

# Anita's Tale





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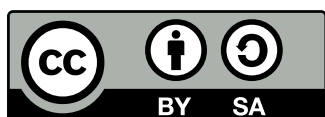
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## INTRODUCTION

This is the story of a young Ugandan girl living with HIV. Anita 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.

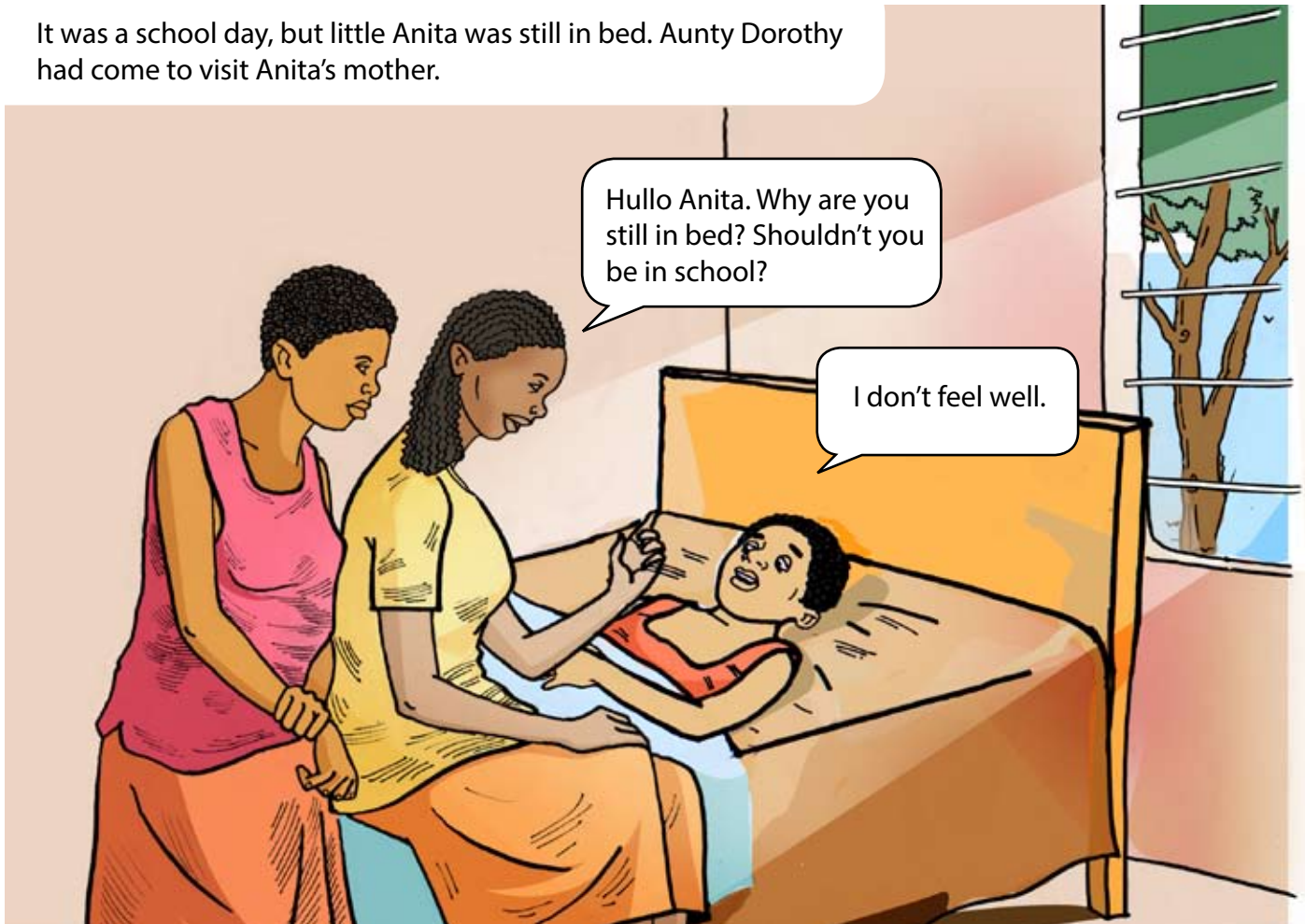
The aim of the ARROW Young Lives project was to find out how young people between the ages of 11 and 13 years managed being HIV-positive. We interviewed 104 young people, their carers and health workers. Some of the young people were interviewed four times, over 18 months. We hope this story will help 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.





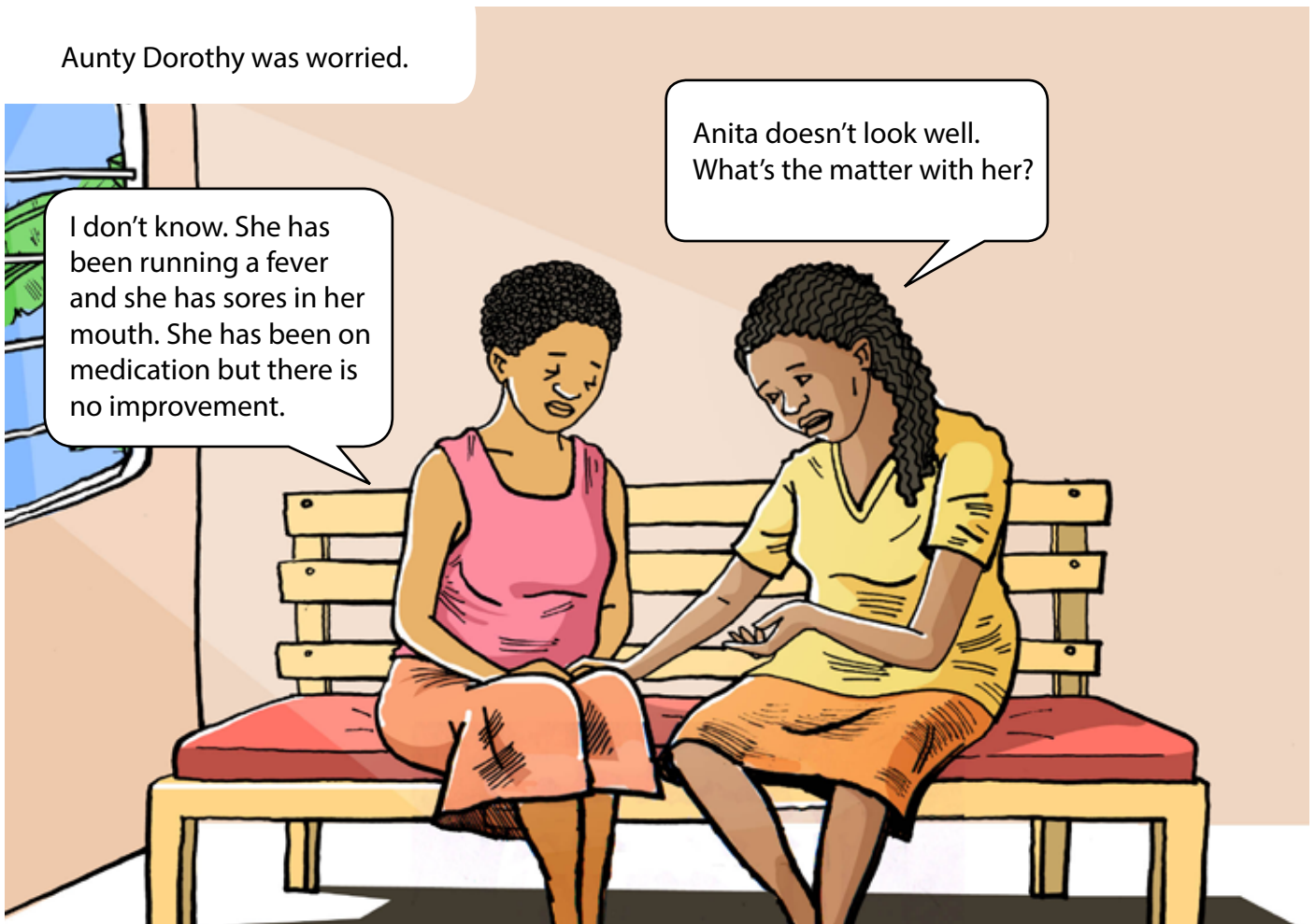
It was a school day, but little Anita was still in bed. Aunty Dorothy had come to visit Anita's mother.



