

KAKANDE'S STORY



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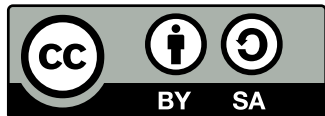
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UKaid
from the British people

THIS IS THE STORY OF A YOUNG UGANDAN BOY LIVING WITH HIV. KAKANDE IS NOT A REAL PERSON. HIS STORY IS BASED ON THE STORIES OF THE LIVES OF THE YOUNG PEOPLE LIVING WITH HIV WHO TOOK PART IN THE ARROW YOUNG LIVES RESEARCH PROJECT IN UGANDA AND ZIMBABWE.

THE AIM OF THE ARROW YOUNG LIVES PROJECT WAS TO FIND OUT HOW YOUNG PEOPLE BETWEEN THE AGES OF 11 AND 13 YEARS MANAGED BEING HIV-POSITIVE. WE INTERVIEWED 104 YOUNG PEOPLE, THEIR CARERS AND HEALTH WORKERS. SOME OF THE YOUNG PEOPLE WERE INTERVIEWED FOUR TIMES, OVER 18 MONTHS.

WE HOPE THIS STORY WILL HELP PEOPLE TO UNDERSTAND BETTER WHAT IT IS LIKE BEING A YOUNG PERSON LIVING WITH HIV.

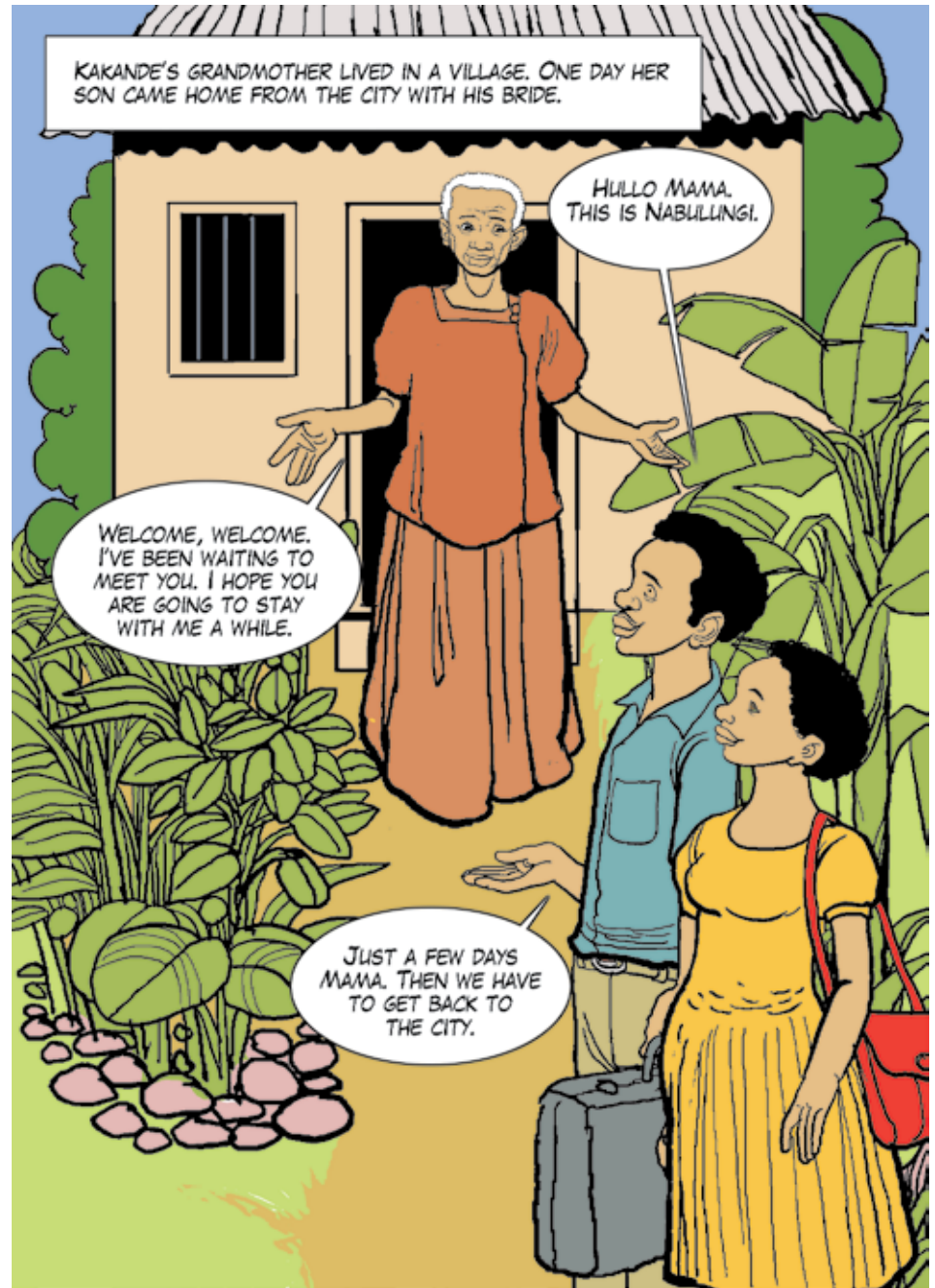
WE WOULD LIKE TO THANK THE CHILDREN WHO TOOK PART IN YOUNG LIVES, THEIR CARERS AND HEALTH CARE WORKERS. WE ARE GRATEFUL TO THE DEPARTMENT FOR INTERNATIONAL DEVELOPMENT (UK GOVERNMENT) FOR FUNDING AND OUR ORGANISATIONS: MEDICAL RESEARCH COUNCIL/UGANDA VIRUS RESEARCH INSTITUTE, JOINT CLINICAL RESEARCH CENTRE, BAYLOR UGANDA, LONDON SCHOOL OF HYGIENE AND TROPICAL MEDICINE AND THE MRC CLINICAL TRIALS UNIT AT UCL.



