

KRISTINA'S STORY



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This book has been converted from text to comic book format by Rajyashree Dutt (rajyashreedutt@gmail.com) with illustrations by B G Gujjarappa.



UKaid
from the British people

This book is an output from ARROW Young Lives, which was funded by the Department for International Development for the benefit of developing countries.

THIS IS THE STORY OF A YOUNG UGANDAN GIRL LIVING WITH HIV. KRISTINA IS NOT A REAL PERSON. HER 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: JOINT CLINICAL RESEARCH CENTRE, MEDICAL RESEARCH COUNCIL/UGANDA VIRUS RESEARCH INSTITUTE, BAYLOR UGANDA, THE LONDON SCHOOL OF HYGIENE AND TROPICAL MEDICINE AND THE MRC CLINICAL TRIALS UNIT AT UCL.



THE BRIGHT SUN HAS CHASED AWAY THE RAINY SEASON. IT IS A BEAUTIFUL DAY.

I AM KRISTINA. I WOULD LIKE TO SHARE WITH YOU THE STORY OF MY LIFE. I AM 13 YEARS OLD AND I AM HIV POSITIVE. I LIVE WITH MY GRANDMOTHER. MY OLDER SISTER CLARA, WHO IS 15 YEARS OLD HAS GONE AWAY TO SECONDARY BOARDING SCHOOL. CLARA IS HIV NEGATIVE AND DOES NOT KNOW THAT I AM HIV POSITIVE.



WHEN I WAS VERY LITTLE - MAYBE ABOUT SIX YEARS OLD - I USED TO FALL SICK ALL THE TIME. I HAD SORES IN MY MOUTH AND OFTEN HAD FEVER. I COUGHED A LOT AND THE HEALTH WORKERS SAID I HAD TUBERCULOSIS. I COULD NOT GO TO SCHOOL - SOMETIMES FOR A WEEK. I HAD TO TAKE DRUGS EVERY DAY.

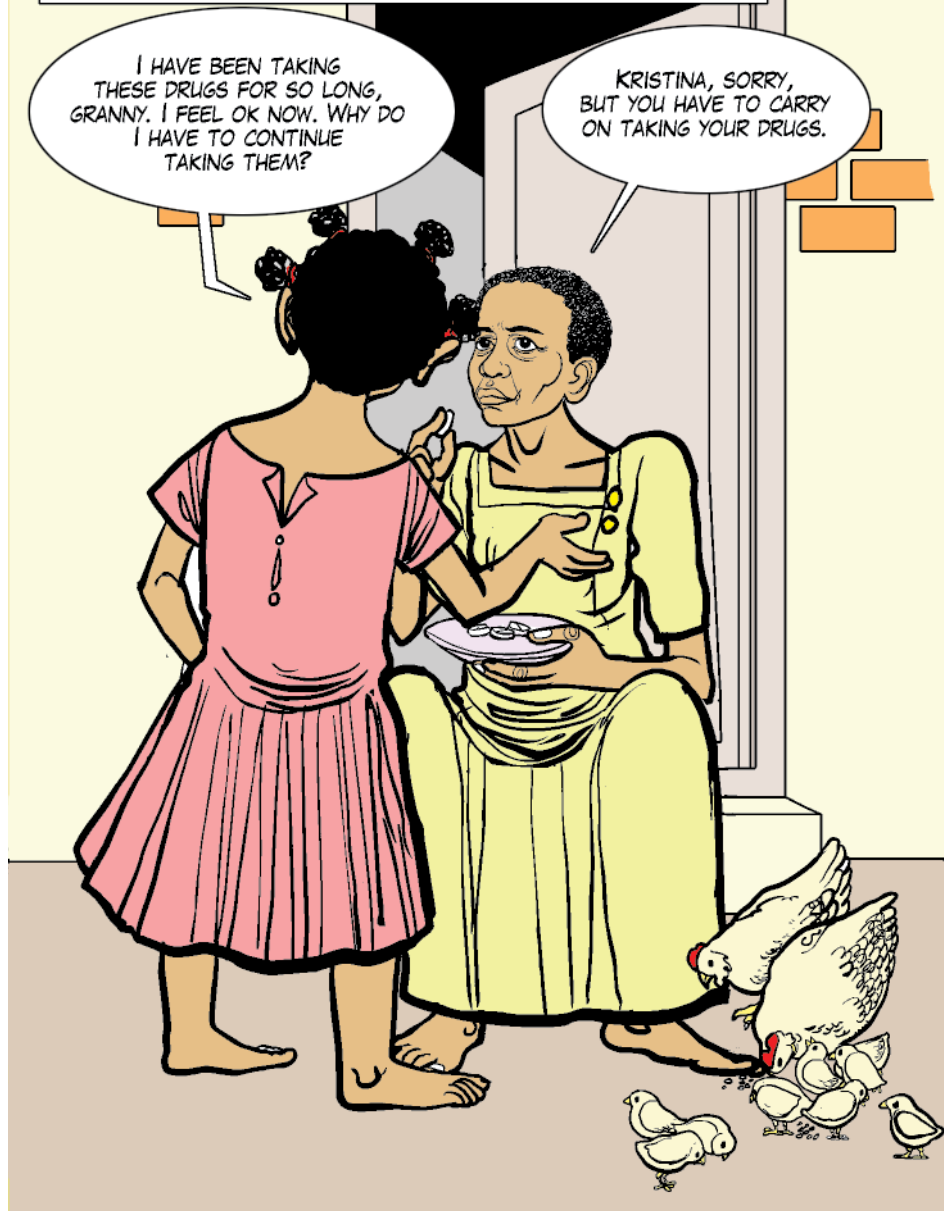
GRANNY, I DON'T FEEL GOOD. I DON'T THINK I CAN GO TO SCHOOL TODAY.



BUT THEN I BEGAN TO FEEL BETTER. I DID NOT SEE WHY I HAD TO GO ON TAKING SO MANY PILLS EVERY DAY.

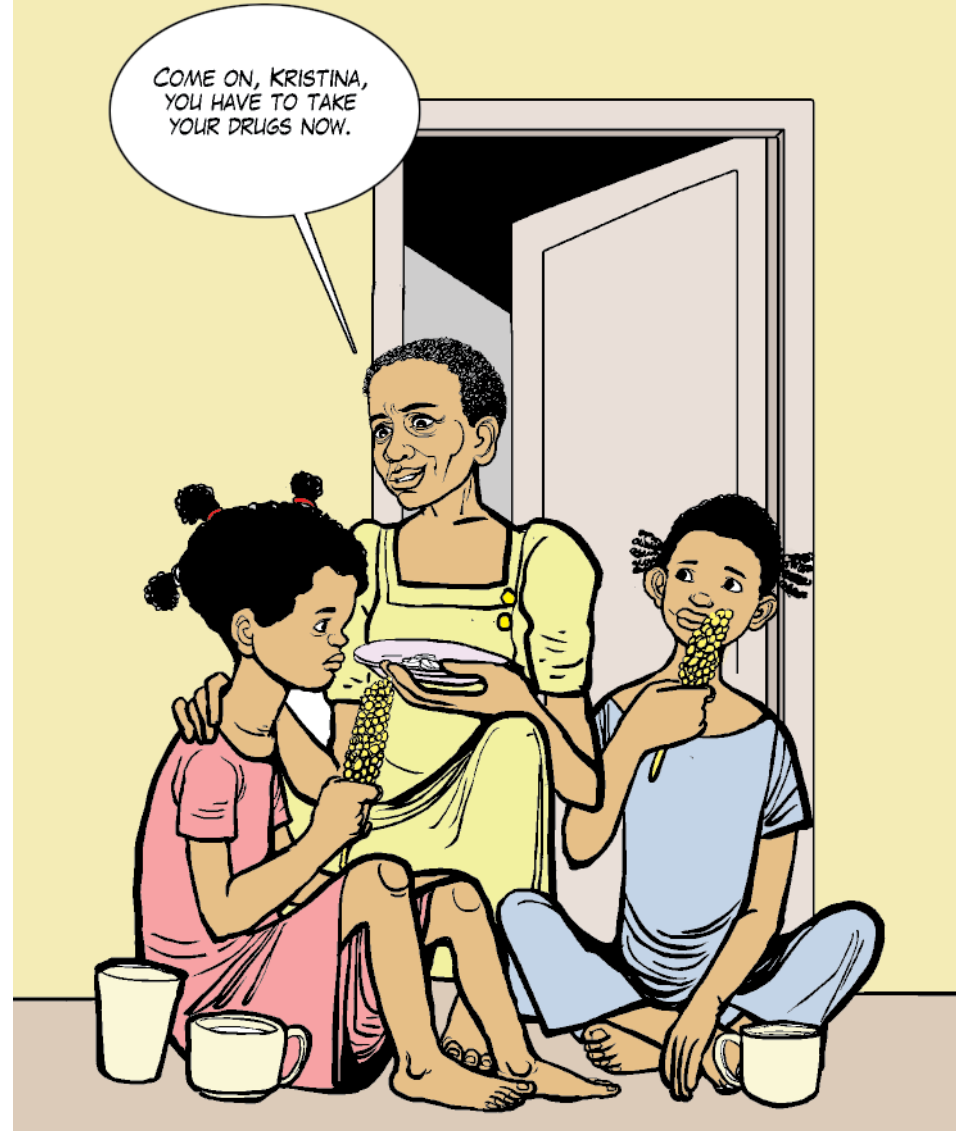
I HAVE BEEN TAKING THESE DRUGS FOR SO LONG, GRANNY. I FEEL OK NOW. WHY DO I HAVE TO CONTINUE TAKING THEM?

