

BOOKLET THREE

My Family and My Treatment



Why is this booklet important?

We all belong to families, even if we aren't all together any more. Our family loves and cares and provides for us, and helps us when we are sick. And we do the same for other members of our family too!

This booklet will help you to think about everything to do with your family, including relationships, illness, death, things you do together and happy times in the past. Knowing the ways of our families can give us strength to face our daily lives. It will also help you to think of ways in which members of your family are involved with your HIV treatment and how they help you take it better.

Facts we must know:

- Every family is different. There are good things about every family, and you need to find those positive things about your family.
- Different family members can support a child on ART and help them to live positively with HIV. Children are entitled to this support – it is their **RIGHT**.



My Family and My Treatment

THIS BOOKLET TELLS THE STORY OF A YOUNG GIRL AGED 9 YEARS, CALLED PALESA, WHO IS HIV POSITIVE AND HAS HAD TO START TAKING ARVS. THIS BOOKLET SHOWS HER FAMILY AND SOME OF THE EVENTS THAT HAVE HAPPENED IN THEIR LIVES.

WE WANT TO FIND OUT ABOUT YOUR FAMILY TOO.

HERE IS A PICTURE OF ALL MY FAMILY. I LOVE MY FAMILY VERY MUCH



My Family and My Treatment

A

Activities:

Let's have fun and share!

A

Activity 1:

My Family

You can draw your family here.

You may wish to do this on a separate piece of paper.



Find a friend to share your drawing with. Take turns to talk about your families, their names and ages. Tell us about those who have died too. Think about ways your family is similar to Palesa's.

In what ways is it different?

*Remember:
When you are the listener,
sit quietly while the other
person talks and listen
carefully.*



Activity 2: Family Memories

Draw a picture or write a story or poem about you doing something you enjoy with a person in your family who loves and cares for you. Show it to that person. You could also draw a memory of a happy time you shared with someone who has died. Show it to someone who cares for you now.

This way you can begin to identify which members of your family can support you to:-

- go for an HIV test.
- go for counselling and check-ups at the clinic.
- take your ARVs.
- encourage you to stay healthy.
- get more information about HIV issues.
- feel loved and cared for.
- catch up with your school work.

A **Activity 3:**
Getting an HIV Test and
Support from Parents

Read the cartoon and think about what it was like for Palesa to find out about her HIV status.



I REMEMBER WHEN I FIRST FOUND OUT I WAS HIV POSITIVE

HERE IS PALESA REMEMBERING BACK TO THAT TIME. HER FATHER WAS STILL ALIVE THEN.

1 PALESA, HAVE YOU EVER HEARD OF HIV? TELL ME WHAT YOU KNOW ABOUT HIV.

2 AT SCHOOL THE TEACHER SAID IT IS A VIRUS IN YOUR BLOOD THAT MAKES YOU SICK AND YOU CAN NEVER GET IT OUT OF YOUR BLOOD. SHE SAID IT MAKES YOUR BODY WEAK AND SO YOU GET SICK A LOT.

5 EXACTLY, YOU ARE RIGHT. YOU ARE A CLEVER GIRL. THAT IS TRUE, SO IF YOUR HIV TEST IS POSITIVE WE WILL KNOW WHETHER YOU SHOULD BEGIN TAKING ART AND WHEN YOU SHOULD BEGIN TAKING IT.

6 YES, I WOULD LIKE TO KNOW, SO THAT IF I NEED ART I BEGIN TAKING IT SOONER AND ENJOY MY SCHOOL AND PLAYING WITH MY FRIENDS AGAIN.

3 THAT'S RIGHT PALESA. YOU KNOW ALL ABOUT IT. YOU HAVE BEEN GETTING SICK A LOT LATELY AND DADDY AND I ARE WORRIED THAT YOU MIGHT BE HIV POSITIVE. WE THINK YOU NEED A BLOOD TEST SO THAT WE CAN KNOW IF YOU HAVE HIV. WHY DO YOU THINK TAKING THE HIV TEST IS IMPORTANT?

4 WELL, OUR TEACHER INVITED A NURSE FROM THE CLINIC WHO TOLD US THAT THERE IS SOME TREATMENT CALLED ANTIRETROVIRAL TREATMENT THAT CAN BE TAKEN TO MAKE SOMEONE WITH HIV FEEL BETTER. ON ART A PERSON IS ABLE TO LIVE LIFE HAPPILY AND WITH STRONGER HEALTH.