TODAY, KAKANDE IS A HAPPY TWELVE-YEAR OLD, BUT HE HAS BEEN THROUGH A LOT IN HIS YOUNG LIFE, AS A CHILD LIVING WITH HIV. HERE IS HIS STORY.



KAKANDE'S GRANDMOTHER LIVED IN A VILLAGE. ONE DAY HER SON CAME HOME FROM THE CITY WITH HIS BRIDE.



HULLO MAMA. THIS IS NABULLINGI.

WELCOME, WELCOME. I'VE BEEN WAITING TO MEET YOU. I HOPE YOU ARE GOING TO STAY WITH ME A WHILE.

JUST A FEW DAYS MAMA. THEN WE HAVE TO GET BACK TO THE CITY.



LATER THAT YEAR, GRANNY RECEIVED A LETTER FROM HER SON, GIVING HER SOME GOOD NEWS.

*Hullo Mama.
I hope you are well. We have some good news. Last week our son was born. We have named him Kakande...*



BUT TWO MONTHS LATER THE BEAUTIFUL DREAM WAS SHATTERED AND KAKANDE AND HIS FATHER CAME TO LIVE WITH HIS GRANDMOTHER.

OH MAMA, NABULLINGI WAS VERY SICK. SHE PASSED AWAY LAST WEEK. I DON'T KNOW WHAT TO DO. HOW WILL I LOOK AFTER KAKANDE? I DON'T FEEL VERY WELL MYSELF.

DON'T WORRY, SON. YOU AND KAKANDE COME AND LIVE WITH ME NOW. I WILL LOOK AFTER YOU. YOUR BROTHER'S CHILDREN, KIGO, SUNDAY AND NAMPIJJA ARE ALREADY HERE, KEEPING ME COMPANY.



WITHIN A FEW MONTHS KAKANDE'S FATHER BECAME VERY SICK AND DIED. GRANNY TOOK CARE OF HIM TILL THE END. SHE ALSO CARED FOR LITTLE KAKANDE WHO WAS ALWAYS SICK. WHEN HE WAS ABOUT FIVE YEARS OLD KAKANDE'S GRANDMOTHER TOOK HIM TO THE VILLAGE HEALTH CENTRE.

HE OFTEN HAS FEVER AND DIARRHEA AND HE IS NOT INTERESTED IN HIS FOOD. AND LOOK AT THE RASH ALL OVER HIS SKIN.

MY FRIENDS CALL ME GONYA BECAUSE MY SKIN IS ROUGH LIKE A CROCODILE'S.

I WILL PRESCRIBE SOME DRUGS AND YOU WILL FEEL BETTER.



THE DRUGS MADE KAKANDE FEEL BETTER, BUT NOT FOR LONG. THEN ONE DAY A NURSE FROM THEIR NEIGHBOURHOOD TOLD KAKANDE'S GRANDMOTHER TO TAKE HIM TO ANOTHER TOWN WHERE THERE WAS A BIG HOSPITAL. IN THIS HOSPITAL THERE WAS AN ORGANIZATION THAT COULD HELP HER GRANDSON.

OH GRANNY, THIS IS FUN. THE BUS IS GOING BUMPETY-BUMPETY-BUMP. WHEN I GROW UP I WILL TAKE YOU TO THE BUS-STOP ON A BICYCLE LIKE KIGO DID TODAY.

YES, KAKANDE THIS IS FUN, BUT MY OLD BONES ARE CREAKING! IT WILL TAKE US THREE HOURS TO GET TO THE HOSPITAL BUT IT IS ALL FOR THE GOOD.





KAKANDE FELT LEFT OUT AND UNHAPPY.

WHY ARE THEY TALKING ABOUT MY MOTHER? SHE DIED MANY YEARS AGO. WHAT'S THAT GOT TO DO WITH MY BEING SICK? AND WHY DOES THE MUSAWO NOT TALK TO ME? AFTER ALL, I AM THE ONE WHO IS SICK. SHE HAS NOT EVEN ASKED ME HOW I AM FEELING!



GRANNY CAME OUT AND TOOK KAKANDE TO THE LABORATORY FOR SOME TESTS. AN HOUR LATER...

GRANNY, DO COME IN. I HAVE GOT THE TEST RESULTS. KAKANDE, I NEED TO SPEAK TO YOUR GRANNY ALONE. COULD YOU PLEASE WAIT OUTSIDE?

WHY DOES THE MUSAWO WANT TO SPEAK TO GRANNY ALONE? WHAT ABOUT ME? WHY DO I ALWAYS HAVE TO WAIT OUTSIDE?





FINALLY, GRANNY CAME OUT OF THE HEALTH WORKER'S ROOM. THEY COLLECTED THE DRUGS FROM THE PHARMACY AND WENT HOME IN A BUS. BUT GRANNY WAS IN DEEP THOUGHT ALL THROUGH THE JOURNEY.