Hullo Anita. Why are you still in bed? Shouldn't you be in school?

I don't feel well.

Aunty Dorothy was worried.



I don't know. She has been running a fever and she has sores in her mouth. She has been on medication but there is no improvement.

Anita doesn't look well. What's the matter with her?

Aunty Dorothy took this very seriously.

You should take her to the clinic. She may be HIV positive. My daughter Bena used to be sick like this and then we discovered that she is HIV positive. Don't waste any more time. If you like I can take you there.

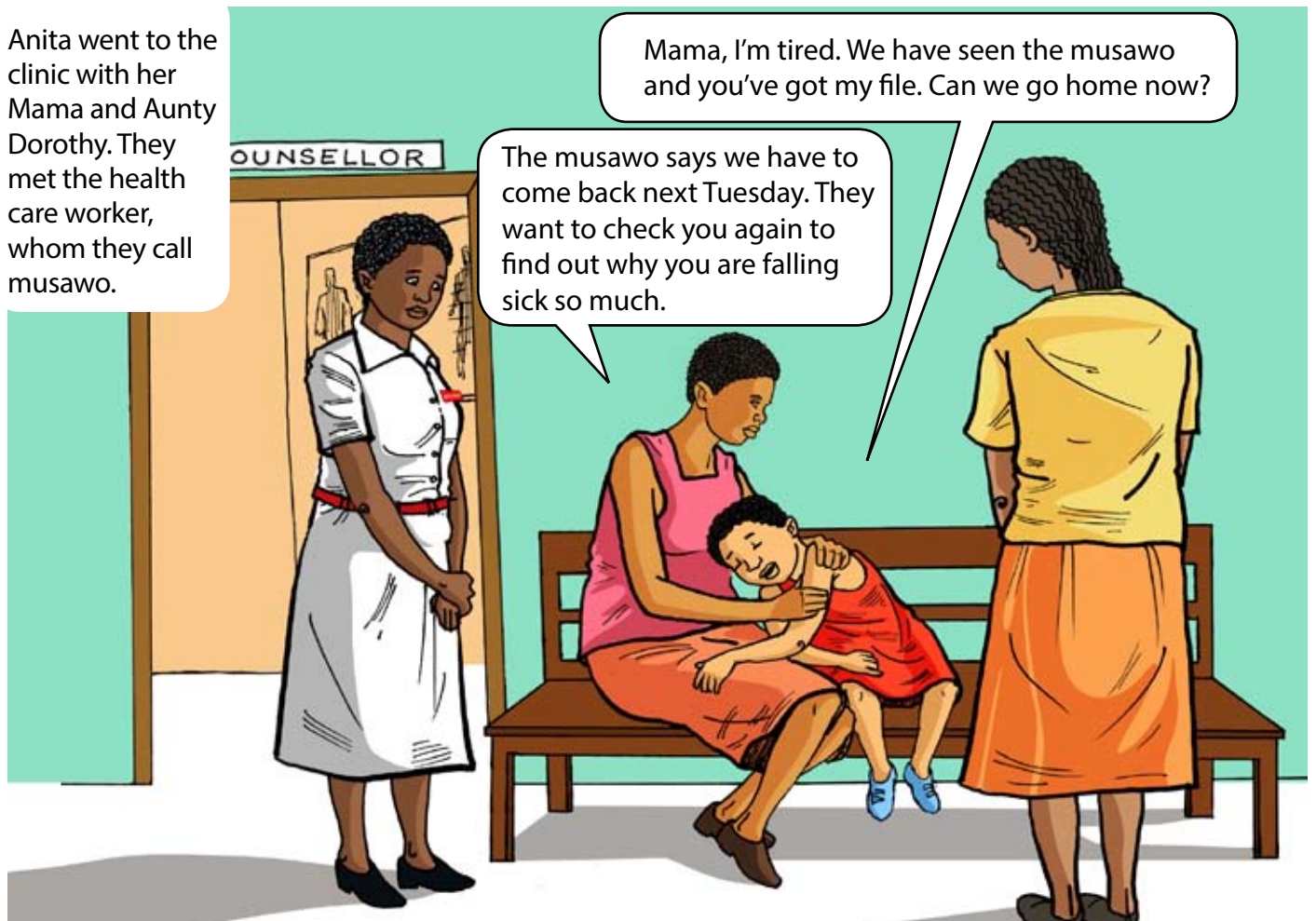
HIV? Oh no! I had hoped that none of my children would get it from me. My boys seem fine. Why should my little girl get it?



Anita went to the clinic with her Mama and Aunty Dorothy. They met the health care worker, whom they call musawo.

Mama, I'm tired. We have seen the musawo and you've got my file. Can we go home now?

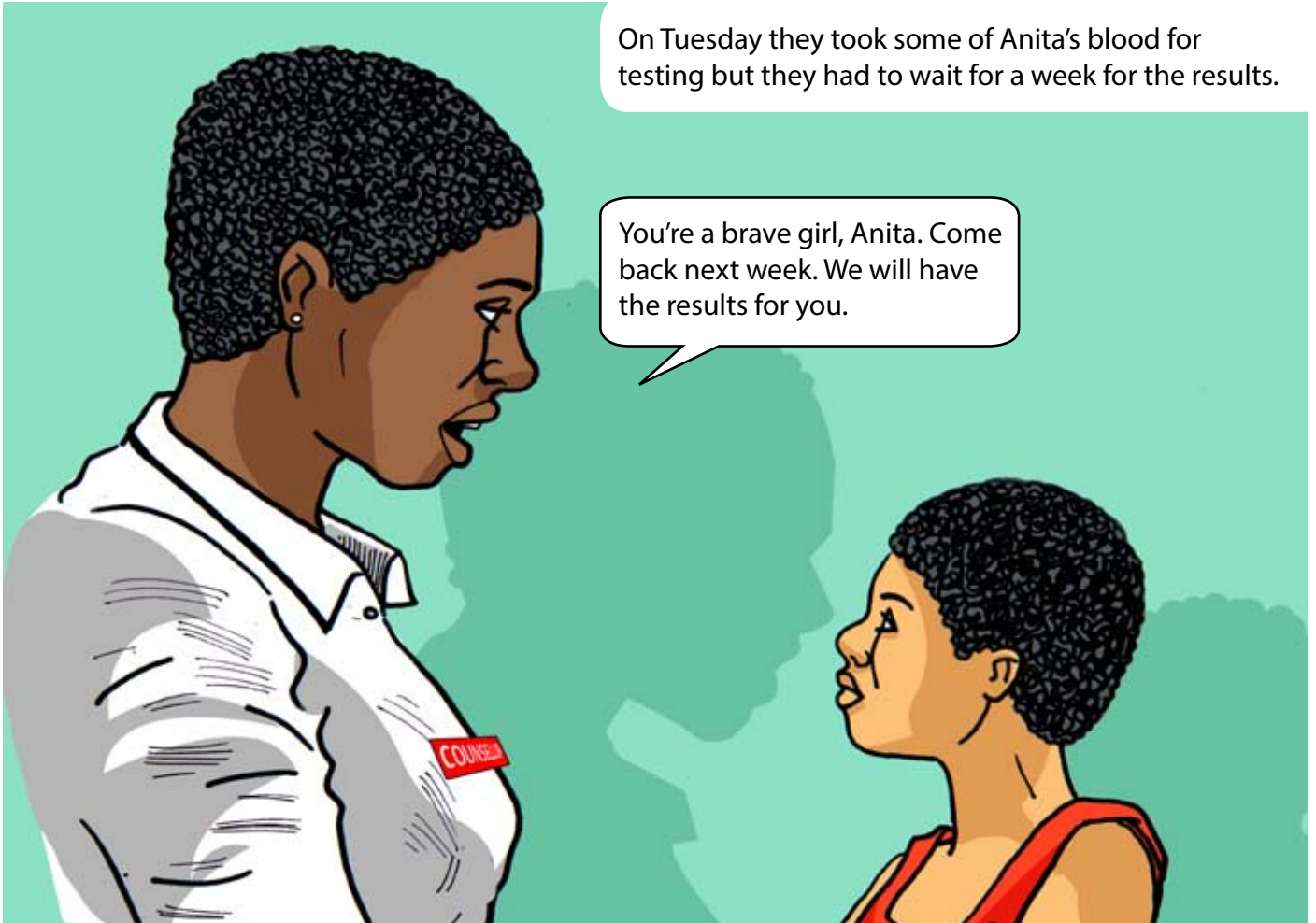
The musawo says we have to come back next Tuesday. They want to check you again to find out why you are falling sick so much.