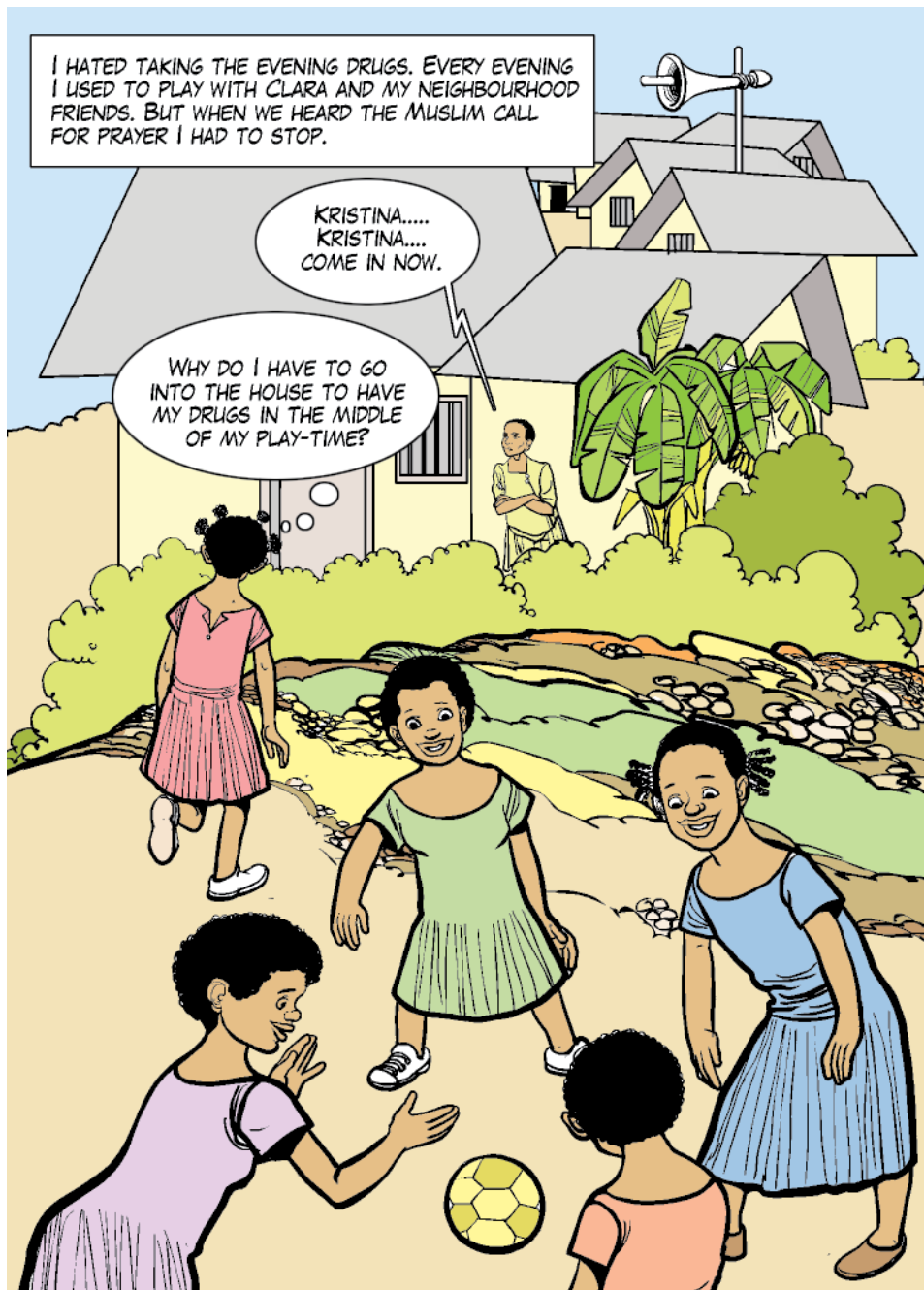
KRISTINA, SORRY, BUT YOU HAVE TO CARRY ON TAKING YOUR DRUGS.



EVERY DAY GRANNY GAVE ME MY TWICE-DAILY DRUGS ON TIME. EVERY MORNING SHE WOKE ME UP AT 6.30 AND HAD MY BREAKFAST READY AT 7. SHE ALWAYS PLACED A GLASS OF WATER ALONGSIDE MY TEA AND SNACK.

COME ON, KRISTINA, YOU HAVE TO TAKE YOUR DRUGS NOW.





THEN I HAD A VERY CLEVER IDEA... OR, AT LEAST I THOUGHT IT WAS VERY CLEVER AT THAT TIME.

I HATE THESE DRUGS. I WILL NOT TAKE THEM ANY MORE. I SLIPPED THE PILLS INTO MY HAIR WHEN GRANNY WAS NOT LOOKING, AND I CAN JUST HIDE THEM HERE. NOBODY EVER LOOKS INSIDE THIS BOX. NO ONE WILL KNOW... NOT GRANNY, NOT THE HEALTH WORKERS IN THE CLINIC... NO ONE.



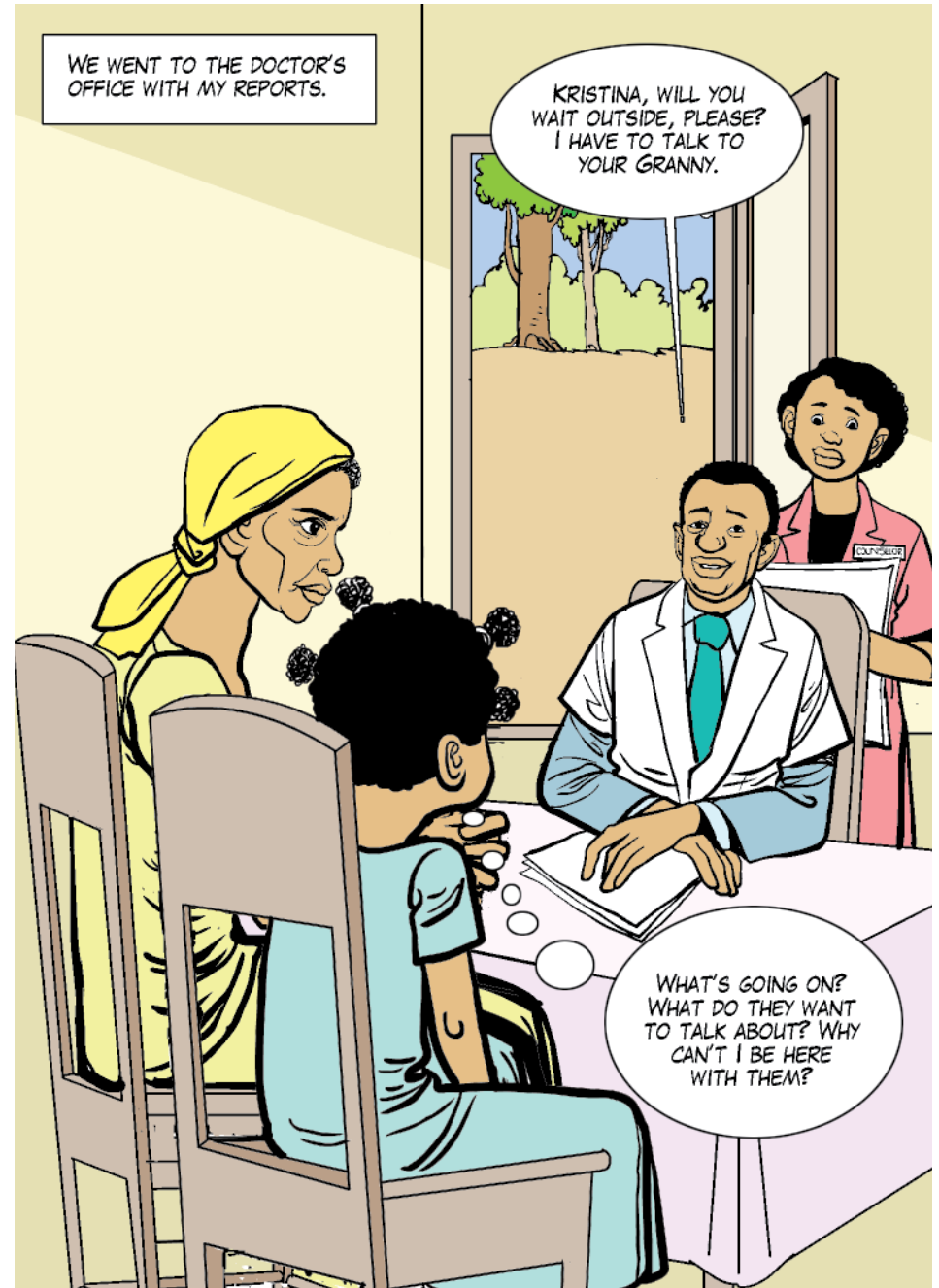
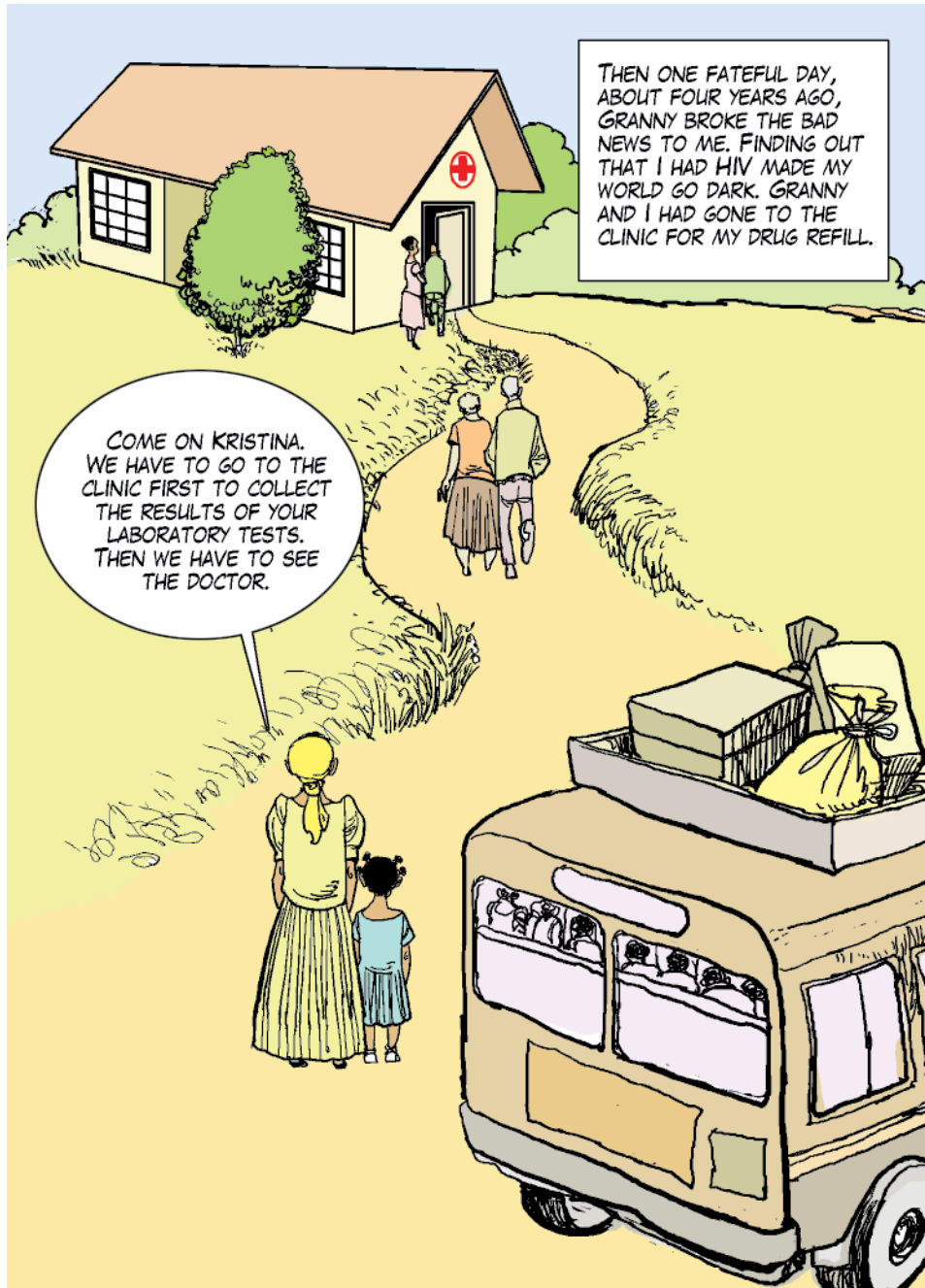
SOON I STARTED TO FEEL BAD AGAIN, BUT I STILL DID NOT KNOW WHAT WAS REALLY WRONG WITH ME.

