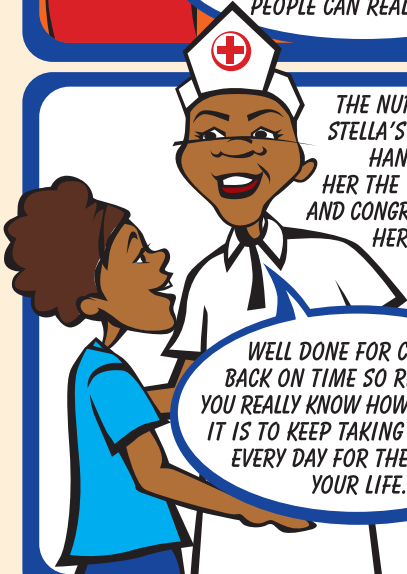
YOU SEE IT DOES NOT FEEL GOOD SAYING BAD THINGS - OR HAVE OTHERS SAY BAD THINGS ABOUT YOU OR TO YOU, YET **IT FEELS VERY GOOD** WHEN YOU SAY GOOD THINGS TO SOMEONE OR HEAR SOMEONE SAYING SUPPORTIVE THINGS ABOUT YOU - DOES IT NOT?

THANK YOU FOR COMING; IT IS MUCH BETTER IF I KNOW ABOUT THE HIV STATUS OF THE CHILDREN. THEN I UNDERSTAND IF THEIR WORK IS NOT GOOD OR THEY ARE TIRED IN CLASS. I CAN ALSO WATCH OUT FOR TEASING AND MAKE SURE THEY ARE NOT STIGMATIZED. I CAN GIVE THEM EXTRA HELP IN CLASS WHEN THEY ARE ILL. CHILDREN HAVE A RIGHT TO EDUCATION WHETHER THEY ARE HIV POSITIVE OR NOT.



TRUSTING PEOPLE TO TELL ABOUT YOUR HIV STATUS IS ALWAYS DIFFICULT, BUT TELLING THE RIGHT PEOPLE CAN REALLY HELP.

THE NURSE AT STELLA'S CLINIC HANDS HER THE TABLETS AND CONGRATULATES HER...



WELL DONE FOR COMING BACK ON TIME SO REGULARLY. YOU REALLY KNOW HOW IMPORTANT IT IS TO KEEP TAKING YOUR PILLS EVERY DAY FOR THE REST OF YOUR LIFE.

A Activity 3: Sharing, and Open Discussions, will Reduce Stigmatizing Behaviour

- The more a problem is talked about the lesser the problem becomes...
- The more information is shared about an issue the less ignorance there is around that issue...
- And eventually less stigmatization of those who are HIV positive!

Sometimes it helps for boys to talk with other boys, and girls to talk to other girls, about issues that concern them relating to being HIV positive and being on ART, and sharing facts with each other.

When boys talk to boys and girls talk to girls they may be more open about their discussions and help each other better as they understand their problems.

But it is also important for boys and girls to talk together as well... so that they inform one another about what worries them – as a girl and as a boy. They need to share what makes them stronger in coping with HIV related stigma, and how together – as boys and girls - they can prevent stigmatization of their peers who are HIV positive or on ART.

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Activity 4:

Share Daily Problems You
Can Have When on ART

STELLA TALKS TO THE NURSE AT THE CLINIC
ABOUT SOME PROBLEMS SHE IS FACING...

HOW HAVE YOU
BEEN SINCE I LAST SAW YOU?

I AM OK.
I HAVE BEEN TRYING TO TAKE MY
MEDICINE AS YOU TOLD ME BUT I
HAVE BEEN HAVING THE FOLLOWING
PROBLEMS:-

YOU HAVE BEEN A
VERY GOOD GIRL TO KEEP TAKING
YOUR MEDICINE. KEEP IT UP..
I'LL HELP YOU WITH
YOUR PROBLEMS.

MY FIRST PROBLEM IS:-
SOMETIMES WHEN IT IS TIME FOR
MY MEDICINE I WILL STILL BE IN
CLASS AND WILL NOT HAVE EATEN.
AND WHEN I TAKE THE MEDICINE
I FEEL LIKE VOMITING. WHAT
DO I DO?

CARRY SOME FOOD WITH
YOU ALWAYS, SO THAT YOU EAT
BEFORE TAKING THE MEDICINE. THIS
WILL HELP WITH THE NAUSEA AND
VOMITING. GINGER TEA, OR JUST
CHEWING GINGER, WILL HELP
YOU TOO.