OH LOOK, GRANNY, LOOK ... THERE'S A BABY MONKEY ON THAT TREE. GRANNY, DON'T LOOK SO SAD. THESE DRUGS WILL SOON MAKE ME BETTER.



GRANNY MADE SURE THAT KAKANDE TOOK HIS DRUGS REGULARLY EVERY DAY.

KIGO, SUNDAY, NAMPIJJA, YOUR BROTHER KAKANDE IS SICK AND NEEDS TO TAKE HIS DRUGS REGULARLY. WHENEVER I AM AWAY I WOULD LIKE YOU TO REMIND HIM TO TAKE HIS DRUGS AT SEVEN IN THE EVENING AND MORNING. MAKE SURE HE DOESN'T MISS.

AS THEY NEARED THE END OF EACH MONTH, GRANNY TOOK KAKANDE BACK TO THE HOSPITAL FOR A REVIEW AND GOT MORE DRUGS.

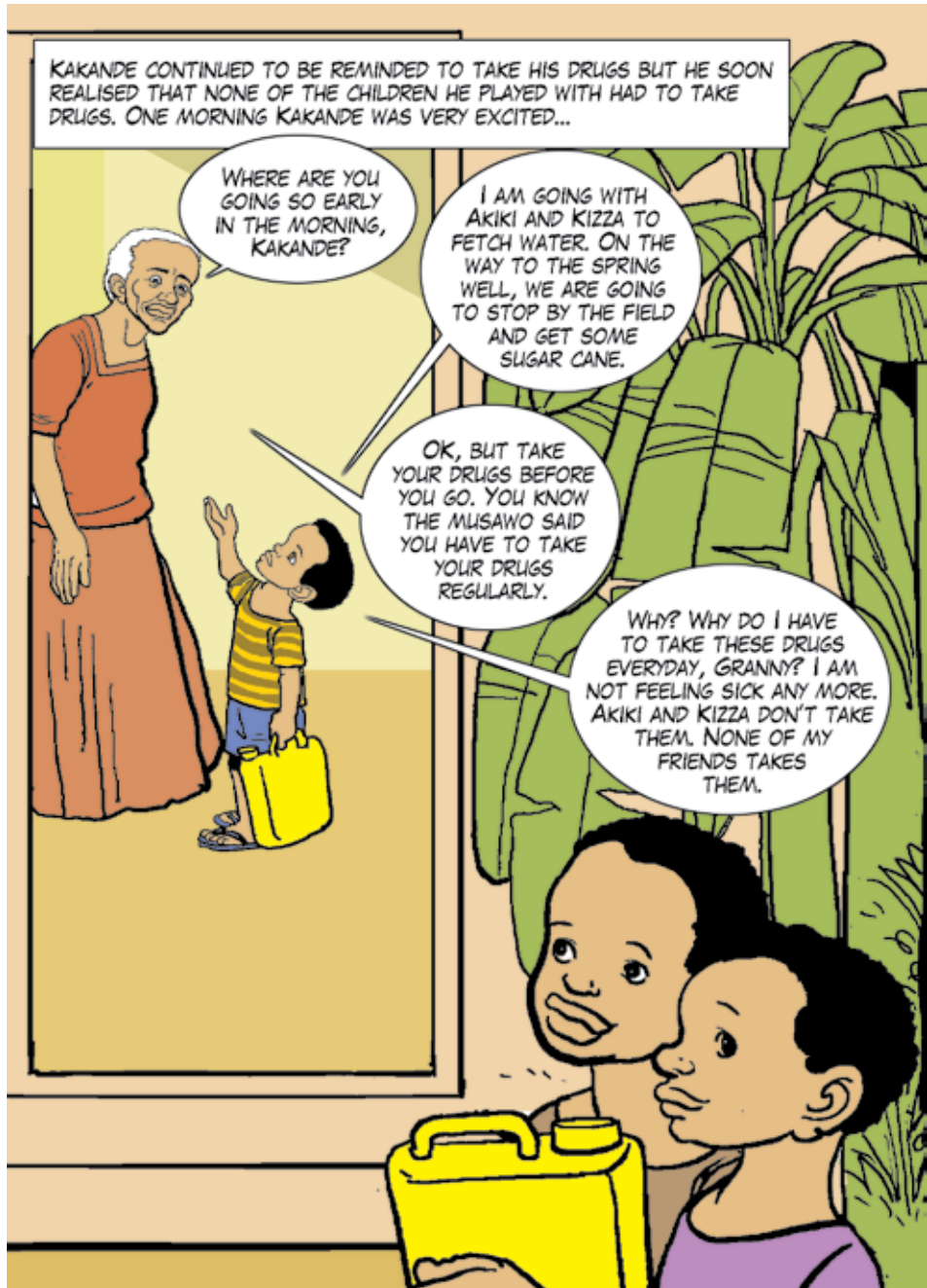
EVERY MONTH THEY GIVE ME THE SAME DRUGS AND I HAVE TO TAKE THEM EVERY DAY. WHY DO I HAVE TO WAKE UP EARLY, EVEN DURING SCHOOL HOLIDAYS, TO TAKE THESE DRUGS? AND WHY DO I HAVE TO TAKE THEM AGAIN AFTER SUPPER? I HATE THESE DRUGS, ESPECIALLY THE YELLOW ONE. AHHH! IT SMELLS AND TASTES REALLY BAD.



AS KAKANDE CONTINUED TO TAKE HIS DRUGS, HIS INFECTIONS CLEARED AND HE FELT NORMAL.