On Tuesday they took some of Anita's blood for testing but they had to wait for a week for the results.

You're a brave girl, Anita. Come back next week. We will have the results for you.



Meanwhile, Anita became weaker and thinner. Her Mama was very worried.

No, Anita can't play now. She is still weak. She needs to rest.

Anita, come on, let's play.



Next week, when they visited the clinic the musawo told Mama that she had the test results. Anita had HIV. She gave Mama a prescription for the drugs which would make Anita feel better.



From that day Anita took the drugs every day, but she hated them.



Mama made sure that Anita took her drugs according to the musawo's instructions. She also told her other children to make sure that Anita took her drugs regularly.

Anita, come and take your drugs.

Anita, Anita, it's time for your drugs. Come and take your drugs.

Why do they shout? Why can't they call me in a nice way? Can't they see that I'm playing? Why do they have to call me now? And why me? My friends are not being called to take their drugs. I don't like this.



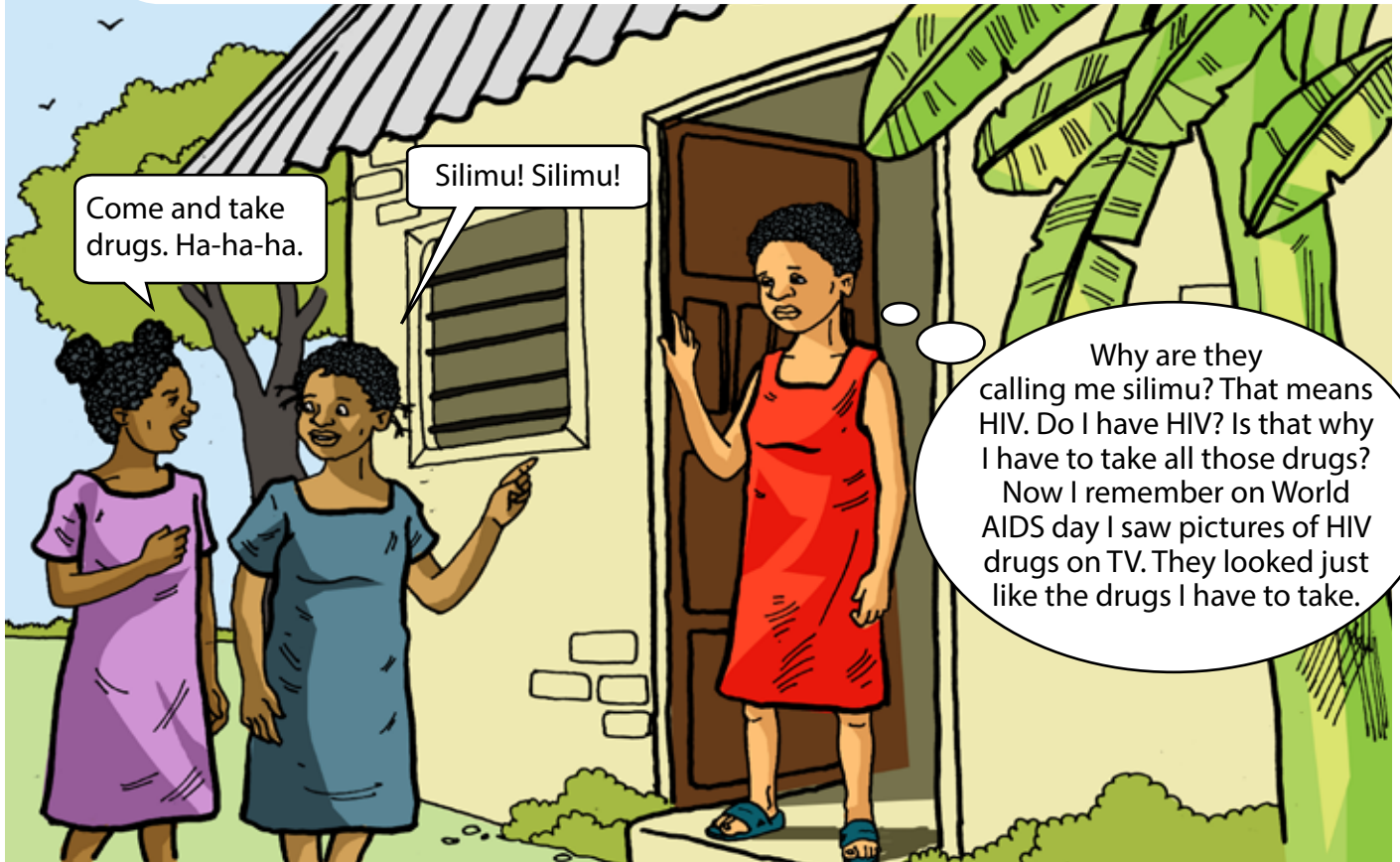
The children in the neighbourhood knew that Anita took drugs. But neither they nor Anita knew the real reason why she took the drugs.

Why do you have to take drugs?

I have a heart disease.



A few months later, one of Anita's friends overheard her mother telling someone about the signs and symptoms of HIV. She immediately thought of Anita and guessed the real reason for Anita's sickness. Anita's friends started teasing her.



Anita ran to her mother.



Anita hated the drugs, so she decided to stop taking them.



Mama says I don't have HIV and I am feeling better so why should I keep taking these drugs? I don't want to take those stupid pills!! It's not fair... none of the others have to. Why do I have to? I will just throw them into the latrine. No one will ever know.