MOTHER TOOK ME TO THE CLINIC WHERE I SAW A COUNSELLOR. THEY CALLED THAT PRE-TEST COUNSELLING. WE ALL DECIDED I SHOULD HAVE A TEST. I WAS TOLD THAT THERE IS A LOT THAT CAN HELP NOWADAYS IF YOU ARE HIV POSITIVE. AS WELL AS TAKING ART WE CAN LIVE POSITIVELY BY EATING WELL AND DOING EVERY DAY THINGS LIKE PLAYING WITH FRIENDS. THEN I REMEMBER MAMA AND DADDY CALLED ME TO TALK TO THEM

YOU REMEMBER, PALESA, WHEN YOU WENT TO THE CLINIC FOR AN HIV TEST? WELL, YOUR TEST HAS COME BACK POSITIVE LIKE YOUR FATHER AND ME WHICH MEANS YOU HAVE THE VIRUS IN YOUR BLOOD. WE WILL ALL GO TO THE CLINIC TO LEARN MORE ABOUT HOW WE CAN STAY AS HEALTHY AS POSSIBLE.

Three starburst shapes for writing. The top one is blue, the middle one is white, and the bottom one is orange. Each starburst contains several horizontal lines for text.

A

Activity 4:
Sharing Your HIV Status

Perhaps you are also HIV positive. If you are, who told you about you having the virus? Who have you told that you are HIV positive? **Write their names in the stars and tell us why you chose them?**

Think about anyone else you would like to know that you are HIV positive. Who has helped you most since knowing that you are HIV positive? **Write their names and what they did that helped you in the flowers.**

My Family and My Treatment

2

NOW THAT YOU ARE ON THE SOCCER TEAM AT SCHOOL AND NEED TO TRAVEL TO OTHER SCHOOLS TO COMPETE, I THINK WE NEED TO TELL YOUR TEACHER THAT YOU ARE ON ART. HE CAN HELP YOU TO REMEMBER TO TAKE YOUR PILLS

I KNOW I DO NEED TEACHER'S HELP, BUT WHAT IF HE TELLS THE OTHER PUPILS? THE COUNSELLOR SAID I SHOULD THINK CAREFULLY ABOUT WHO I TELL.

THAT IS TRUE. THERE IS ALWAYS THE RISK THAT YOUR TEACHER WILL NOT REACT WELL TO THE INFORMATION.

PEOPLE, EVEN TEACHERS, DON'T KNOW EVERYTHING ABOUT HIV AND ARE OFTEN AFRAID THEY WILL CATCH IT JUST BY BEING WITH SOMEONE LIKE ME. AND THEY DON'T UNDERSTAND ABOUT ART. SOME EVEN SAY IT IS A BAD THING TO TAKE IT.

SO WE MUST EDUCATE THEM. I WILL COME WITH YOU TO SEE YOUR TEACHER AND TOGETHER WE WILL ASK FOR HIS HELP AND EXPLAIN ALL ABOUT THE MEDICINE AND ANYTHING ELSE HE NEEDS TO KNOW. WE WILL TELL HIM HOW IMPORTANT IT IS THAT HE KEEPS THIS INFORMATION CONFIDENTIAL.

WE WILL ALSO REMIND HIM OF THE IMPORTANT ROLE HE PLAYS AS A TEACHER IN FIGHTING STIGMA AND DISCRIMINATION. THANK YOU FOR HELPING ME FATHER.

THINK ABOUT THIS STORY AND PRACTICE IN YOUR HEAD HOW YOU WOULD TELL SOMEONE THAT YOU ARE HIV POSITIVE.

My Family and My Treatment

Why not get together with a few of your friends and **design a play**, or **put together a poem or song** that shows a few scenes of a father and son (who is on ART) discussing the need to disclose the son's HIV status to his school teacher. End the play or song or poem with the following questions to the audience or listeners...

“ What would you do in this situation - if you were the father and if you were the son ?”

“ What choices does one have when disclosing their HIV status ?”

“ What can be done to make disclosure easier? ”

This will encourage a lot of discussion and everyone will learn about better ways of handling disclosure of HIV status.

Here are some other things to think about:

Do you think it is easier if your mother or someone else in your family helps you tell others? Can a counselor help when you want to tell someone new about your HIV status?

How else can I share my HIV status?

Who can I share my HIV status with?

A

Activity 5:

Staying on ART to Live a Longer Life - Adherence is a MUST!

MAMA WAS SICK BUT IS BETTER NOW SINCE SHE STARTED TREATMENT. I ALSO HAVE TO TAKE THESE PILLS NOW. I WILL FEEL BETTER SOON AND THIS WILL HELP ME TO LIVE LONGER.



PALESA'S FATHER DIED. HERE SHE IS AT HER FATHER'S GRAVE TELLING HIM ABOUT HER LIFE NOW.

Has anyone in your family died? Perhaps there are also people in your family who are sick with HIV. Are any of them taking ART like Palesa and her mother?

Look at the 'adherence calendar' see how it has every day of the year in it. Each day when you take your pills, tick that you have taken them and write the time you took them. The times must be same for each day. If you forget to take your pills, also write that you forgot – and do not forget again!

Show your 'adherence calendar' to your parents and treatment buddy and your doctor on each of your check-up visits. Please do not forget.