LOOK, GRANNY, ALL THAT ROUGH SKIN HAS GONE. MY FRIENDS DON'T CALL ME GONYA ANY MORE. THEY PLAY WITH ME IN SCHOOL AND I'M GOING WITH THEM TO GRAZE THE CATTLE TOMORROW.







BUT THERE WAS NO IMPROVEMENT
IN KAKANDE'S HEALTH.

KAKANDE, HAVE
YOU BEEN TAKING
YOUR DRUGS
EVERYDAY?

OF COURSE,
GRANNY.
DON'T YOU SEE THAT
THE TIN IS HALF
EMPTY?

GOOD BOY. OK,
NOW GET SOME REST.
YOU STILL HAVE
A FEVER.



GRANNY WAS GOOD AT REMINDING KAKANDE TO TAKE HIS DRUGS BUT SHE DID
NOT ACTUALLY MAKE SURE THAT HE WAS TAKING THEM.

THESE DRUGS ARE HORRIBLE.
I'M JUST GOING TO HIDE THEM.
GRANNY NEVER CHECKS TO SEE
IF I AM ACTUALLY TAKING THEM.
AND SHE NEVER LOOKS UNDER
MY MATTRESS, SO SHE
WON'T KNOW.





BUT KAKANDE DID NOT GET BETTER. TWO MONTHS LATER A HEALTH WORKER VISITED THEIR HOME TO CHECK ON HIS HEALTH.

HAS HE BEEN TAKING HIS DRUGS REGULARLY?

YES, HE HAS.

MAY I PLEASE SEE THE DRUGS?

HERE ARE HIS DRUGS. YOU CAN COUNT THEM.

WELL, THE NUMBERS ARE TALLYING SO HE MUST BE TAKING HIS DRUGS. BUT HIS LAST TEST SHOWED THAT HIS CD4 COUNT IS LOW. THAT MEANS THE DRUGS HE HAS BEEN TAKING ARE NO LONGER WORKING ON HIM. PLEASE TAKE HIM BACK TO THE CLINIC. THE DOCTOR WILL HAVE TO CHANGE HIS DRUGS.

KAKANDE'S GRANDMOTHER WAS VERY WORRIED AND STRESSED ABOUT HIS HEALTH. SHE OFTEN SPOKE ON THE PHONE TO HER DAUGHTER WHO LIVED IN THE CITY.

THANK YOU, I GOT THE MONEY YOU SENT ME FOR THIS MONTH'S NEEDS. I WILL BE BUYING KAKANDE'S UNIFORM AS WELL NEXT WEEK. BUT I AM VERY WORRIED ABOUT THE BOY. HE IS TAKING HIS DRUGS EVERY DAY SO I CANNOT UNDERSTAND WHY HE IS GETTING ILL.

THAT WOULD BE WONDERFUL.

WELL, MAMA, THE SCHOOL HOLIDAYS WILL BEGIN SOON. WHY DON'T I COME AND VISIT YOU? WE CAN TALK ABOUT KAKANDE'S PROBLEM AS WELL.

WHEN THE SCHOOL HOLIDAYS BEGAN, KAKANDE'S AUNT CAME TO VISIT HIS GRANNY. AUNT KNEW THAT KAKANDE HAD HIV.

MAMA, KAKANDE DOES NOT LOOK VERY HEALTHY. HOW IS HE DOING IN SCHOOL?

HERE IS HIS REPORT CARD. HE HAS NOT PERFORMED WELL IN CLASS. THE POOR BOY MISSED SO MANY DAYS DUE TO ILLNESS.

HMMM. THAT IS NOT GOOD. WHY DON'T I TAKE KAKANDE WITH ME TO THE CITY? MAYBE GOING TO A DIFFERENT PLACE WILL MAKE HIM FEEL BETTER.



KAKANDE WAS VERY HAPPY IN THE CITY, IN HIS AUNT'S HOUSE. HE COULD PLAY WITH HIS COUSINS, WATCH TELEVISION AND THERE WAS ALWAYS A LOT OF GOOD FOOD TO EAT.

EAT WELL, KAKANDE. I MADE YOUR FAVOURITE CHICKEN.

THANK YOU AUNT. I LOVE THE FOOD HERE.





ONE EVENING, DURING SUPPER, THERE WAS A HEALTH TALK SHOW ON TV. THEY WERE DISCUSSING HIV IN THE LOCAL LANGUAGE.

MEDIA REPORTS THAT WE HAVE RUN OUT OF ARVS ARE INCORRECT.

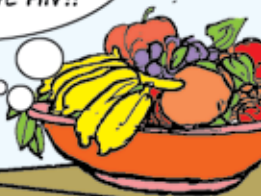
THESE ARE THE DIFFERENT DAILY DRUGS THAT ARE GIVEN TO CHILDREN WHO HAVE HIV. THIS ONE IS ALLVIA AND THIS IS EFAVERINZ... THEY ARE ALL AVAILABLE IN OUR NATIONAL MEDICAL STORES.

THOSE YELLOW PILLS ON THE CHART LOOK EXACTLY LIKE THE ONES I HAVE TO TAKE EVERY DAY. I MUST CHECK IF IT IS THE SAME DRUG THAT I HAVE.



KAKANDE WAS VERY WORRIED. AS SOON AS HE HAD FINISHED EATING, HE LEFT THE TABLE. HE DID NOT EVEN WAIT FOR EVERYONE TO FINISH.