MY SECOND PROBLEM IS:-
I STILL SOMETIMES EXPERIENCE A
LOT OF PAIN IN MY BODY

FOR THE PAIN IN YOUR
BODY I WILL GIVE YOU SOME PAIN
KILLERS, BUT YOU SHOULD NOT STOP
YOUR ART. IF IT CONTINUES, PLEASE
COME AND SEE ME AGAIN.

MY THIRD PROBLEM IS:-
I DON'T REALLY FEEL
LIKE CONTINUING WITH THE
MEDICATION, BUT MOTHER INSISTS
THAT I MUST TAKE THEM
EVERY DAY.

WHAT YOU ARE EXPERIENCING
IS CALLED 'PILL FATIGUE'. I SUGGEST
YOU GET A TREATMENT BUDDY TO HELP
YOU. THIS COULD BE YOUR FRIEND AT
SCHOOL, OR SOMEONE IN YOUR FAMILY.
COME TOGETHER NEXT TIME I SEE
YOU, SO THAT I CAN ADVISE
YOU BOTH ON ART.

WRITE DOWN, ON A SEPARATE PIECE OF PAPER, ANY PROBLEMS YOU FACE. THEN TAKE THIS WITH YOU TO THE CLINIC AND SHARE THEM WITH YOUR DOCTOR OR NURSE. YOU COULD ALSO ASK YOUR TEACHER, SUPPORT GROUP, FRIENDS, FAMILY, AND YOUR TREATMENT BUDDY TO HELP YOU FIND THE SOLUTIONS.

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EAT RIGHT AND
DON'T MISS MEAL TIMES.

YES THANKS GRANDPA,
AND THESE DAYS I MAKE
SURE I DO NOT MISS OUR
MEALTIMES, AND COME HOME
EARLY FROM SOCCER PRACTICE,
BECAUSE I NEED THE GOOD
FOOD AND ENOUGH FOOD

EAT UP EVERYONE.
DON'T YOU KNOW THAT
GOOD FOOD KEEPS ALL OF
US HEALTHY?

YES AND THAT IS
WHY YOUR MEDICINES ARE
WORKING WELL NOW AND YOU
ARE GETTING STRONGER

PRACTICING POSITIVE
PREVENTION – SAFE SEX TO
PREVENT HIV RE-INFECTION
WHILE ON ART

BEN AND HIS SISTER KATHY
TALK ABOUT A GIRL AND BOY IN
THEIR SCHOOL...

1
DID YOU SEE SIMBA
AND CHARITY AT
SCHOOL TODAY?

3
IT DOESN'T HAVE
TO BE LIKE THAT. YOU DON'T
ALWAYS HAVE TO SAY YES TO SEX
BECAUSE YOU LIKE SOMEONE

2
YES, THEY WERE
GETTING REALLY CLOSE. SHE
HAD BETTER WATCH OUT OR SHE
WILL BE PREGNANT SOON

5
IT IS HARD FOR GIRLS
TOO, BUT WE CAN ALL BE
RESPONSIBLE, ESPECIALLY WITH
THE RISK OF BEING INFECTED
WITH HIV

4
BUT IT IS HARD TO SAY NO,
ESPECIALLY FOR THE BOY AS IT
CAN BE HARD FOR HIM TO
ABSTAIN FROM SEX

6
YES, I THINK THEY SHOULD BE
CONCENTRATING ON THEIR EDUCATION
FOR NOW, AND NOT THINKING OF SEX
YET. THEY CAN STILL LOVE EACH OTHER
WITHOUT HAVING SEX

7
HAVING SEX TOO
YOUNG COULD REALLY MESS
UP MY DREAM OF BECOMING A TAILOR!
ALSO, BEING HIV POSITIVE MEANS WHEN
I CHOOSE TO HAVE SEX, I MUST NOT LET
MYSELF GET RE-INFECTED WITH HIV AND
NOT INFECT MY PARTNER. SO I MUST
WAIT UNTIL I AM OLD ENOUGH AND
HAVE FINISHED SCHOOL

8
YES, THAT IS CALLED
'POSITIVE PREVENTION'! SO PRACTICING
SAFE SEX IS IMPORTANT FOR EVERYONE, AND
INVOLVES SAYING 'NO' TO SEX TOO

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Activity 5:

What Else Can Happen
in Your Day?

YOU MAY HAVE MANY QUESTIONS THAT COME TO YOUR MIND. SOMETIMES WHEN WE ARE UNHAPPY, WE BLAME GOD.

THESE ARE SOME SPIRITUAL QUESTIONS THAT WE ASK WHEN WE GET ILL:

WHY ME?