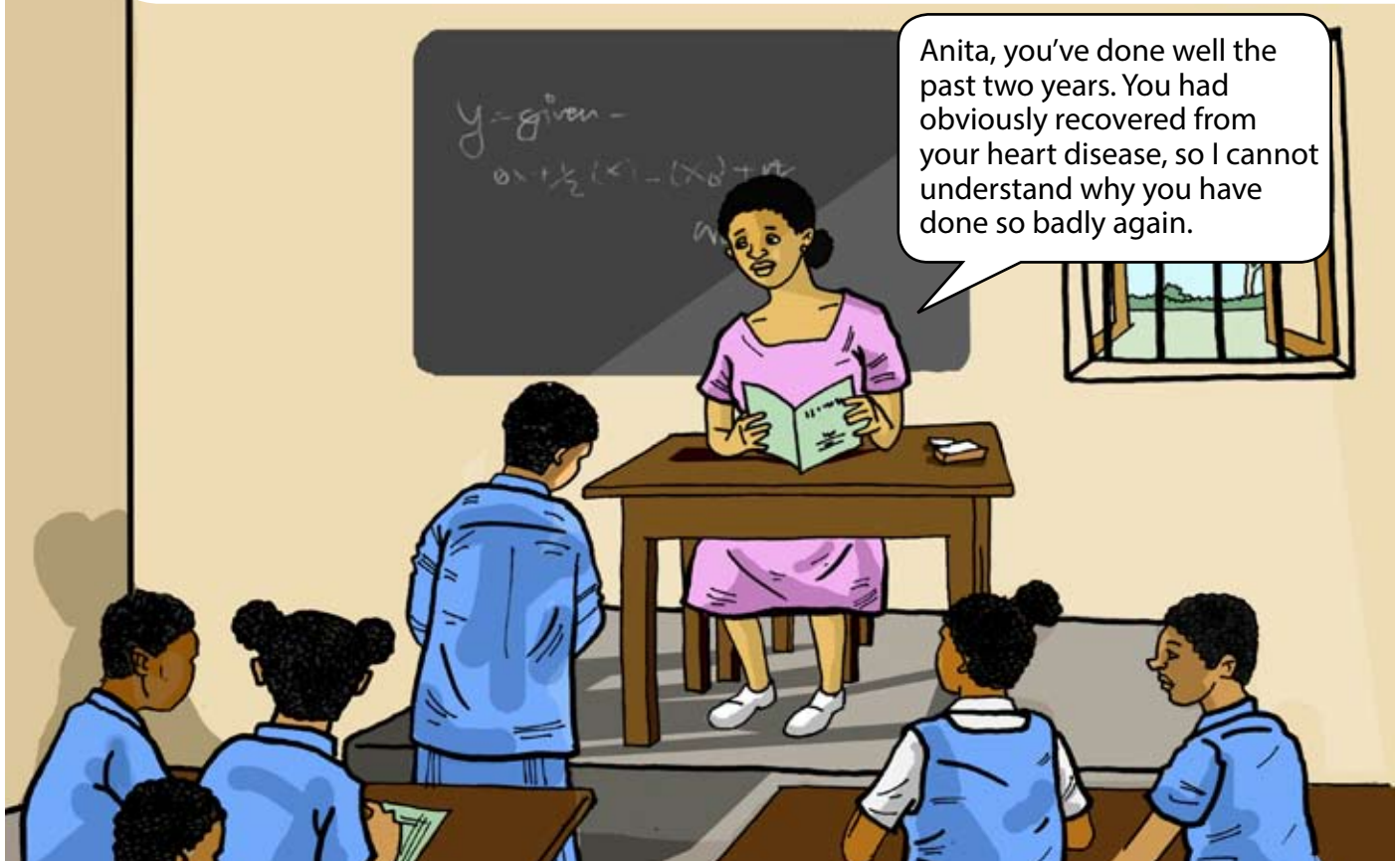
For two weeks, Anita threw her drugs into the latrine. No one knew about this. Soon she started feeling weak and tired, just like she used to feel before she started taking the drugs.



Anita, are you OK? You looked very tired all evening at the party.

I'm fine Mama.

Anita had told her teachers that she had a heart disease. None of them knew that Anita had HIV. And no one knew that she wasn't taking her drugs. A few days later, Anita got her report card. She was the second last in class.

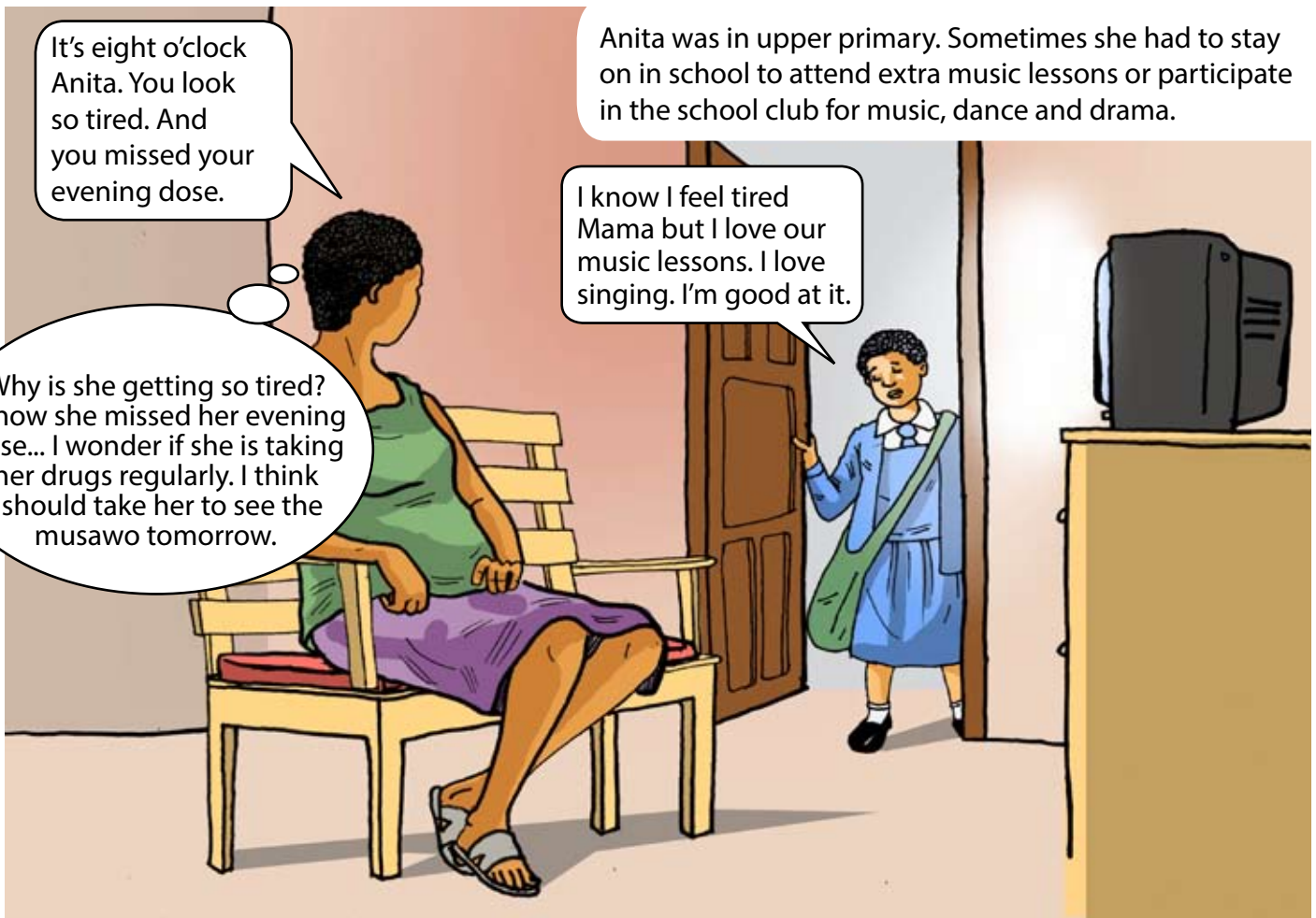


It's eight o'clock Anita. You look so tired. And you missed your evening dose.