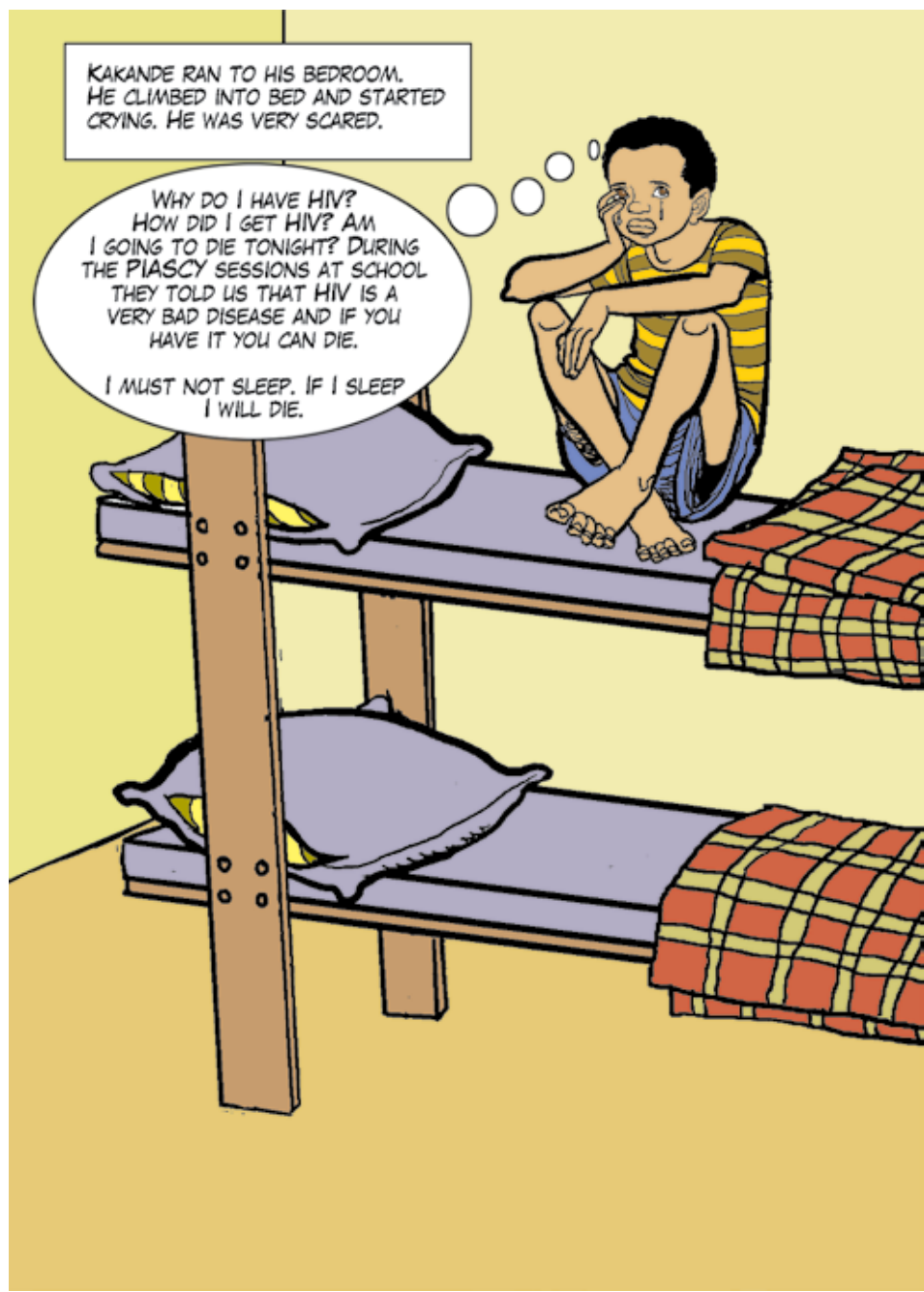
THEY ARE THE SAME DRUGS THAT I JUST SAW ON THE HIV CHART ON TV. DOES THAT MEAN... THAT MEANS... I HAVE HIV!!



KAKANDE RAN TO HIS BEDROOM. HE CLIMBED INTO BED AND STARTED CRYING. HE WAS VERY SCARED.

WHY DO I HAVE HIV?
HOW DID I GET HIV? AM
I GOING TO DIE TONIGHT? DURING
THE PIASCY SESSIONS AT SCHOOL
THEY TOLD US THAT HIV IS A
VERY BAD DISEASE AND IF YOU
HAVE IT YOU CAN DIE.

I MUST NOT SLEEP. IF I SLEEP
I WILL DIE.



KAKANDE COULD NOT SLEEP. SO MANY THOUGHTS AND QUESTIONS WERE GOING ROUND AND ROUND IN HIS HEAD.

WHOM CAN I ASK? GRANNY
MIGHT BEAT ME IF I ASK HER. AUNT
MAY BE UPSET THAT I WAS WATCHING TV
WHILE EATING. WHAT IF SHE REFUSES TO
BRING ME BACK TO THE CITY AGAIN? MY
COUSINS ARE YOUNG LIKE ME. THEY
PROBABLY WON'T KNOW ANYTHING
DIFFERENT FROM WHAT I KNOW. BESIDES,
IN PIASCY THEY SAID THAT HIV KILLS.
WHAT IF THEY STOP PLAYING WITH ME
BECAUSE I MIGHT DIE ANYTIME?