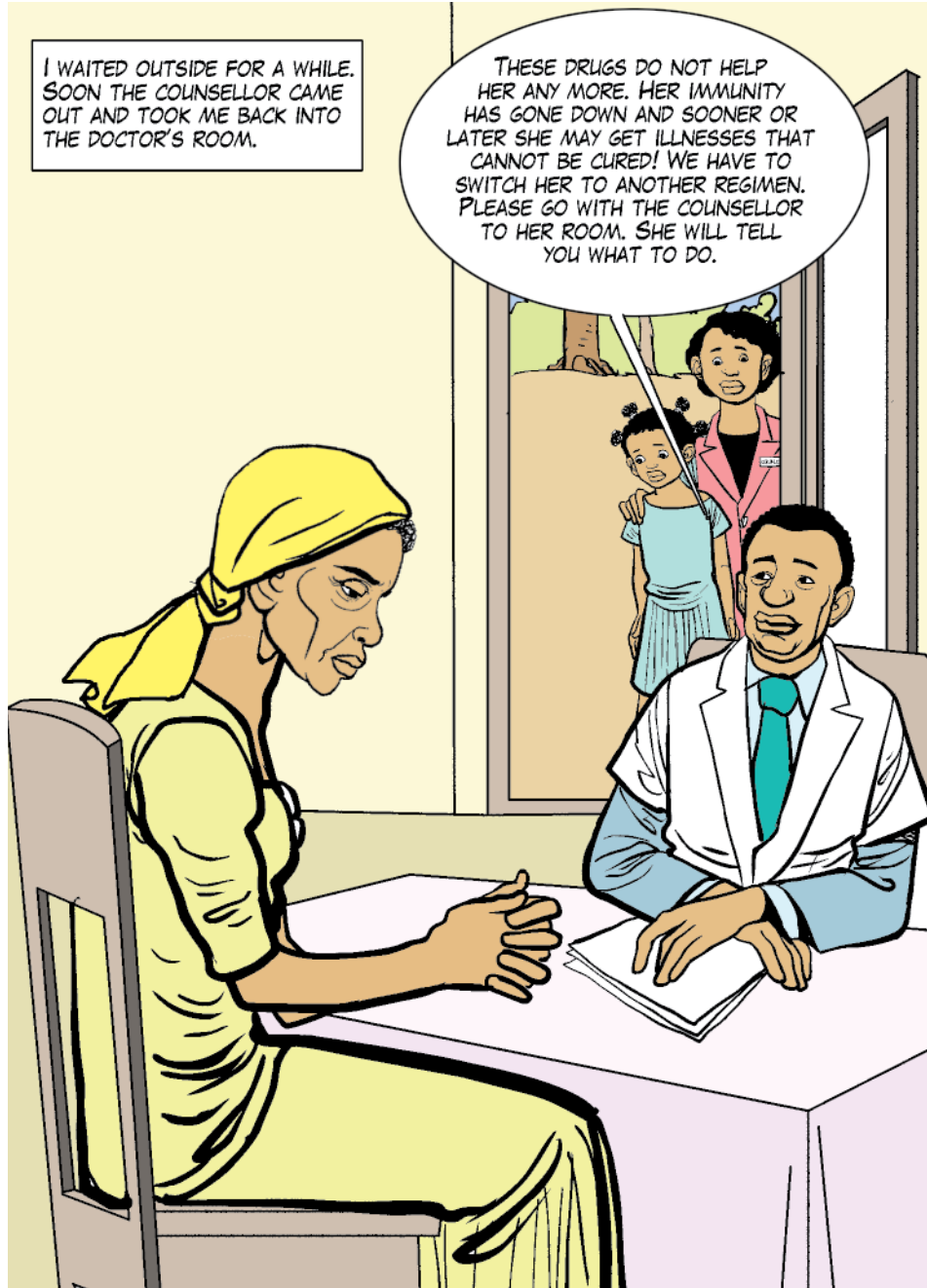
GRANNY, LOOK AT THIS SKIN RASH. IT'S ALL OVER MY BODY.

HERE, USE THIS MEDICATED SOAP. IT WILL MAKE THE RASH GO AWAY.

GRANNY, THE SOAP DOES NOT HELP. I USED IT BEFORE. LOOK WHAT THE RASH HAS DONE TO MY SKIN. LOOK AT THESE UGLY SCARS ON MY ARMS AND LEGS.







I WAS SCARED. AFTER A WHILE, I WAS CALLED BACK INTO THE COUNSELLING ROOM. AND THAT'S WHEN GRANNY GAVE ME THE NEWS.

KRISTINA.... MY DEAR GIRL... I HAVE TO TELL YOU SOMETHING. YOU KNOW YOU HAVE TO TAKE ALL THOSE DRUGS EVERY DAY. THAT'S BECAUSE YOU ARE HIV POSITIVE. I'M SORRY I DID NOT TELL YOU BEFORE... I WAS JUST AFRAID TO DO IT.



THE NEWS BROKE MY HEART... I FELT GOOSE PIMPLES ALL OVER MY BODY AND TEARS SLOWLY TRICKLED DOWN MY CHEEKS. GRANNY CRIED TOO. FORTUNATELY, THE COUNSELLOR WAS PRESENT AND CALMED US DOWN. MY WORLD HAD CHANGED DRAMATICALLY.

AM I GOING TO DIE?

NO, THE DRUGS WILL KEEP YOU ALIVE AND HEALTHY.

IF YOU TAKE YOUR DRUGS WELL, YOU WILL BE ABLE TO ACHIEVE ALL YOUR DREAMS.



I WAS WORRIED ABOUT WHAT OTHER PEOPLE WOULD THINK OF ME.

WILL GRANNY NOW TREAT ME DIFFERENTLY? WHAT ABOUT OTHER PEOPLE? I CANNOT SHARE THIS SECRET WITH ANYONE, NOT EVEN CLARA, EVEN THOUGH SHE IS MY SISTER, BECAUSE SHE WOULD PROBABLY TELL ALL OUR FRIENDS AND THE NEWS WOULD SPREAD LIKE WILD FIRE IN THE VILLAGE AND IN SCHOOL. I HOPE GRANNY NEVER TELLS HER ABOUT IT.



MOST OF US CHILDREN TRY TO KEEP OUR HIV STATUS A SECRET. SOMETIMES WE ARE AFRAID THAT EVEN CLOSE MEMBERS OF THE HOUSEHOLD MAY TELL OTHER PEOPLE WHO MAY NOT TREAT US VERY WELL.



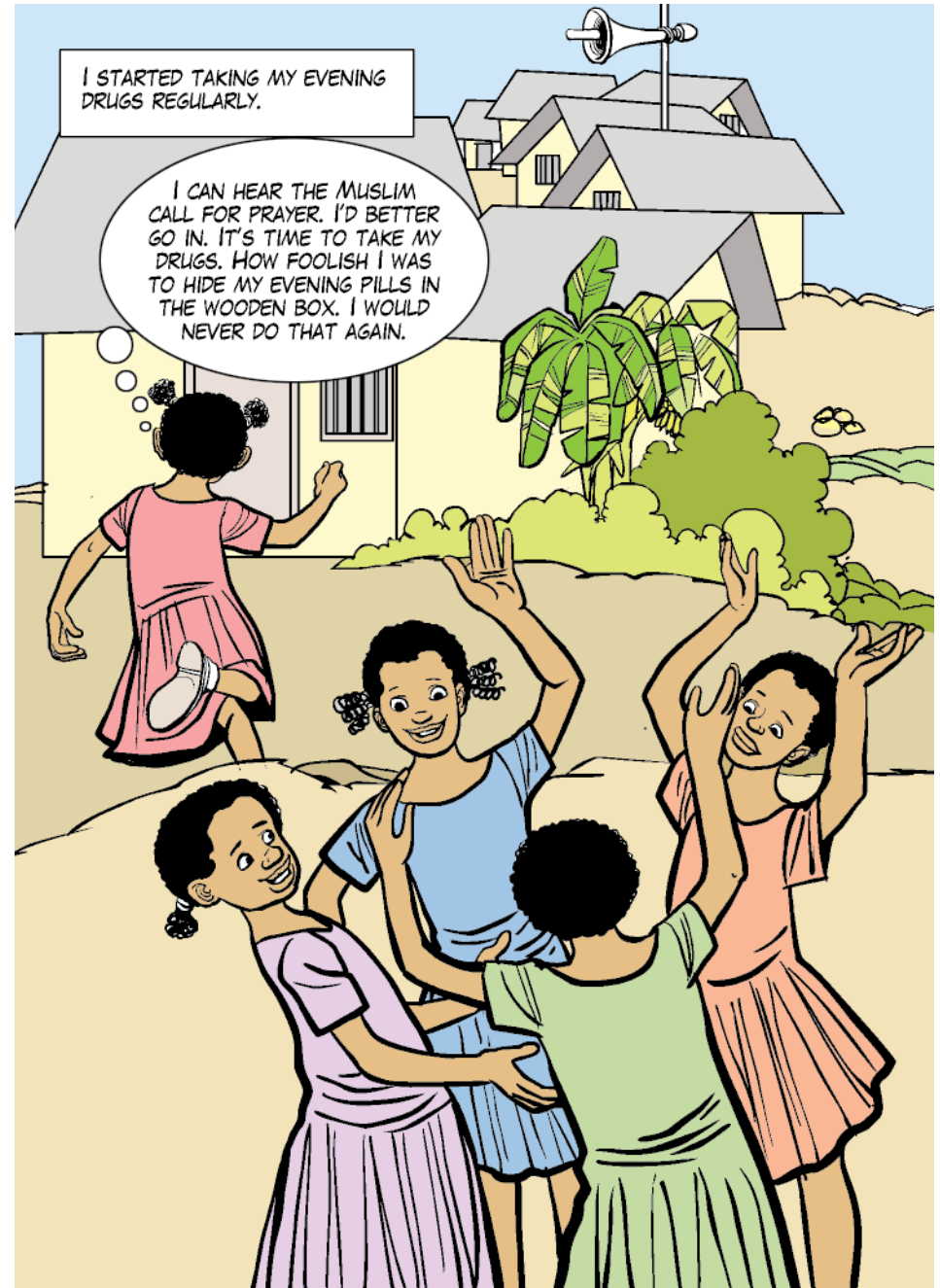


AFTER THAT DAY, GRANNY AND I NEVER TALKED ABOUT HIV AGAIN.

I WONDER WHY GRANNY NEVER TALKS TO ME ABOUT WHAT I LEARNT AT THE CLINIC THAT DAY?



VERY OFTEN, THOSE WHO TAKE CARE OF US ARE SCARED TO TELL US WE HAVE HIV, BECAUSE THEY DO NOT WANT TO HURT US. OR THEY FIND IT DIFFICULT TO START THAT CONVERSATION. SO ONCE IT HAS BEEN SPOKEN ABOUT IT SOON SEEMS VERY NORMAL THAT WE NEVER TALK ABOUT IT AGAIN. BUT IT MAKES IT MORE DIFFICULT FOR US YOUNG PEOPLE LIVING WITH HIV TO UNDERSTAND AND ACCEPT WHAT IS HAPPENING TO US. MAYBE IF WE ARE ASKED IF WE HAVE ANY QUESTIONS ABOUT HIV WE COULD TALK AND GET ANSWERS TO ALL THOSE QUESTIONS THAT TROUBLE US.





I HAD KNOWN ABOUT MY HIV STATUS FOR SOME TIME NOW. BUT I STILL HAD MANY QUESTIONS ABOUT IT.

KRISTINA... KRISTINA... LOOK, YOUR FRIENDS ARE WAITING FOR YOU.

I HAVE MADE A LIST OF ALL THE QUESTIONS THAT TROUBLE ME. BUT WHO CAN I ASK? HOW DO I ASK THESE QUESTIONS?

Q1... I was told that HIV is "a virus". So... is HIV an insect?
Q2... What is the size of HIV?
Q3... How did I get HIV?
Q4... Will I ever be cured of HIV?
Q5... My science teacher said HIV can be transmitted through sharing sharp instruments like razor blades with someone infected with it - so how can I stop HIV?