Anita was in upper primary. Sometimes she had to stay on in school to attend extra music lessons or participate in the school club for music, dance and drama.

I know I feel tired Mama but I love our music lessons. I love singing. I'm good at it.

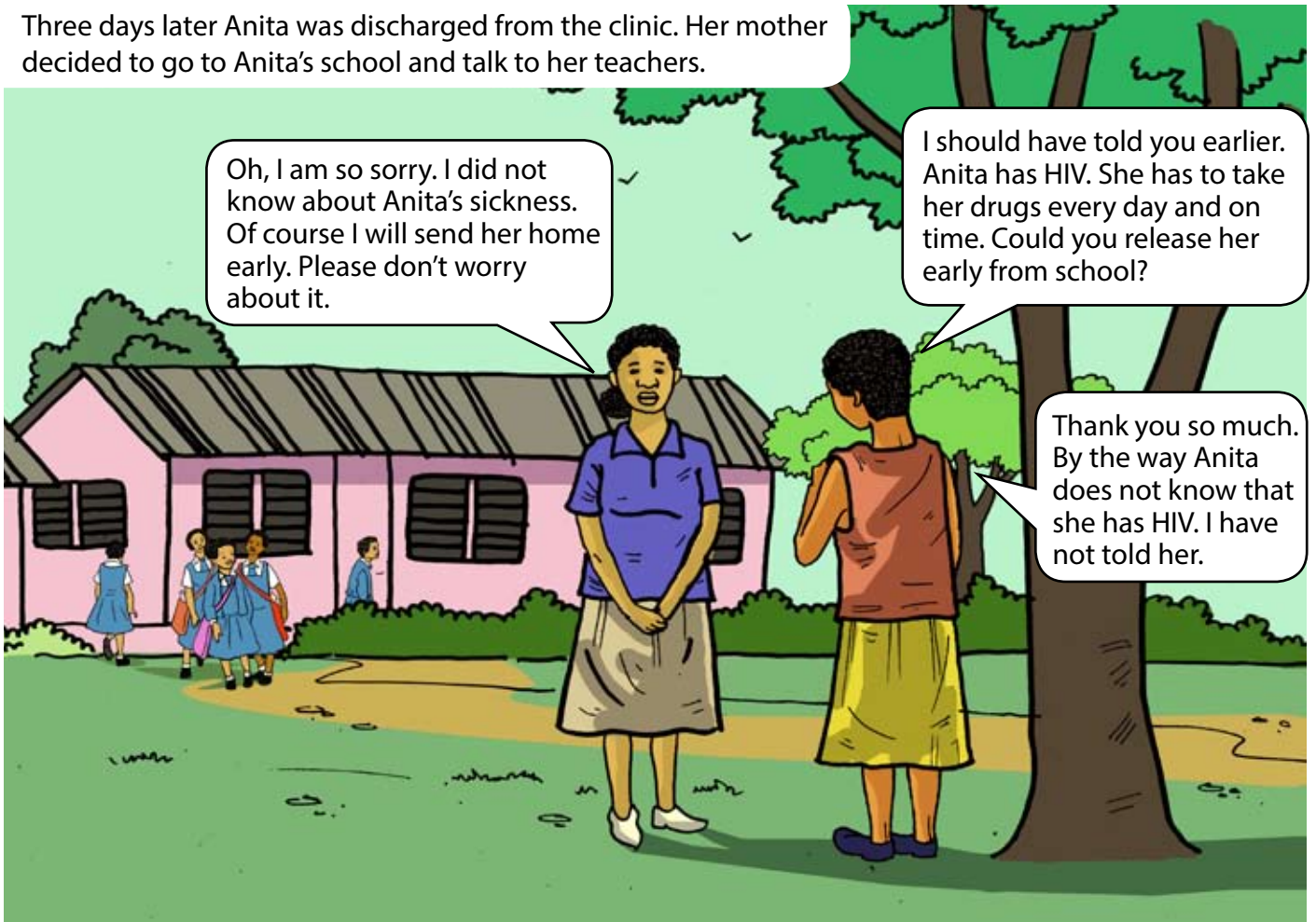
Why is she getting so tired? I know she missed her evening dose... I wonder if she is taking her drugs regularly. I think I should take her to see the musawo tomorrow.



But the next morning Anita collapsed in her room and her mother had to rush her to the clinic.




Three days later Anita was discharged from the clinic. Her mother decided to go to Anita's school and talk to her teachers.




Anita knew that her mother had come to school but didn't know what she and her teacher had talked about. Later that evening, when Anita got home, she was very angry and upset.








She is so upset but I cannot tell her that she has HIV. She will be even more upset.




How could you do that? You just don't want me to do the things I really love and I am good at. I want to take part in the music competition. I know I can win. You are against me. You, and the teachers. There is nothing wrong with my heart but you make me have those horrible drugs. Why? Why don't my brothers have to take any drugs? Why only me?



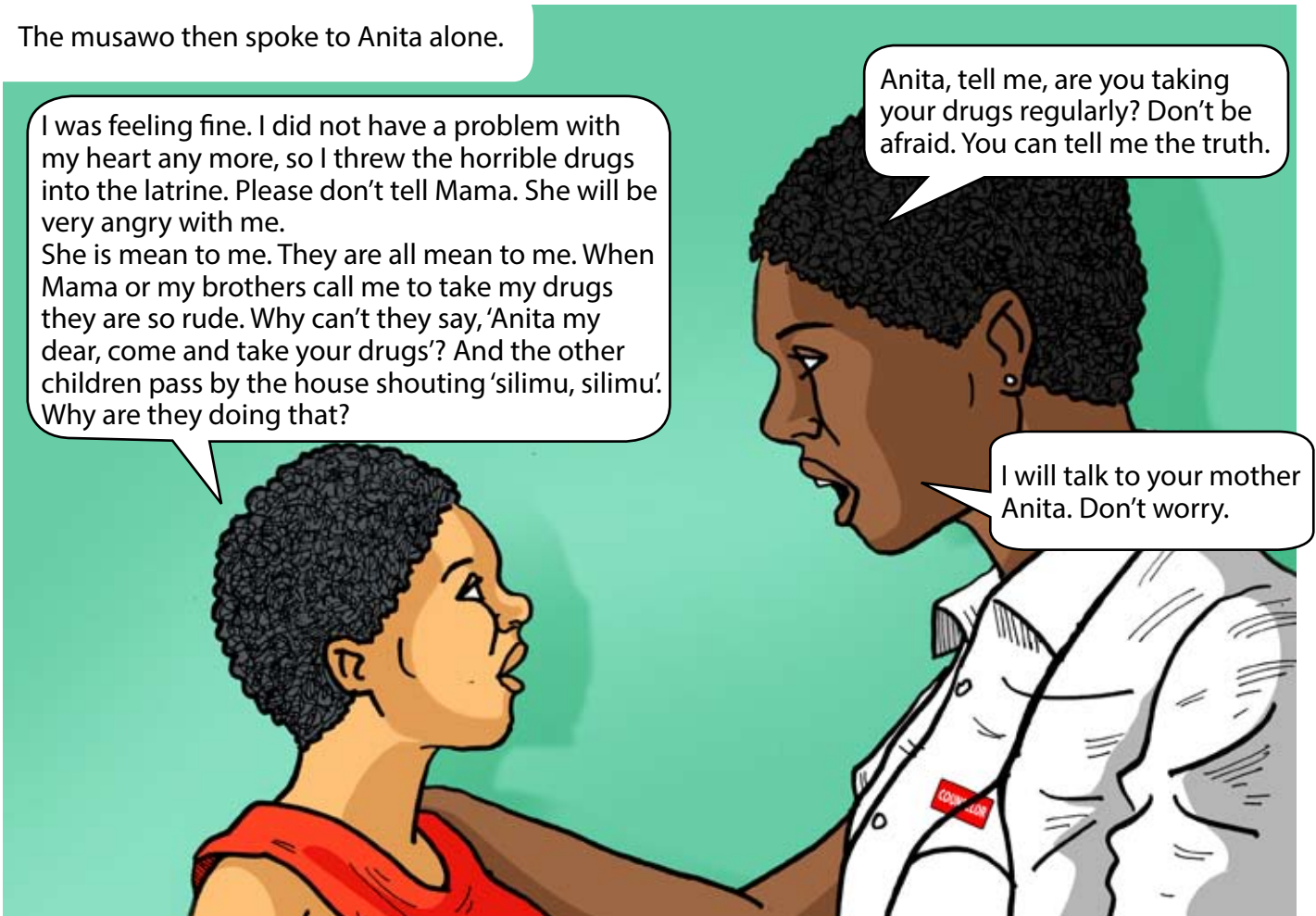
I stopped Anita from taking extra music lessons so that she could come home in time for her evening dose. She is very upset about it. I think it is time to tell her why she has to take the drugs. But I cannot tell her that she has HIV. Please help me. Will you tell her?