THE NEXT DAY AUNT TOOK KAKANDE TO THE CLINIC WHICH WAS NEAR HER HOME. THERE WERE MANY PEOPLE THERE, MOSTLY CHILDREN. KAKANDE HAD TO GO FOR MANY TESTS.

WELL, AUNT, THE TEST RESULTS SHOW THAT HIS CD4 COUNT IS STILL LOW. KAKANDE, ARE YOU TAKING YOUR DRUGS REGULARLY?

YES MUSAWO, I AM. AUNT, DON'T YOU SEE ME TAKE MY DRUGS EVERY MORNING AFTER BREAKFAST AND EVERY NIGHT WHEN WE FINISH SUPPER?

YES.

WELL, OK THEN, JUST GO ON TAKING YOUR DRUGS REGULARLY.



WHEN THEY CAME HOME FROM THE CLINIC, KAKANDE AND HIS AUNT SAT DOWN TO CHAT.

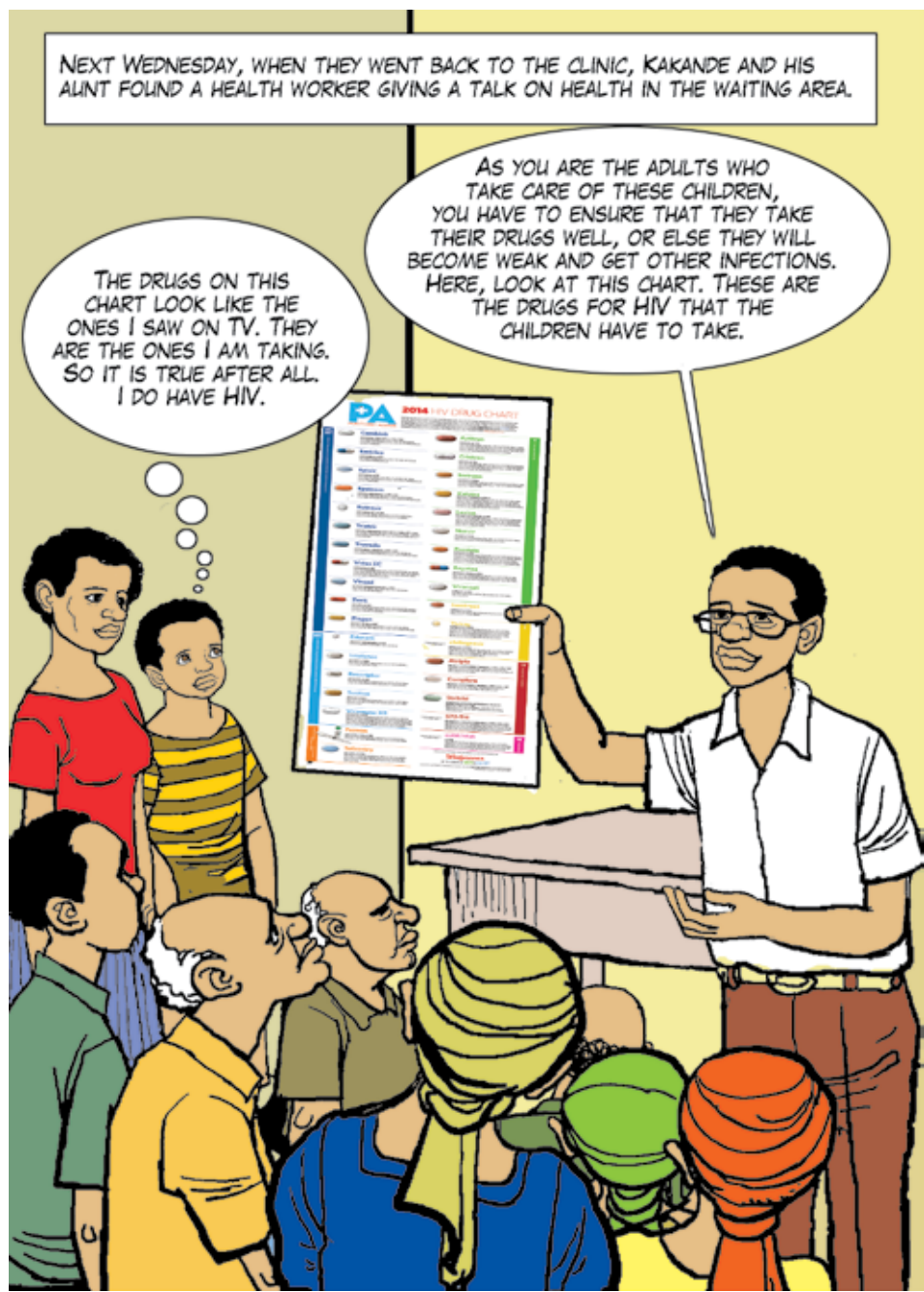
KAKANDE, WHAT DID YOU THINK OF THIS CLINIC?

I LIKED THE MUSAWO. WHEN I GO TO THE HEALTH CENTRE WITH GRANNY, THE MUSAWO TALKS TO GRANNY ALONE, EVEN THOUGH I AM THE ONE WHO IS SICK. SHE GIVES ME BITTER DRUGS WHICH I HATE. TODAY THE MUSAWO ALLOWED ME TO STAY WHILE SHE TALKED TO YOU. THAT MADE ME HAPPY. I TOLD HER THAT THE DRUGS MADE ME FEEL SICK IN THE STOMACH, SO SHE GAVE ME DIFFERENT DRUGS. PLEASE CAN WE VISIT THE FRIENDLY MUSAWO AGAIN? I WOULD LIKE TO ASK HER SOME QUESTIONS.