GRANNY IS ALWAYS INTERRUPTING MY THOUGHTS. I DON'T KNOW HOW I WILL EVER GET ANSWERS TO ALL MY QUESTIONS. AH WELL. MAYBE I SHOULD JUST GO OUT AND PLAY WITH MY FRIENDS. BY THE TIME I COME BACK HOME I WILL BE TIRED AND READY TO GO TO BED.



I HAD SO MANY QUESTIONS ABOUT HIV. I WAS SCARED AND WORRIED, BUT THERE WAS NO-ONE I COULD TALK TO. GRANNY NEVER DISCUSSED IT. IN SCHOOL WE WERE TOLD ABOUT HIV PREVENTION BUT THERE WAS NOTHING FOR SOMEONE WHO ALREADY HAD HIV. SOMETIMES I HEARD PEOPLE TALKING ON THE STREETS ABOUT HIV AND AIDS. I DID NOT KNOW WHAT WAS TRUE AND WHAT WAS NOT. EVEN IN THE CLINIC THE COUNSELLOR ONLY TOLD ME TO TAKE MY DRUGS REGULARLY. SHE DID NOT TALK ABOUT ANYTHING ELSE. HEALTHCARE SERVICES AND SCHOOLS, WHICH ARE PROVIDING INFORMATION ABOUT HIV, SHOULD HAVE MESSAGES WHICH SPECIFICALLY ADDRESS THE WORRIES AND THOUGHTS AND FEELINGS OF CHILDREN LIKE ME WHO HAVE BEEN BORN WITH HIV. WE AND OUR CARERS SHOULD ROUTINELY BE ASKED HOW MUCH WE KNOW ABOUT HIV AND THE KNOWLEDGE GAPS SHOULD BE FILLED IN BY PROVIDING US WITH NEW INFORMATION ON HIV AND SEXUAL REPRODUCTIVE HEALTH WHICH WE CAN UNDERSTAND. THIS WILL HELP TO CLEAR MISCONCEPTIONS AND ANSWER QUESTIONS WHICH WE HAVE AND DON'T ASK.

GRANNY AND I DID NOT SPEAK ABOUT MY PARENTS BUT ONE DAY, A COUPLE OF YEARS AGO, I CAME ACROSS GRANNY FLIPPING THROUGH HER PAPERS AND BOOKS.

KRISTINA, LOOK AT THIS PICTURE.

WHO ARE THESE PEOPLE?

THIS IS A WEDDING PHOTOGRAPH OF YOUR PARENTS. THEY BOTH DIED OF HIV. UNFORTUNATELY, AT THAT TIME THERE WERE NO DRUGS FOR HIV. YOUR MOTHER DIDN'T EVEN KNOW THAT SHE WAS HIV POSITIVE. I DID NOT TELL YOU ABOUT THIS EARLIER BECAUSE I FELT YOU MIGHT THINK BADLY ABOUT YOUR PARENTS.

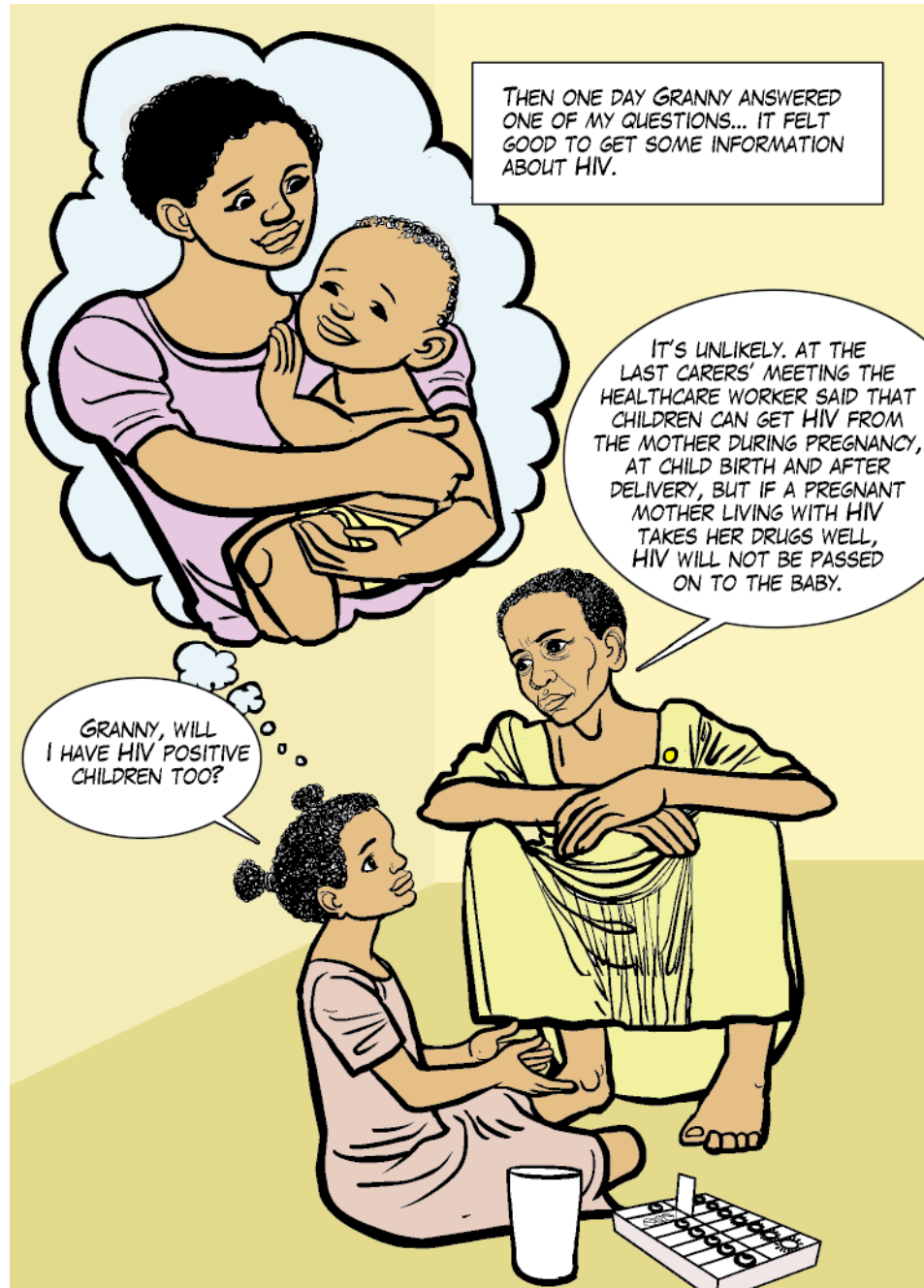
SO... DID I GET HIV FROM THEM?



I DID NOT GET AN ANSWER TO THE UNSPOKEN QUESTION IN MY HEAD.

SADLY, A YEAR AFTER YOUR FATHER PASSED ON, YOUR MOTHER FELL SICK AND DIED TOO. BEFORE SHE DIED, SHE ASKED ME TO TAKE CARE OF YOU AND CLARA.





WHEN I WAS IN PRIMARY FOUR, OUR SCIENCE TEACHER IN SCHOOL TAUGHT US ABOUT HIV/AIDS.

WHAT ARE THE SIGNS OF A PERSON WITH HIV?

SIGNS OF HIV/AIDS

- THINNESS
- ILLNESSES SUCH AS RECURRENT FEVERS

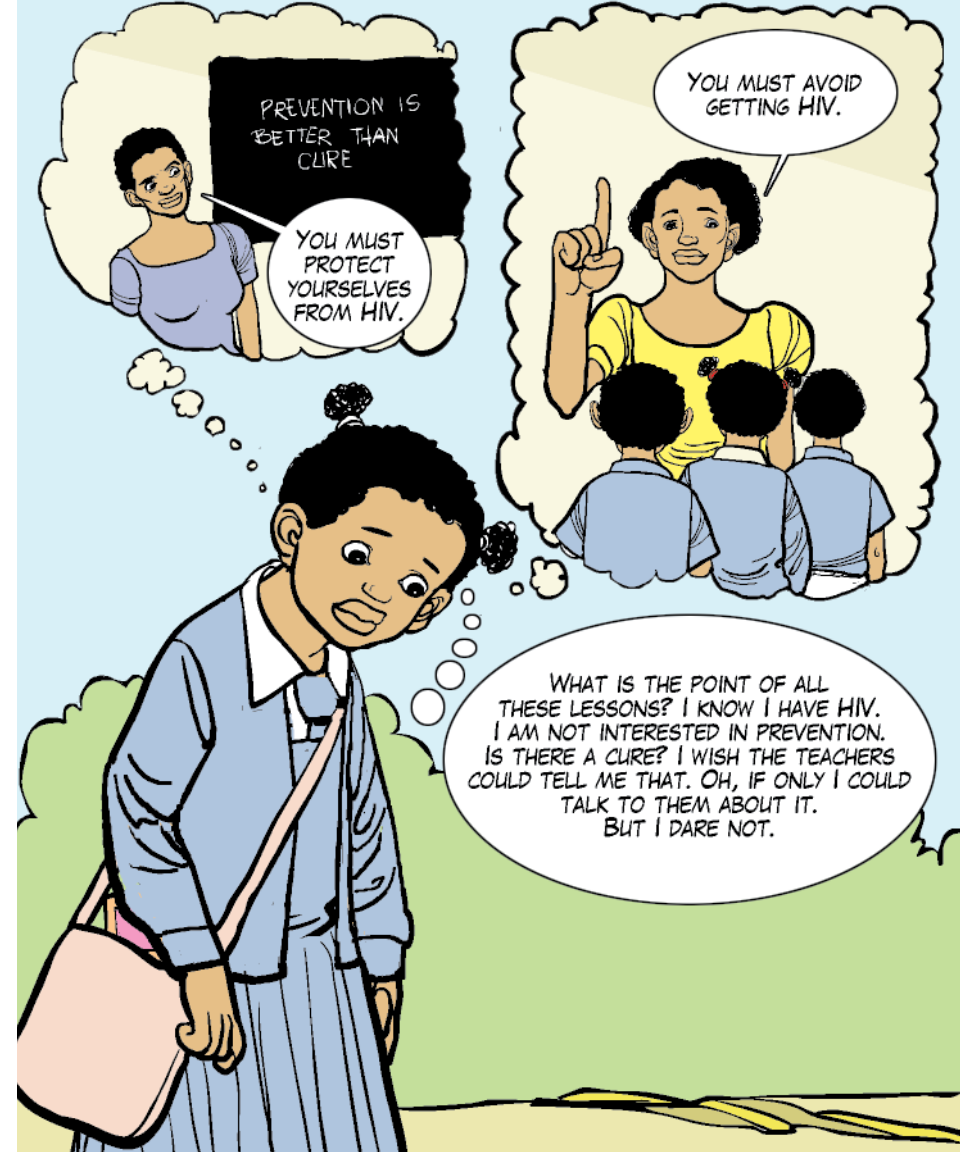


IN PRIMARY FIVE ANOTHER TEACHER TAUGHT US ABOUT HIV PREVENTION MEASURES. I ALSO ALWAYS ATTENDED THE PRESIDENTIAL INITIATIVE ON AIDS STRATEGY FOR COMMUNICATION TO YOUTH (PIASCY) SESSIONS EVERY FRIDAY AFTERNOON WHERE THEY TOLD US ABOUT THE DANGERS OF AIDS.

PREVENTION IS BETTER THAN CURE

YOU MUST PROTECT YOURSELVES FROM HIV.

YOU MUST AVOID GETTING HIV.