Anita's mother could not tell her that she had HIV, even though the musawo had advised her to do so. During Anita's school holidays her mother took her back to the clinic.



No, I cannot do it. That would not be right. You are her mother. You must tell her yourself.

The musawo then spoke to Anita alone.



I was feeling fine. I did not have a problem with my heart any more, so I threw the horrible drugs into the latrine. Please don't tell Mama. She will be very angry with me. She is mean to me. They are all mean to me. When Mama or my brothers call me to take my drugs they are so rude. Why can't they say, 'Anita my dear, come and take your drugs'? And the other children pass by the house shouting 'silimu, silimu'. Why are they doing that?

Anita, tell me, are you taking your drugs regularly? Don't be afraid. You can tell me the truth.

I will talk to your mother Anita. Don't worry.

That evening when Mama called Anita there was a change.



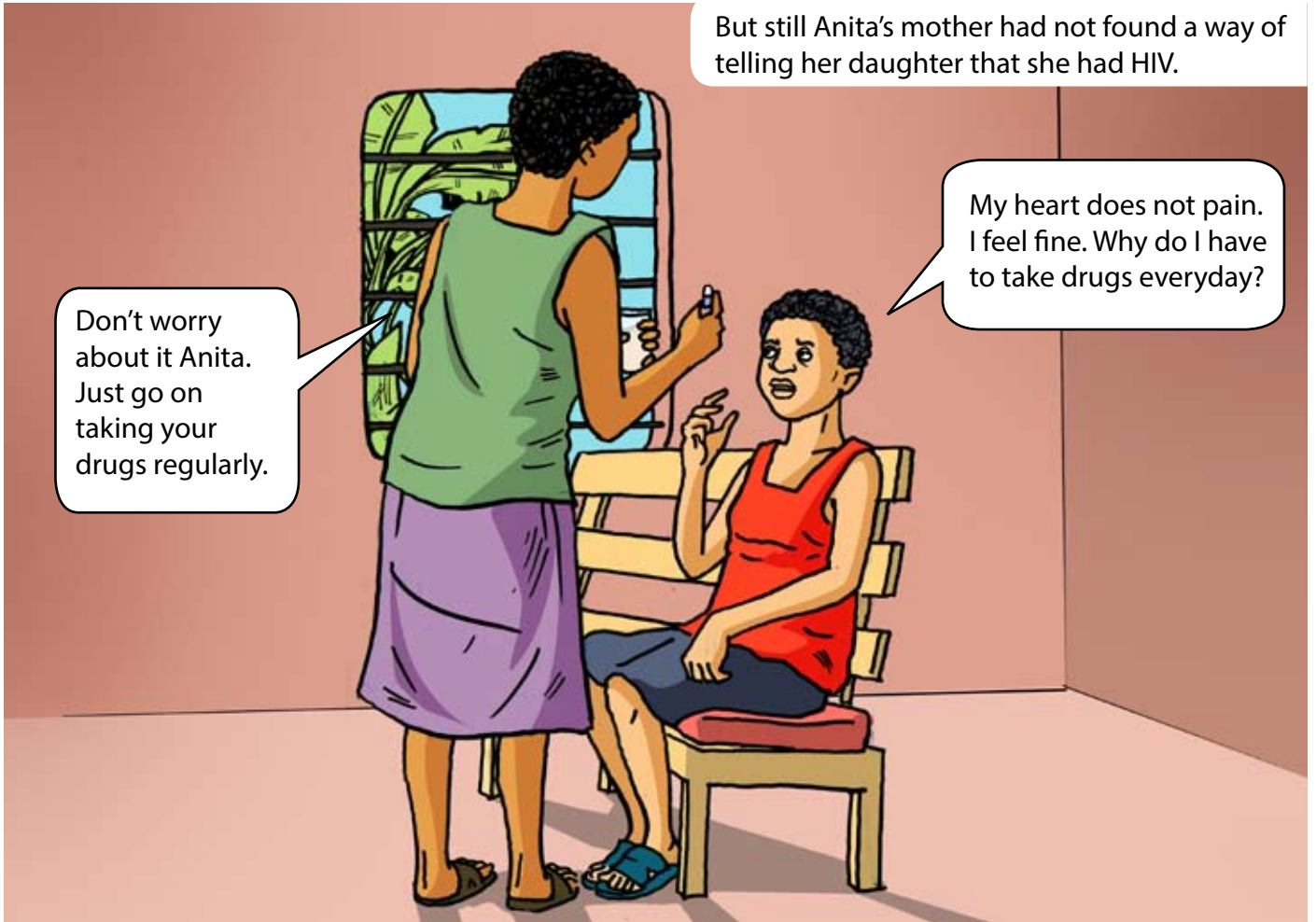
Mama is calling me so politely. That's nice. But I must remind myself to take my drugs every evening and morning so that no one has to call me.

Anita my dear, please come and take your drugs.

But still Anita's mother had not found a way of telling her daughter that she had HIV.