YES KAKANDE, I PROMISE WE WILL GO BACK NEXT WEDNESDAY.







NEXT WEDNESDAY, WHEN THEY WENT BACK TO THE CLINIC, KAKANDE AND HIS AUNT FOUND A HEALTH WORKER GIVING A TALK ON HEALTH IN THE WAITING AREA.

THE DRUGS ON THIS CHART LOOK LIKE THE ONES I SAW ON TV. THEY ARE THE ONES I AM TAKING. SO IT IS TRUE AFTER ALL. I DO HAVE HIV.

AS YOU ARE THE ADULTS WHO TAKE CARE OF THESE CHILDREN, YOU HAVE TO ENSURE THAT THEY TAKE THEIR DRUGS WELL, OR ELSE THEY WILL BECOME WEAK AND GET OTHER INFECTIONS. HERE, LOOK AT THIS CHART. THESE ARE THE DRUGS FOR HIV THAT THE CHILDREN HAVE TO TAKE.



KAKANDE FELT COLD FEAR INSIDE. WHEN THE MUSAWO INVITED THEM INTO HER ROOM HE BROKE DOWN.

HOW ARE YOU FEELING NOW KAKANDE? WHAT'S THE MATTER? WHY ARE YOU CRYING?

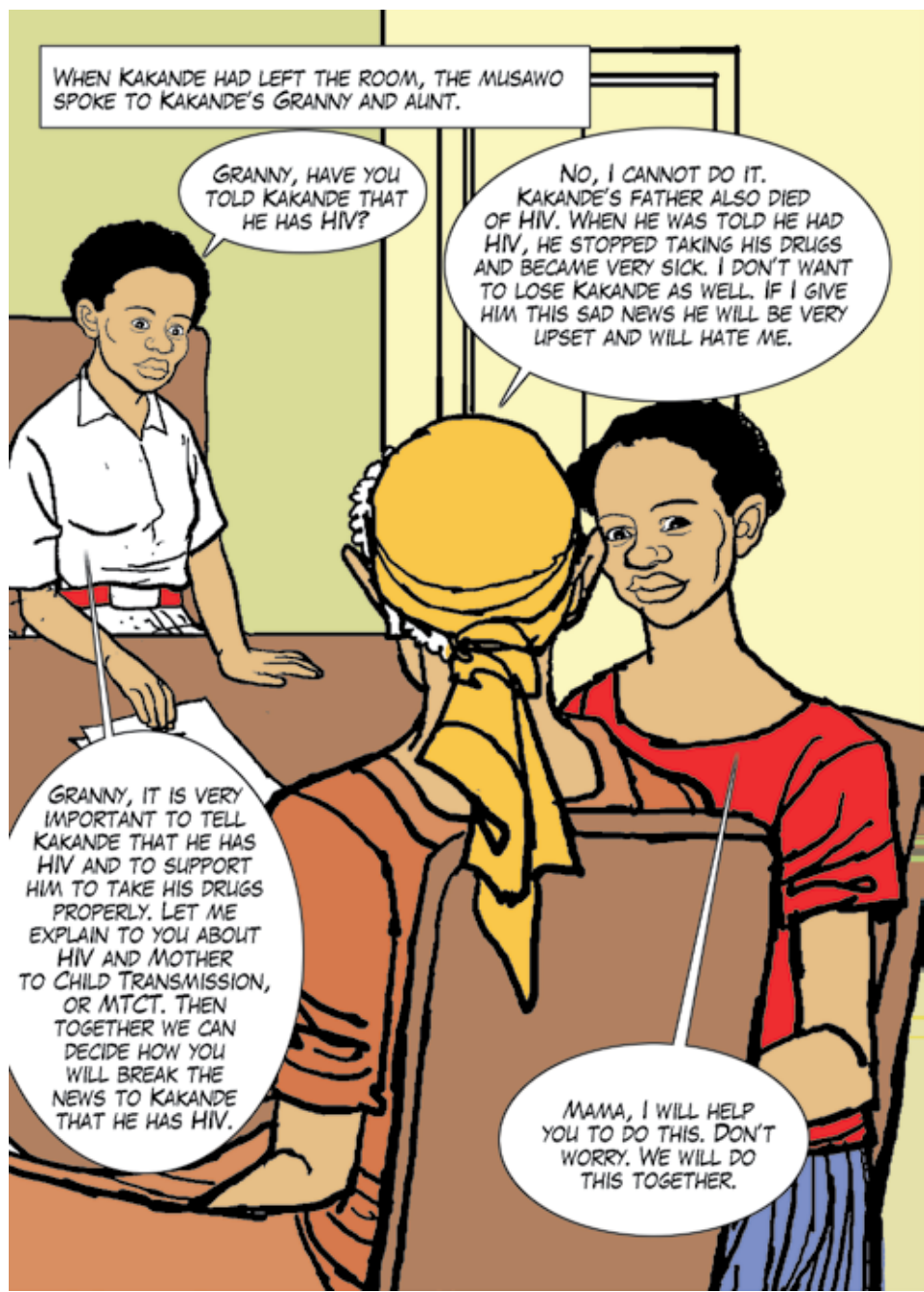
AUNT, MAYBE IF YOU LEFT US ALONE FOR A BIT I COULD TALK TO HIM AND FIND OUT WHAT IS MAKING HIM SO SAD.