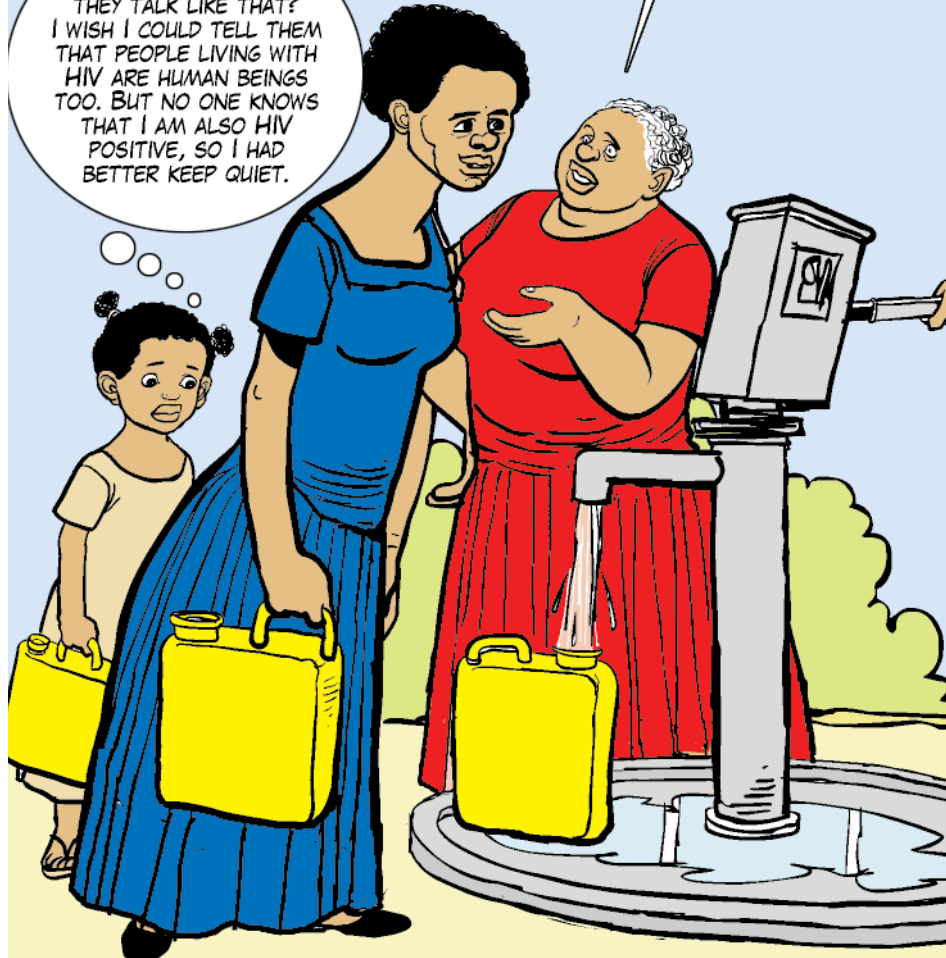


LATER, GRANNY AND I SHIFTED TO A NEW AREA. SOMETIMES I HEARD ADULTS TALKING ABOUT PEOPLE LIVING WITH HIV. SINCE I NOW KNEW I HAD HIV IT MADE ME VERY UPSET.

THAT JOVIA IS ALWAYS SICK. I AM SURE SHE HAS HIV.

I HOPE SHE DOESN'T COME HERE. SHE WILL GIVE HER DISEASE TO ALL OF US.

NO, NO, NO... WHY DO THEY TALK LIKE THAT? I WISH I COULD TELL THEM THAT PEOPLE LIVING WITH HIV ARE HUMAN BEINGS TOO. BUT NO ONE KNOWS THAT I AM ALSO HIV POSITIVE, SO I HAD BETTER KEEP QUIET.



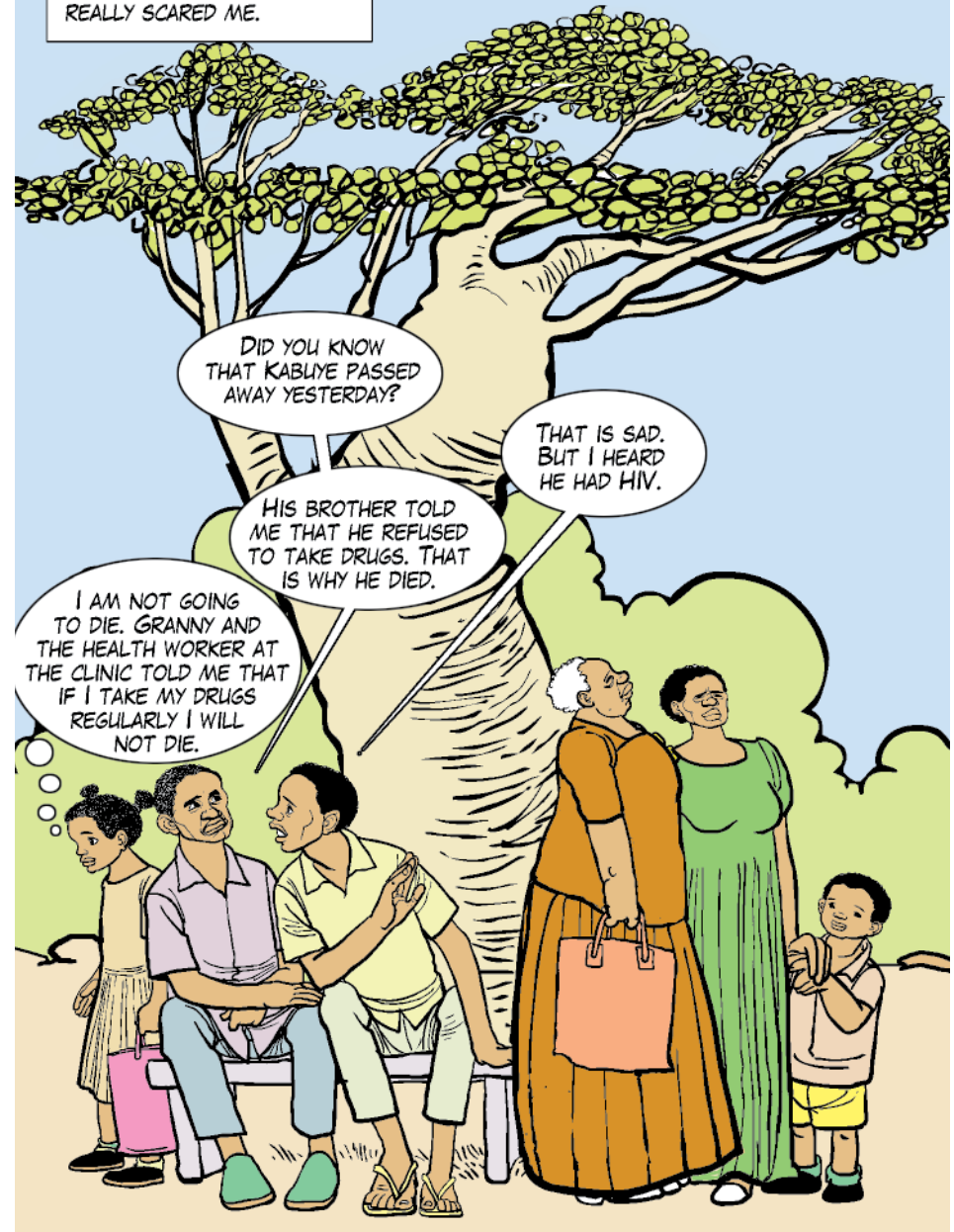
SOMETIMES THE COMMENTS REALLY SCARED ME.

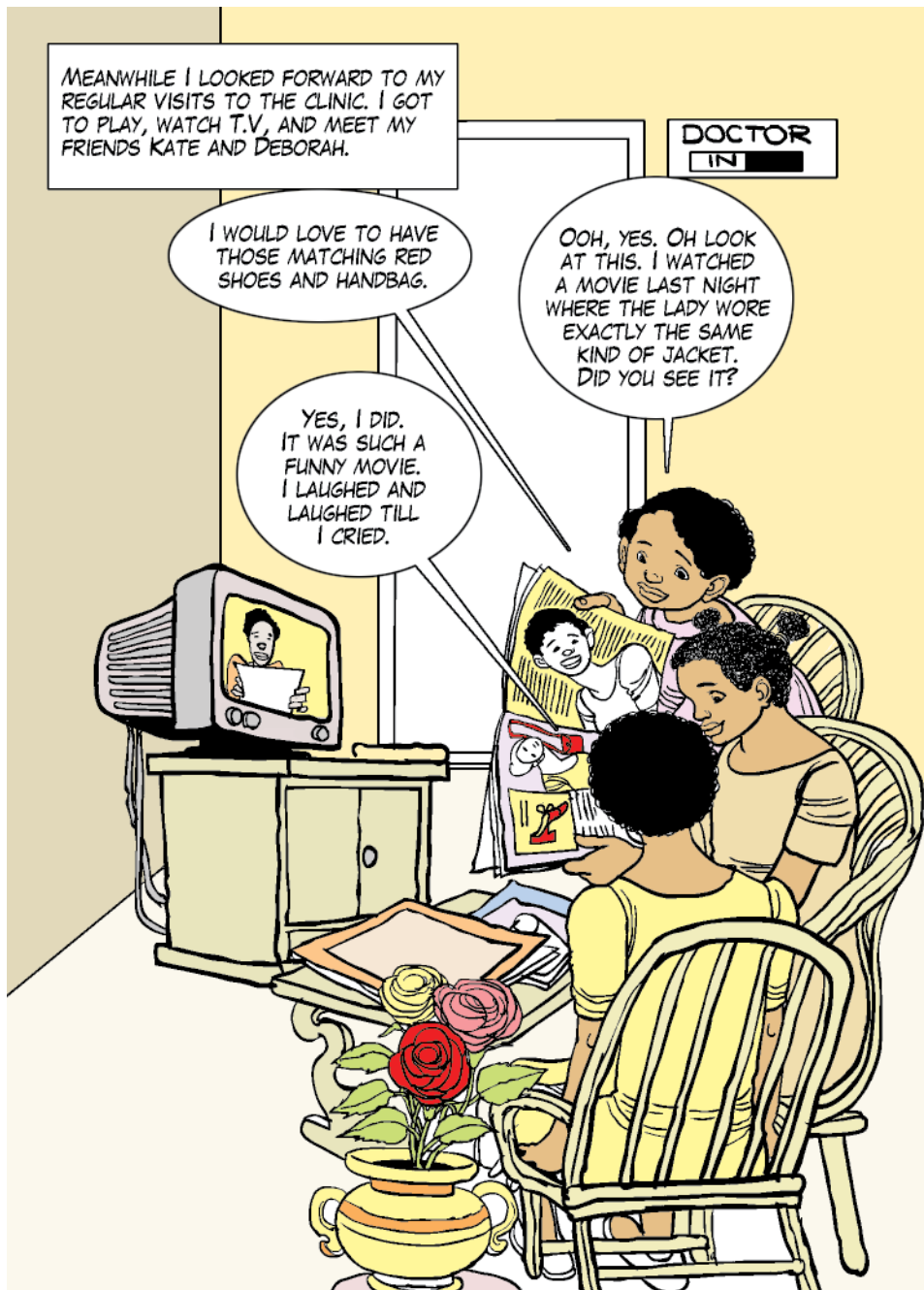
DID YOU KNOW THAT KABUYE PASSED AWAY YESTERDAY?

THAT IS SAD, BUT I HEARD HE HAD HIV.