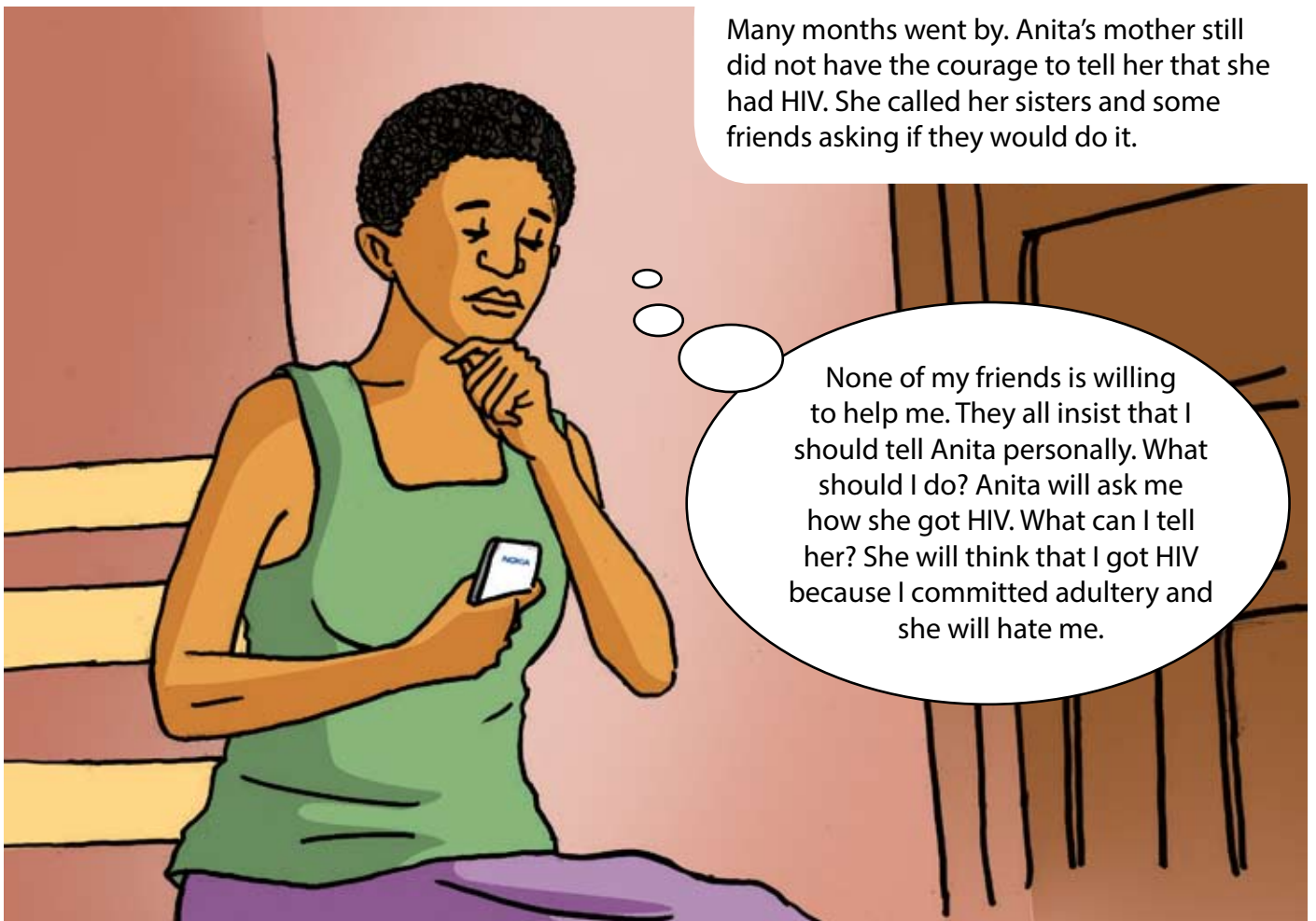
Don't worry about it Anita. Just go on taking your drugs regularly.

My heart does not pain. I feel fine. Why do I have to take drugs everyday?

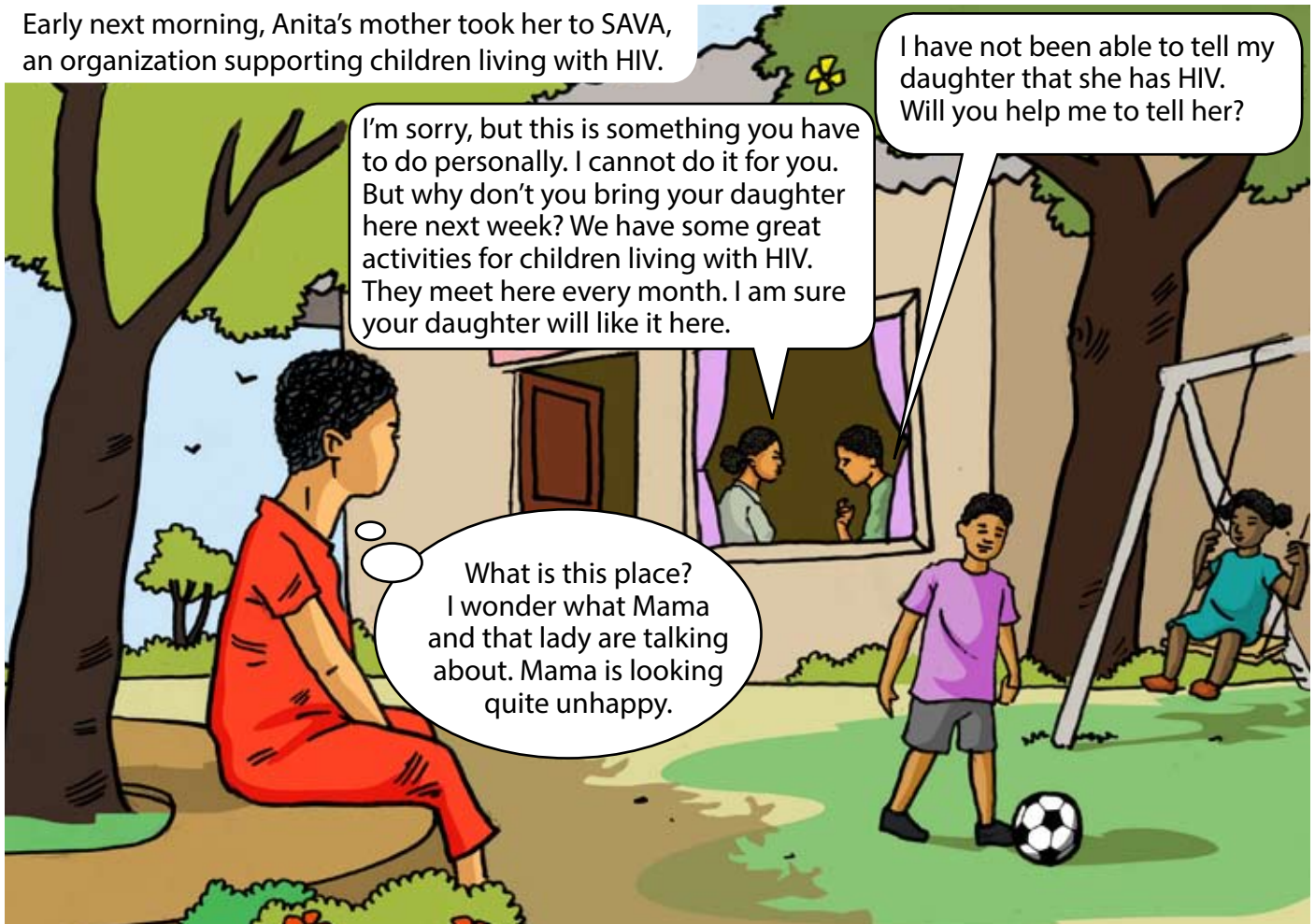


Many months went by. Anita's mother still did not have the courage to tell her that she had HIV. She called her sisters and some friends asking if they would do it.

None of my friends is willing to help me. They all insist that I should tell Anita personally. What should I do? Anita will ask me how she got HIV. What can I tell her? She will think that I got HIV because I committed adultery and she will hate me.