KAKANDE, WHAT HAPPENED? TELL ME WHAT IS UPSETTING YOU.









WHEN KAKANDE HAD LEFT THE ROOM, THE MUSAWO SPOKE TO KAKANDE'S GRANNY AND AUNT.

GRANNY, HAVE YOU TOLD KAKANDE THAT HE HAS HIV?

NO, I CANNOT DO IT. KAKANDE'S FATHER ALSO DIED OF HIV. WHEN HE WAS TOLD HE HAD HIV, HE STOPPED TAKING HIS DRUGS AND BECAME VERY SICK. I DON'T WANT TO LOSE KAKANDE AS WELL. IF I GIVE HIM THIS SAD NEWS HE WILL BE VERY UPSET AND WILL HATE ME.

GRANNY, IT IS VERY IMPORTANT TO TELL KAKANDE THAT HE HAS HIV AND TO SUPPORT HIM TO TAKE HIS DRUGS PROPERLY. LET ME EXPLAIN TO YOU ABOUT HIV AND MOTHER TO CHILD TRANSMISSION, OR MTCT. THEN TOGETHER WE CAN DECIDE HOW YOU WILL BREAK THE NEWS TO KAKANDE THAT HE HAS HIV.

MAMA, I WILL HELP YOU TO DO THIS. DON'T WORRY. WE WILL DO THIS TOGETHER.



MY GRANDMOTHER DID NOT TELL ME THAT I HAVE HIV BECAUSE SHE DID NOT WANT TO UPSET ME OR HURT ME. SHE COULD NOT FORGET THAT HER SON - MY FATHER - GAVE UP ON LIFE AND STOPPED TAKING HIS DRUGS ONCE HE KNEW HE HAD HIV. WE DO NEED TO KNOW ABOUT OUR HIV CONDITION. ONLY THEN WILL WE SEE THE NEED TO TAKE OUR DRUGS, WHICH WILL KEEP US WELL.

AFTER LISTENING TO THE MUSAWO'S TALK ON HIV GRANNY FINALLY AGREED THAT THEY SHOULD BREAK THE NEWS TO KAKANDE. ALINT SAID SHE WOULD ALSO HELP GRANNY TO SUPPORT KAKANDE. THE MUSAWO THEN CALLED KAKANDE INTO THE ROOM AND BROKE THE NEWS TO HIM.

KAKANDE, YOU WERE RIGHT. YOU DO HAVE HIV. BUT DO NOT WORRY. YOUR GRANNY AND ALINT WILL TAKE CARE OF YOU. THESE DRUGS WILL KEEP YOU WELL, BUT ONLY IF YOU TAKE THEM DAILY, AS THE DOCTOR TELLS YOU. IF YOU HAVE ANY WORRIES OR QUESTIONS YOU MUST TALK TO SOMEONE YOU TRUST. NOW, DO YOU HAVE ANYTHING TO SAY TO US?



KAKANDE FELT SAD BUT RELIEVED. HE FELT HE COULD TALK TO THE MUSAWO AND EVEN GRANNY.

NOW I UNDERSTAND WHY I TAKE DRUGS. I WILL TAKE THEM REGULARLY. CAN I TELL YOU SOMETHING? PLEASE DON'T BE ANGRY WITH ME, GRANNY. AT HOME I USED TO REMOVE THE DAY'S DOSE AND PUT THE DRUGS UNDER MY MATTRESS. I WAS TIRED OF TAKING THEM AND I DID NOT FEEL UNWELL SO...

OH KAKANDE! AFTER YOU LEFT I WAS CLEANING UP YOUR ROOM AND FOLIND ALL THE DRUGS. BUT I DID NOT SAY ANYTHING TO THE MUSAWO BECAUSE I THOUGHT YOU WOULD HATE ME.

KAKANDE, THANK YOU FOR BEING HONEST WITH US. NOW WE UNDERSTAND WHY YOU WERE BECOMING MORE SICK AND WEAK EVEN THOUGH WE THOUGHT THAT YOU WERE TAKING YOUR DRUGS REGULARLY.





GRANNY AND OTHER HEALTH WORKERS ONLY ASKED ME IF I HAD TAKEN MY DRUGS. THEY NEVER ASKED ME IF I HAD ANY QUESTIONS OR HOW I FELT. IF THIS MUSAWO HAD ASKED ME, "WHY DID YOU MISS TAKING YOUR DRUGS?" I WOULD HAVE BEEN FRIGHTENED AND NOT ANSWERED HER. BUT SHE WAS SO POLITE AND UNDERSTANDING I WAS NOT AFRAID TO TELL HER THAT I HAD NOT BEEN TAKING THEM.



KAKANDE WENT BACK TO THE VILLAGE WITH HIS GRANNY. HE TOOK HIS DRUGS REGULARLY AND HIS HEALTH IMPROVED A LOT. NOW HE AND HIS GRANNY ARE HAPPY.

LOOK GRANNY, I'VE GOT A GOOD REPORT CARD.

YOU ARE DOING WELL IN SCHOOL BECAUSE YOUR HEALTH HAS IMPROVED AND YOU ARE NOT MISSING ANY CLASSES NOW. IT WAS A GOOD IDEA FOR US TO KEEP YOUR DRUGS IN THE CLIPBOARD SO THAT I CAN MAKE SURE THAT YOU ARE TAKING THEM REGULARLY. IF YOU CARRY ON LIKE THIS YOU CAN LOOK FORWARD TO A HAPPY FUTURE.