WHAT DID I DO WRONG?

WHERE IS GOD?

WHY DID GOD LET ME GET SICK?

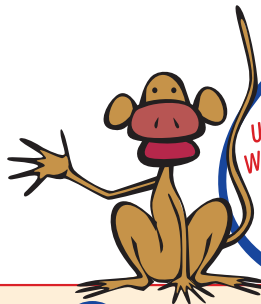
**WHAT IS THE MEANING OF
THIS LIFE?**

WHAT HAPPENS WHEN I DIE?

IT IS TIME FOR
EVENING PRAYERS.



I AM GRATEFUL TO GOD
THAT I HAVE A SUPPORTIVE FAMILY
AND I CAN GET ART AND STAY HEALTHY
AND ATTEND SCHOOL AND HAVE
FUN LIKE OTHER CHILDREN
MY AGE



ASK AN ADULT TO HELP YOU
UNDERSTAND THESE QUESTIONS...
WHAT ANSWERS CAN YOU GIVE TO SOME
OF THESE QUESTIONS?
WRITE THEM HERE, AS WELL AS YOUR
OWN QUESTIONS, AND DISCUSS
THESE WITH OTHERS.

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MEETING AND TALKING WITH
OTHERS HELPS YOU TO DEAL WITH
YOUR OWN DAILY PROBLEMS.
YOU ARE NOT ALONE!



I GO TO THIS GROUP TWICE
A WEEK WHICH IS REALLY HELPING ME. I CAN TALK
ABOUT MY CONCERNS AND THE OTHER CHILDREN HELP
ME TO FIND SOLUTIONS. BUT TODAY I AM GOING TO HELP
LINDIWE. SHE SHARED HER PROBLEM IN THE LAST GROUP
SESSION AND I HAVE BEEN THINKING ABOUT A SOLUTION
- THIS WEEK I SHALL OFFER HER MY SUPPORT



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Advocacy sticker 3:

Message:
ANSWER ME!
I have a **RIGHT**
to know...



You can stick it
somewhere, such as on
a school bag,
a door, a wall,
a parent's car



Look for this sticker
in your pack!

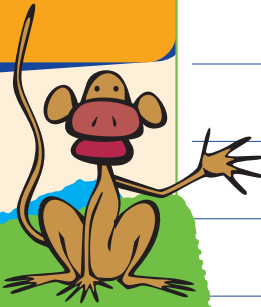
Let's remember

- Every child has the right to education, to leisure and to enjoy life.
- Boys and girls who like and love each other can do many things together - and avoid having sex too early - like playing games, reading books, taking walks together, helping needy people in their community and even watching movies.
- The more you read and the more you share and discuss, the more you will be able to avoid stigmatizing and discriminating people who are living with HIV. **AND** you can help others to stop stigmatising.
- Good nutrition every day, taking ART medicines everyday, practising 'positive prevention' if you are a teenager, and keeping active, will help your ART to work better for you.
- Telling people about your HIV status can help them understand what you are going through. Remember though, to carefully choose who you tell.

*You have a right to education, to leisure,
and to enjoy life... play games, read books,
watch movies, take walks...
enjoy your life... and help another
child to enjoy theirs too!*

*You can make a
difference!*

- Speak positively about people with HIV, and support them. Anyone can get infected with HIV.
- Don't gossip, just as you would not like anyone to gossip or say bad things about you.
- Stand up for someone who is being bullied because they are taking ART or they are HIV positive.
- Ask people what scares them about HIV. This gives you a chance to share correct information.



Try this later...

- ...at home or at school
- Think about how your beliefs help you. Are you like Stella, who prays to God, or do you do things differently?
- Talk with your family about how support groups have helped you. Perhaps they too can find support in that way.

All Children Have Rights



**ALL CHILDREN NEED TO PLAY –
A CHILD HAS A RIGHT TO LEISURE**

I AM GETTING MUCH
BETTER MARKS NOW I
AM ON ART

**WHAT OTHER RIGHTS DO CHILDREN WHO
ARE HIV POSITIVE HAVE? LIST THEM AND
DISCUSS THEM WITH OTHERS. ALSO
DISCUSS WHY HELPING CHILDREN WHO
ARE HIV POSITIVE TO GET THEIR RIGHTS
IS SO IMPORTANT**



YES AND YOU ARE LUCKY
YOUR CLASSMATES AND
TEACHER SUPPORT YOU
SO MUCH

**ALL CHILDREN HAVE
A RIGHT TO EDUCATION**

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