HIS BROTHER TOLD ME THAT HE REFUSED TO TAKE DRUGS. THAT IS WHY HE DIED.

I AM NOT GOING TO DIE. GRANNY AND THE HEALTH WORKER AT THE CLINIC TOLD ME THAT IF I TAKE MY DRUGS REGULARLY I WILL NOT DIE.





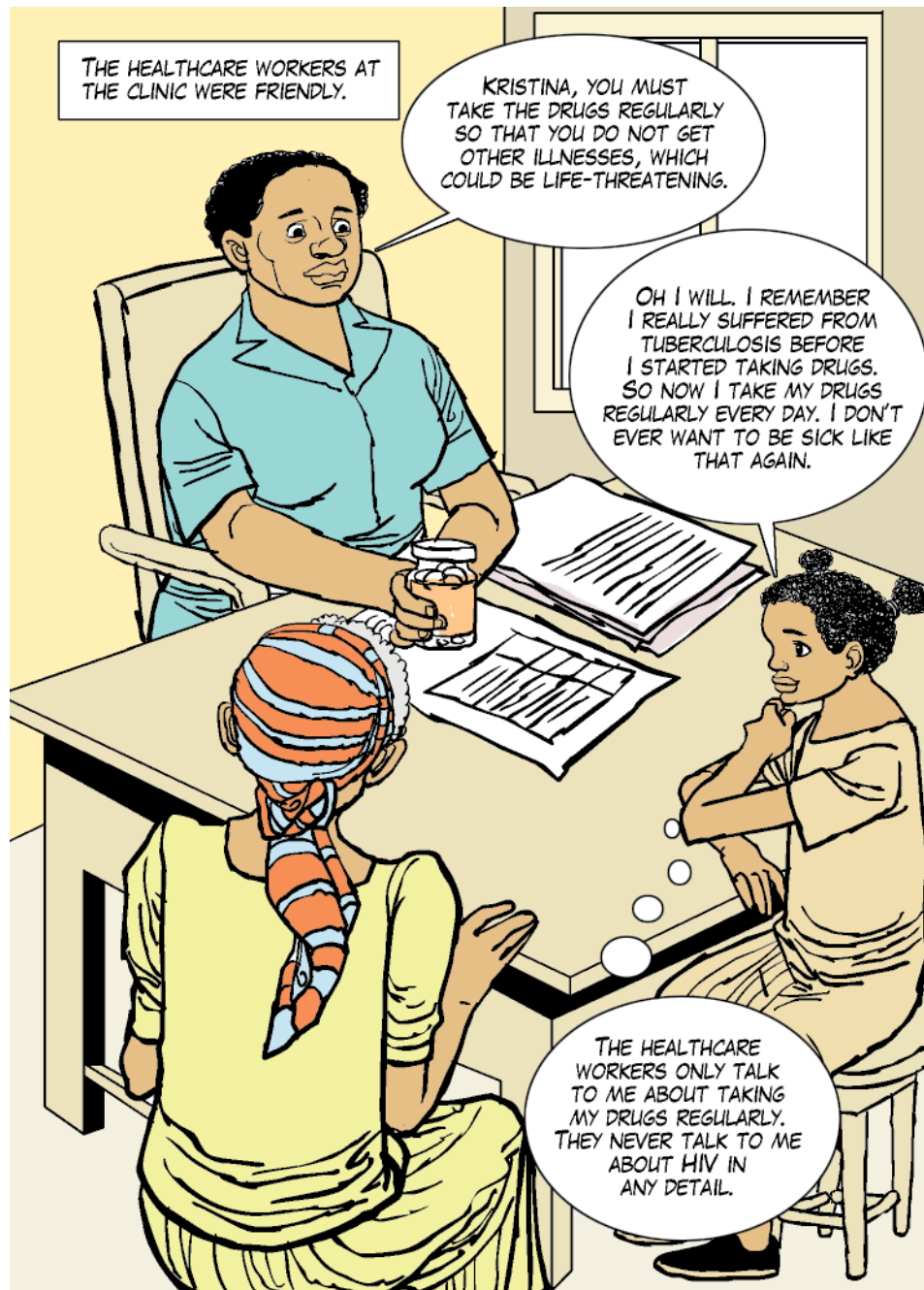
MEANWHILE I LOOKED FORWARD TO MY REGULAR VISITS TO THE CLINIC. I GOT TO PLAY, WATCH T.V, AND MEET MY FRIENDS KATE AND DEBORAH.

DOCTOR
IN

I WOULD LOVE TO HAVE THOSE MATCHING RED SHOES AND HANDBAG.

OOH, YES. OH LOOK AT THIS. I WATCHED A MOVIE LAST NIGHT WHERE THE LADY WORE EXACTLY THE SAME KIND OF JACKET. DID YOU SEE IT?

YES, I DID. IT WAS SUCH A FUNNY MOVIE. I LAUGHED AND LAUGHED TILL I CRIED.



THE HEALTHCARE WORKERS AT THE CLINIC WERE FRIENDLY.

KRISTINA, YOU MUST TAKE THE DRUGS REGULARLY SO THAT YOU DO NOT GET OTHER ILLNESSES, WHICH COULD BE LIFE-THREATENING.

OH I WILL. I REMEMBER I REALLY SUFFERED FROM TUBERCULOSIS BEFORE I STARTED TAKING DRUGS. SO NOW I TAKE MY DRUGS REGULARLY EVERY DAY. I DON'T EVER WANT TO BE SICK LIKE THAT AGAIN.

THE HEALTHCARE WORKERS ONLY TALK TO ME ABOUT TAKING MY DRUGS REGULARLY. THEY NEVER TALK TO ME ABOUT HIV IN ANY DETAIL.

I DID NOT WANT ANYONE TO KNOW THAT I WAS HIV POSITIVE. I WAS AFRAID THAT THE CHILDREN WOULD STOP PLAYING WITH ME ONCE THEY KNEW ABOUT IT AND ALSO SPREAD RUMOURS ABOUT ME.

THANK GOODNESS OUR SCHOOL UNIFORM HAS A LONG SKIRT AND A JACKET THAT HAS LONG SLEEVES. IT HIDES THE SCARS ON MY ARMS AND LEGS THAT I GOT FROM THE SKIN RASH. I DON'T WANT THE CHILDREN TO SEE THE SCARS.



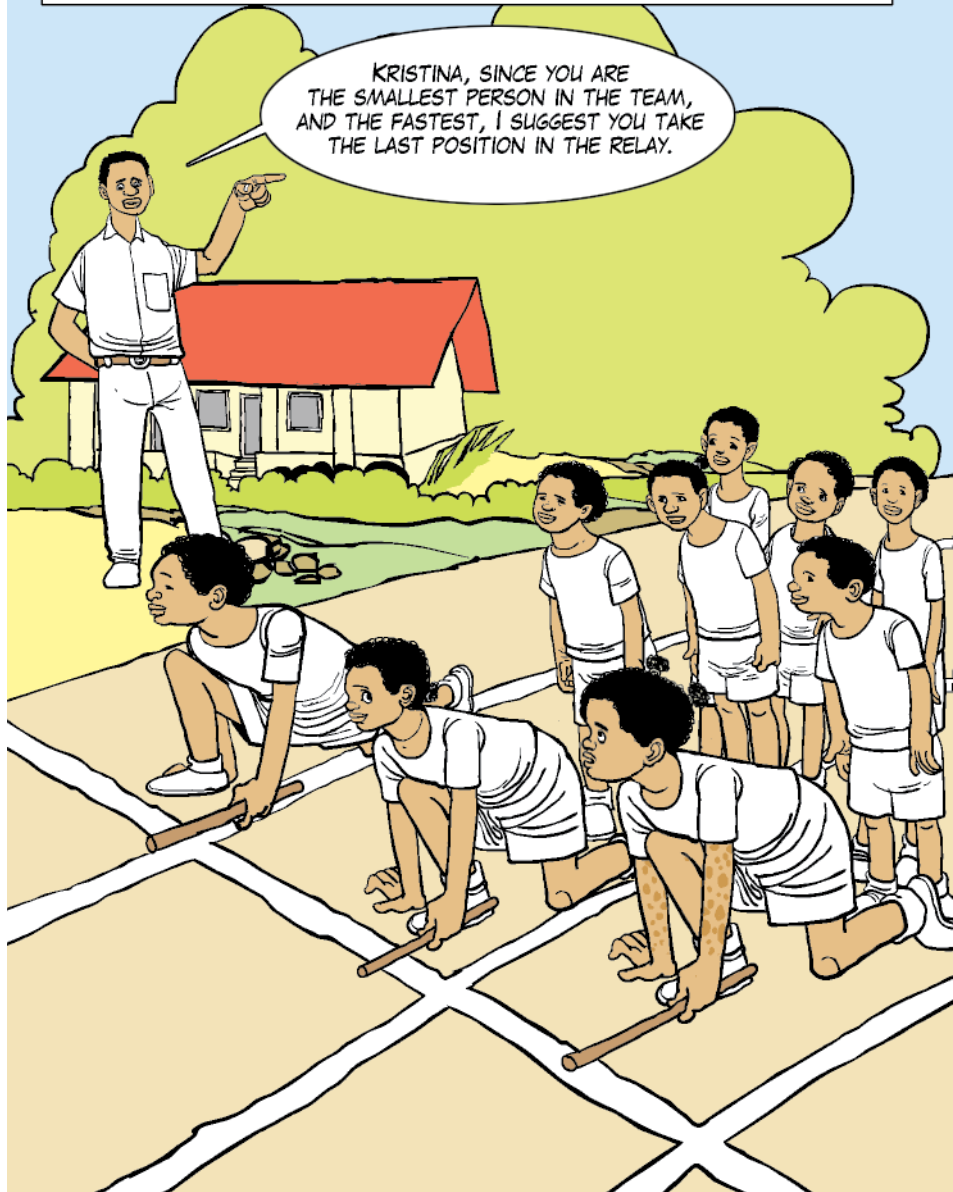
UNFORTUNATELY, WHAT I FEARED MOST, SOON HAPPENED. I WAS IN PRIMARY SIX. IT WAS OUR SCHOOL SPORTS DAY AND I WAS A MEMBER OF OUR CLASS TEAM FOR THE SHORT-RELAY.

WILL ALL THOSE WHO ARE TAKING PART IN THE SHORT-RELAY PLEASE CHANGE INTO YOUR SPORTS UNIFORMS.