For each month you remembered to take your pills at the correct time and every day of the month draw a picture for yourself...

...and show it off to anyone you like.

Note: If you are a treatment buddy for someone on ART share an 'adherence calendar' with them and encourage them to complete it. Draw a nice picture for them as they take their pills everyday and at the right time for a month. This will encourage them.



TOMORROW IS THE DAY FOR YOUR CHECK-UP WITH THE DOCTOR. I WILL COME WITH YOU IF YOU LIKE?

A

Activity 6: Family Support Is Important to Positive Living

PALESA'S FAMILY SUPPORT HER WITH HER TREATMENT. THIS HELPS HER LIVE POSITIVELY.
NUTRITIOUS FOOD KEEPS ME HEALTHY.

1



IT IS IMPORTANT TO TAKE PILLS EVERY DAY AT THE SAME TIME - THIS IS CALLED ADHERENCE. PALESA TAKES HER PILLS AFTER COOKING DINNER WITH HER MOM EVERY NIGHT.

2

PALESA'S SISTER MADE HER SOMETHING...

HERE IS A CALENDAR I MADE FOR YOU. YOU CAN TICK EACH DAY WHEN YOU TAKE YOUR PILLS. I WILL HELP YOU REMEMBER WHEN TO TAKE YOUR PILLS BY USING THE CLOCK OR YOUR FAVOURITE RADIO PROGRAM!

DON'T LET ANYTHING STOP YOU FROM TAKING YOUR PILLS - CREATE ADHERENCE METHODS

3

PALESA'S BROTHER WALKS HER HOME AFTER SCHOOL...

YES! I WOULD REALLY LIKE THAT, AND CAN WE TALK TO THE TEACHER AND ASK FOR PERMISSION FOR ME TO GO TO THE CHECK-UP?

YES AND I'LL ALSO TELL YOUR TEACHER THAT I'LL HELP YOU WITH THE HOMEWORK YOU MAY MISS DURING YOUR CHECK-UP, SO THAT YOU DON'T FALL BACK AND WILL STAY TOP OF YOUR CLASS

I ALWAYS GO FOR MY DOCTOR CHECK-UPS.

4

PALESA WORRIES WHEN GOING ON A SCHOOL TRIP

PEOPLE MIGHT TEASE ME WHEN THEY SEE ME TAKING MY ART.

WE CAN HIDE THE PILLS IN A SPECIAL POCKET I HAVE SEWN SO YOU CAN TAKE THEM WITH YOU.

Advocacy sticker 2:

Message:
Children on ART
do better with
family love and
support



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!

5

PALESA HAS LUNCH WITH HER
GRANDMOTHER REGULARLY

THE PILLS ARE SO
BITTER AND I DON'T WANT
TO TAKE THEM ANYMORE.
ANYWAY, I'M FEELING
BETTER NOW.

TRY TAKING THIS
HONEY WITH YOUR PILLS. IT IS
IMPORTANT TO KEEP ON TAKING
THE PILLS EVEN WHEN YOU
ARE FEELING BETTER

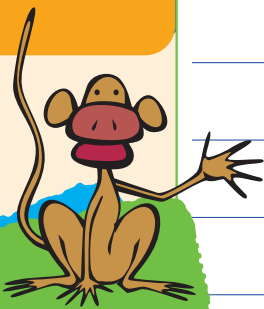
Let's remember...

Children on ART do better with family love and support. Children have the right to be on ART and have family support.

- Adherence to ART is VERY important – it will keep you healthy, help you do better at school, enjoy playing with your friends and prevent you from being sick or dying.
- Use an 'adherence calendar' to check how well you are doing in taking your pills at the right time and everyday.
- Support other children who are on ART to adhere to their treatment and to identify which of their family members will support them.

You can make a
difference!

- Share what you know about HIV and ART with your family. Do not be shy or afraid. Children have a lot to teach others – even their parents and teachers.
- Encourage family members of another child you know, who is on ART, to support that child.
- Help someone on ART to use an “adherence calendar”



Try this later...

- Write down all the reasons you love your family and display your list at home for everyone to see.
- Write down all the different ways your family members can support you to adhere to your treatment. You can also tell people directly.

A large rectangular area with a green border and horizontal blue lines, intended for writing notes or answers.

ISBN: 978-0-7974-3627-5

SaFAIDS:

17 BEVERIDGE ROAD, P O BOX A509, AVONDALE, HARARE, ZIMBABWE.

TEL: +263-4-336193/4. FAX: +263-4-336195.

EMAIL: info@safaids.org.zw WEB: www.safaids.org.zw



SaFAIDS Southern Africa
HIV and AIDS Information
Dissemination Service



DFID Department for
International
Development



Irish Aid
Government of Ireland
Bialtas na hÉireann



UNAIDS
Jointly funded by
UNAIDS
UNAIDS
UNAIDS
UNAIDS