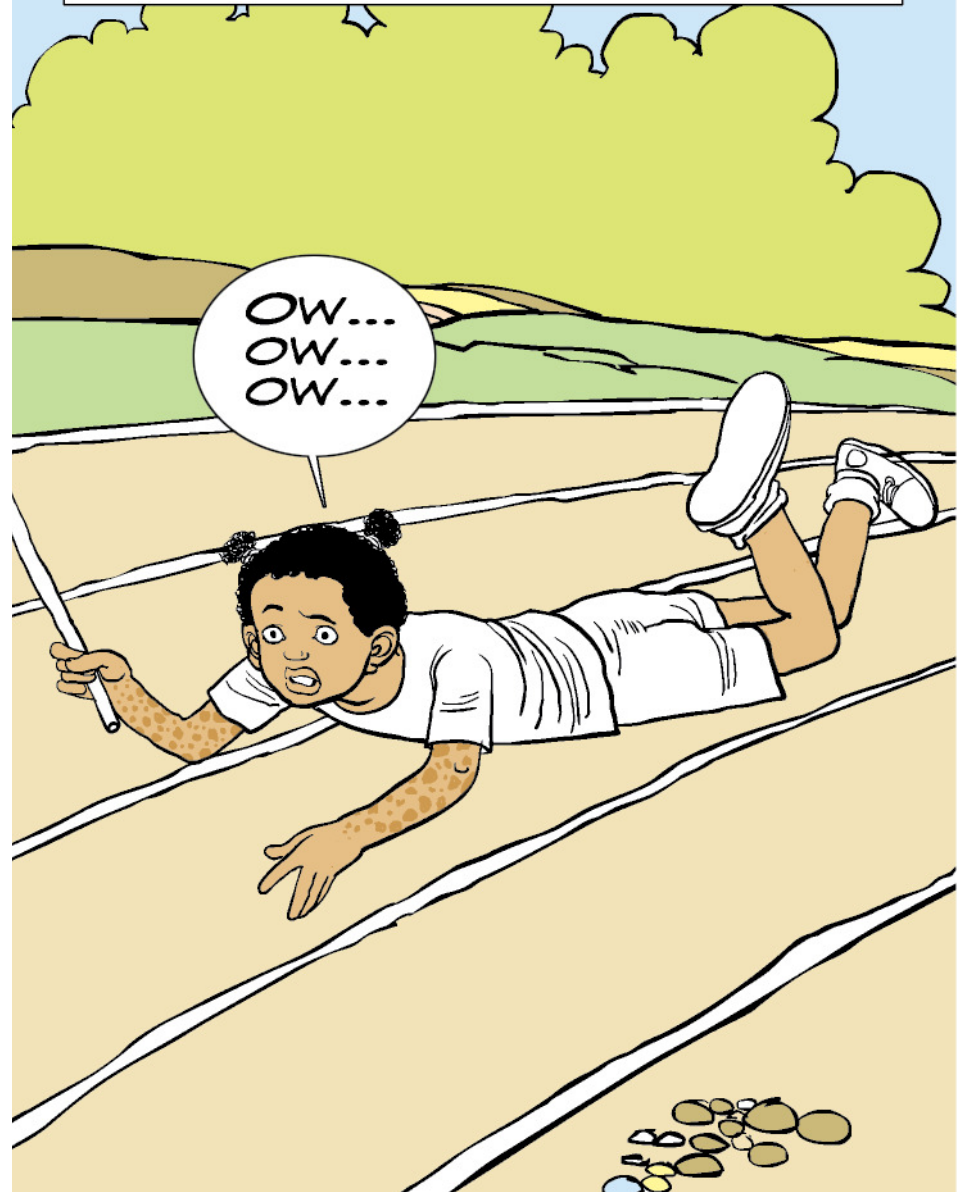
I WAS TOO EXCITED TO REMEMBER THAT I HAVE SCARS ON MY ARMS AND LEGS, SO I WORE MY T-SHIRT AND A PAIR OF SHORTS. I TOOK THE FIRST POSITION ON THE FIELD FOR THE SHORT RELAY.

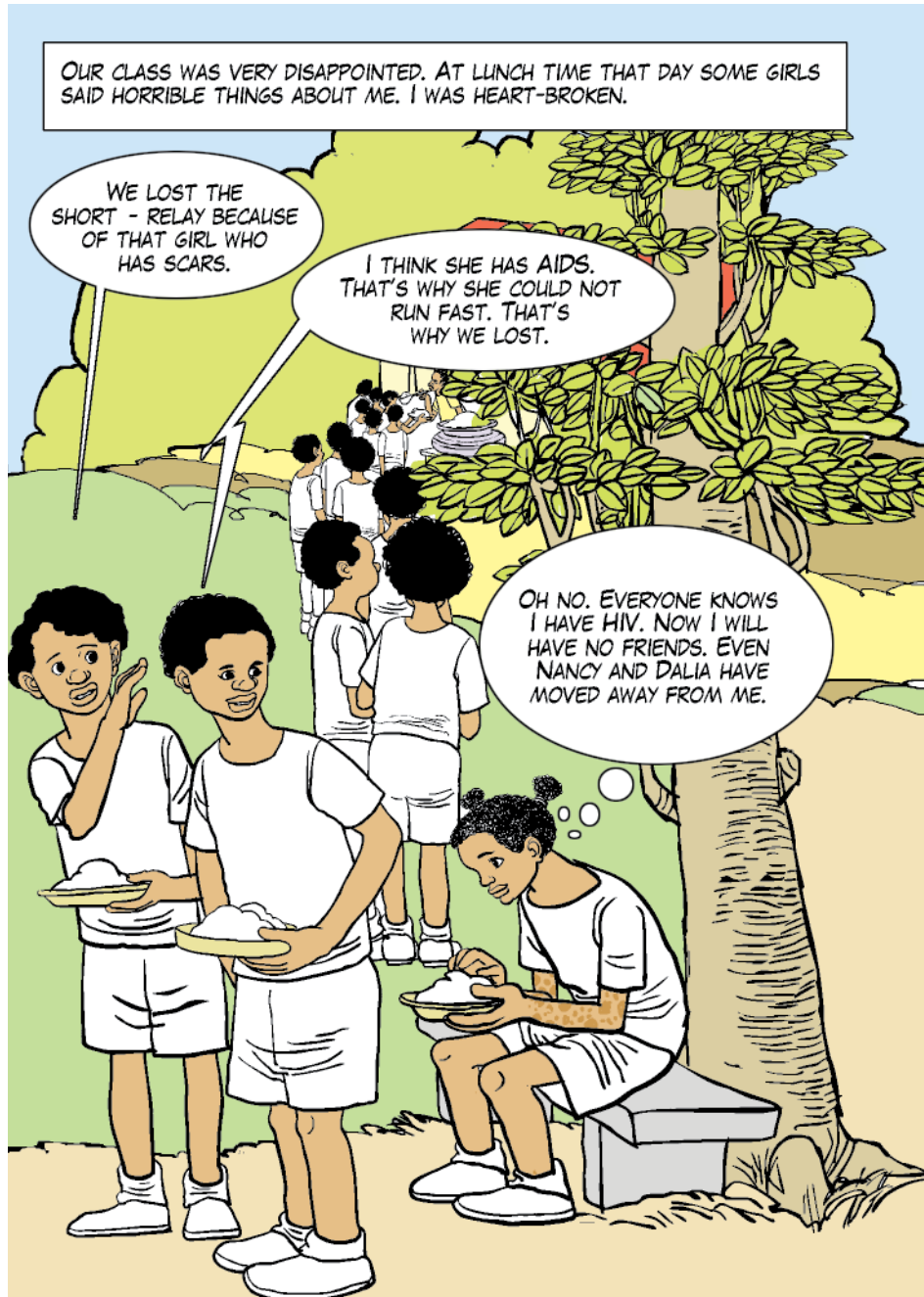
KRISTINA, SINCE YOU ARE THE SMALLEST PERSON IN THE TEAM, AND THE FASTEST, I SUGGEST YOU TAKE THE LAST POSITION IN THE RELAY.



THE RACE STARTED. AT FIRST IT SEEMED LIKE WE WERE TO GOING TO WIN, BUT ALAS... NO SOONER HAD THE BATON BEEN PASSED TO ME THAN I TRIPPED AND FELL DOWN. OUR CLASS TEAM CAME LAST.

OW...
OW...
OW...



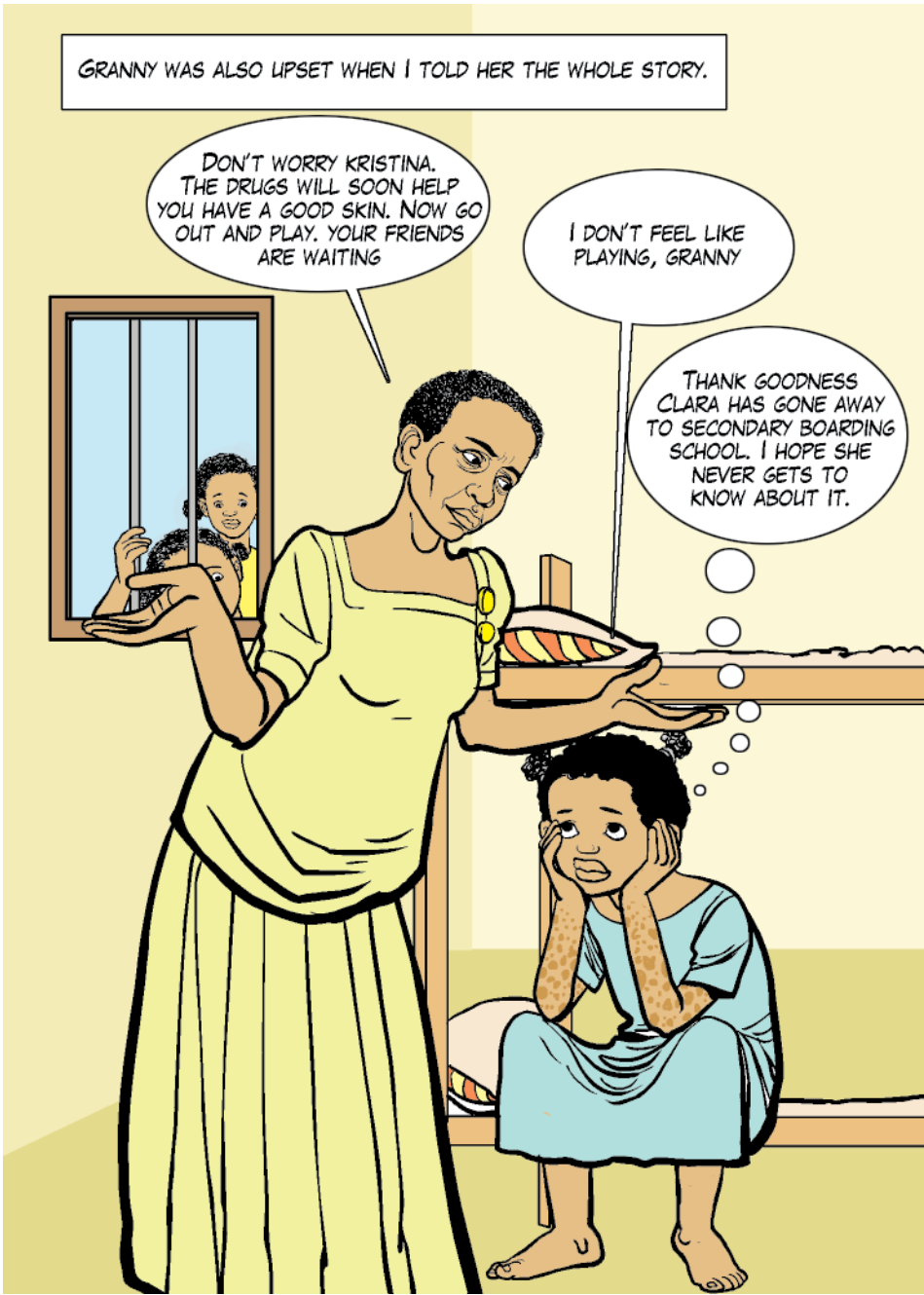


GRANNY WAS ALSO UPSET WHEN I TOLD HER THE WHOLE STORY.

DON'T WORRY KRISTINA. THE DRUGS WILL SOON HELP YOU HAVE A GOOD SKIN. NOW GO OUT AND PLAY. YOUR FRIENDS ARE WAITING

I DON'T FEEL LIKE PLAYING, GRANNY

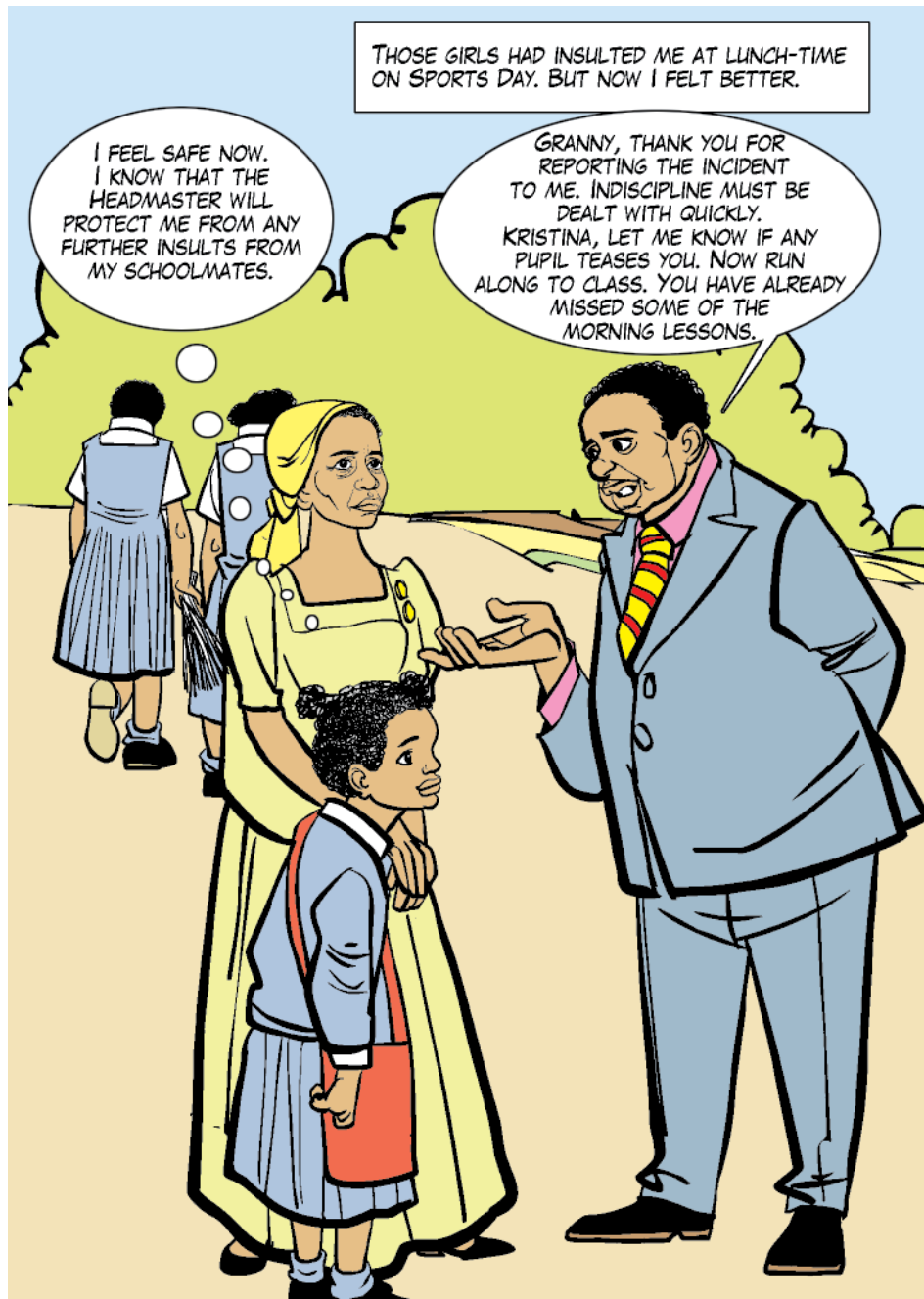
THANK GOODNESS CLARA HAS GONE AWAY TO SECONDARY BOARDING SCHOOL. I HOPE SHE NEVER GETS TO KNOW ABOUT IT.



THE WEEKEND PASSED SLOWLY. ON MONDAY, GRANNY WENT WITH ME TO SCHOOL. SHE TOLD THE HEADMASTER ABOUT MY SPORTS DAY ORDEAL. HE IMMEDIATELY SENT FOR THE TWO GIRLS WHO HAD INSULTED ME.



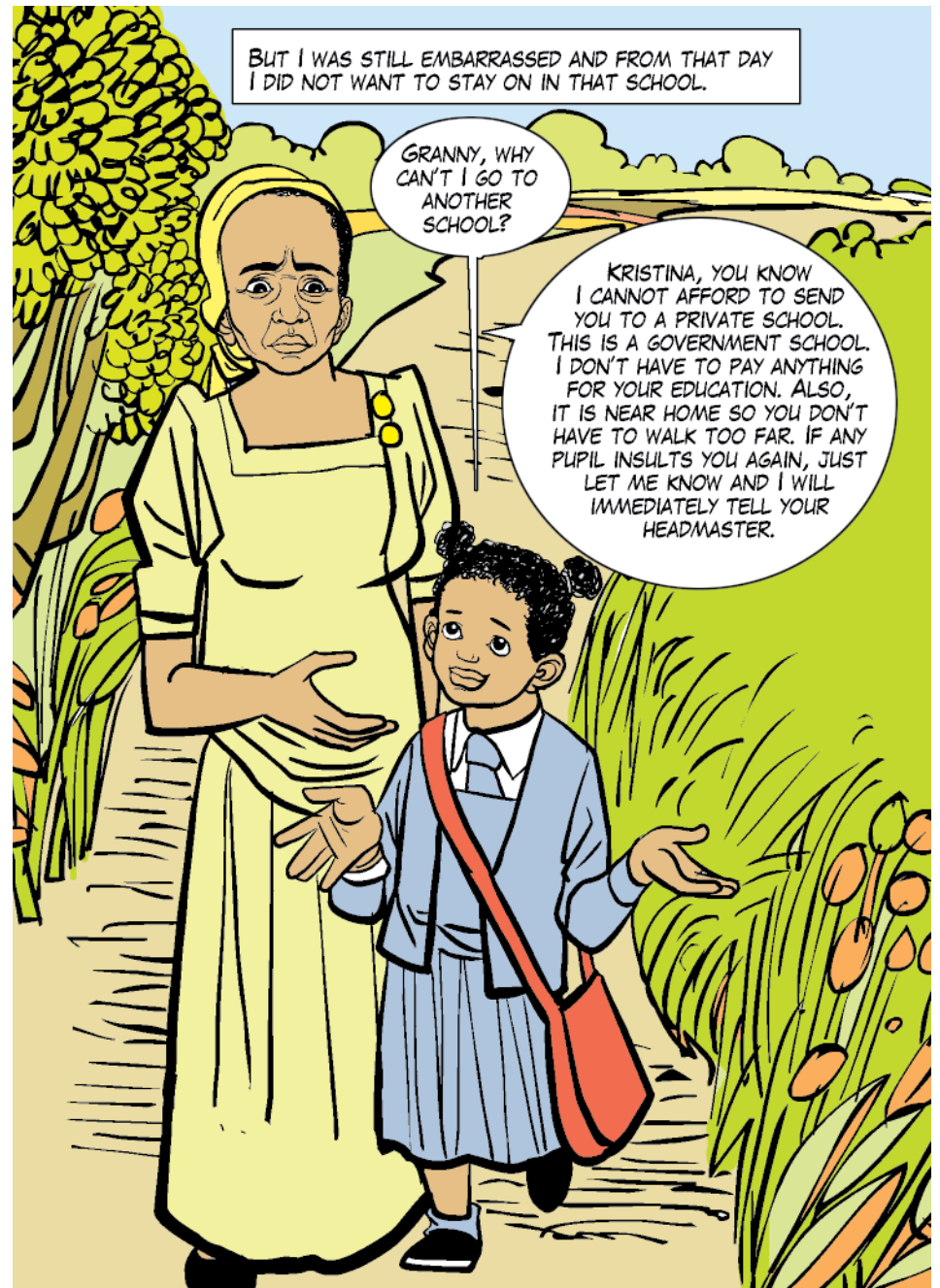
IF YOU EVER DO THIS AGAIN, I WILL EXPEL YOU FROM THE SCHOOL. NOW AS A PUNISHMENT YOU WILL SWEEP THE CLASSROOM FOR A WHOLE WEEK.



THOSE GIRLS HAD INSULTED ME AT LUNCH-TIME ON SPORTS DAY. BUT NOW I FELT BETTER.

I FEEL SAFE NOW. I KNOW THAT THE HEADMASTER WILL PROTECT ME FROM ANY FURTHER INSULTS FROM MY SCHOOLMATES.

GRANNY, THANK YOU FOR REPORTING THE INCIDENT TO ME. INDISCIPLINE MUST BE DEALT WITH QUICKLY. KRISTINA, LET ME KNOW IF ANY PUPIL TEASES YOU. NOW RUN ALONG TO CLASS. YOU HAVE ALREADY MISSED SOME OF THE MORNING LESSONS.



BUT I WAS STILL EMBARRASSED AND FROM THAT DAY I DID NOT WANT TO STAY ON IN THAT SCHOOL.

GRANNY, WHY CAN'T I GO TO ANOTHER SCHOOL?

KRISTINA, YOU KNOW I CANNOT AFFORD TO SEND YOU TO A PRIVATE SCHOOL. THIS IS A GOVERNMENT SCHOOL. I DON'T HAVE TO PAY ANYTHING FOR YOUR EDUCATION. ALSO, IT IS NEAR HOME SO YOU DON'T HAVE TO WALK TOO FAR. IF ANY PUPIL INSULTS YOU AGAIN, JUST LET ME KNOW AND I WILL IMMEDIATELY TELL YOUR HEADMASTER.

IN SCHOOL I WAS UNCOMFORTABLE WHEN TEACHERS TALKED ABOUT HIV IN CLASS OR AT THE PIASCY SESSIONS.

IF I KEEP MY HEAD DOWN THEY WON'T NOTICE ME. THEY ALL SAW THE SIGNS AND SYMPTOMS OF HIV ON ME ON SPORTS DAY. WHY DO I HAVE TO ATTEND THE PIASCY SESSIONS? I AM SURE THE FACILITATORS WILL DISCOVER MY STATUS AS WELL.



BUT, I HAD TO STAY ON IN THAT SCHOOL UNTIL I COMPLETED PRIMARY SEVEN. THEN I JOINED A SECONDARY DAY SCHOOL WHERE NOBODY KNOWS MY SECRET.

I AM NOT AFRAID TO PARTICIPATE IN THE AIDS CLUB IN THIS SCHOOL. MY SECOND LINE DRUGS ARE WORKING WELL. I FEEL STRONG AND HEALTHY. MY SKIN HAS CLEARED AND NO ONE CAN SUSPECT THAT I HAVE HIV. I HAVE HOPE. ONE DAY I WILL BECOME A LAWYER AND HAVE A FAMILY.



THE SUN IS NOW QUITE HIGH IN THE SKY. IT IS STILL COOL.

I BREATHE IN THE FRESH AIR AND I AM HAPPY TO BE ALIVE. I MUST END MY STORY HERE, BUT BEFORE I LEAVE YOU I WOULD LIKE TO SHARE SOME THOUGHTS WITH YOU.



To other young people who, like me, are living with HIV:
"Let's take our drugs well so that we lead healthy lives and achieve all our dreams."
To those who take care of us:
"Love us and encourage us to take drugs regularly so that we don't fall sick like we were before starting ART."
To our health care workers:
"Please continue giving us drugs so that together we can fight the 'robber' HIV/AIDS."