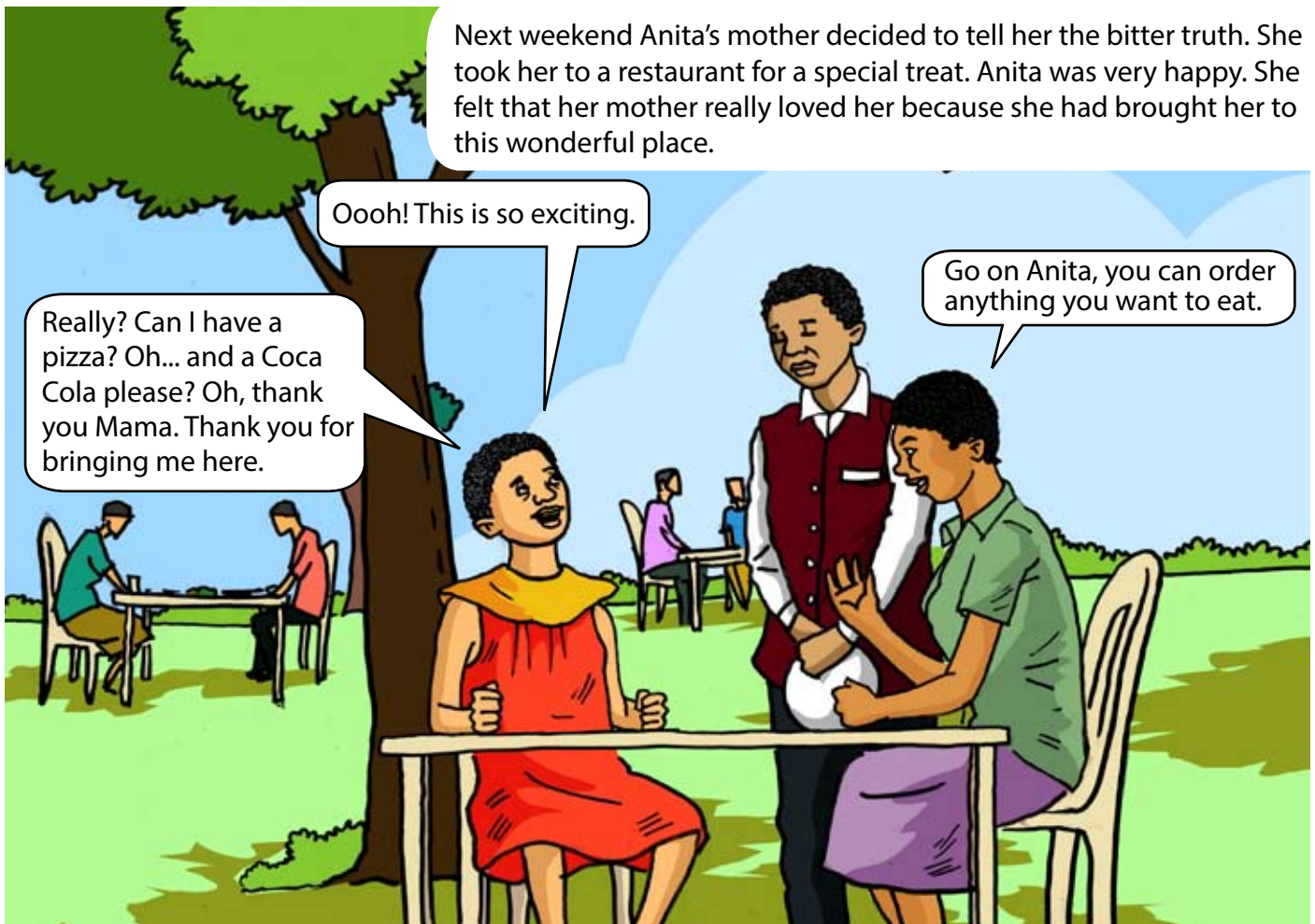
Early next morning, Anita's mother took her to SAVA, an organization supporting children living with HIV.



I'm sorry, but this is something you have to do personally. I cannot do it for you. But why don't you bring your daughter here next week? We have some great activities for children living with HIV. They meet here every month. I am sure your daughter will like it here.

I have not been able to tell my daughter that she has HIV. Will you help me to tell her?

What is this place? I wonder what Mama and that lady are talking about. Mama is looking quite unhappy.



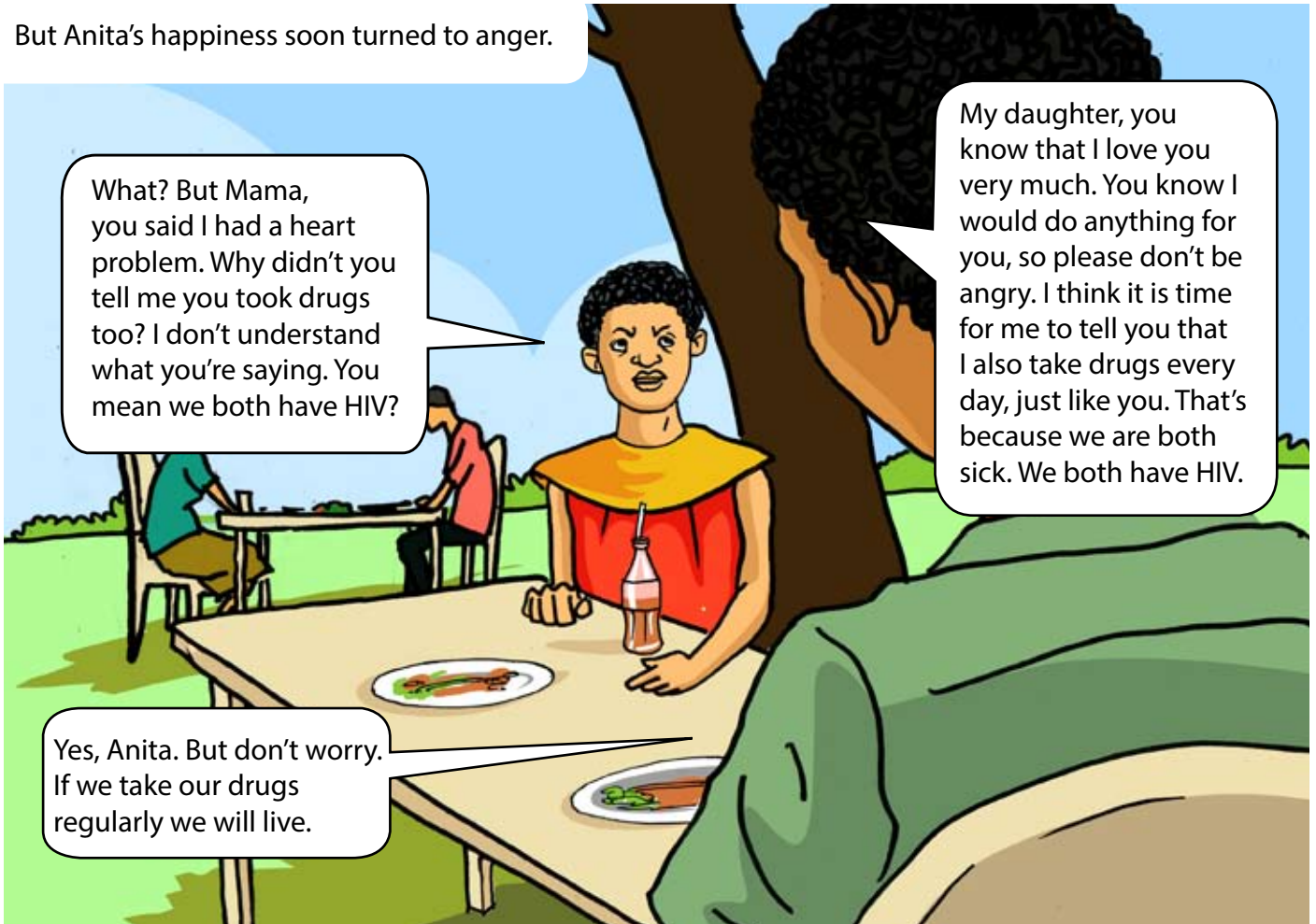
Next weekend Anita's mother decided to tell her the bitter truth. She took her to a restaurant for a special treat. Anita was very happy. She felt that her mother really loved her because she had brought her to this wonderful place.

Oooh! This is so exciting.

Really? Can I have a pizza? Oh... and a Coca Cola please? Oh, thank you Mama. Thank you for bringing me here.

Go on Anita, you can order anything you want to eat.

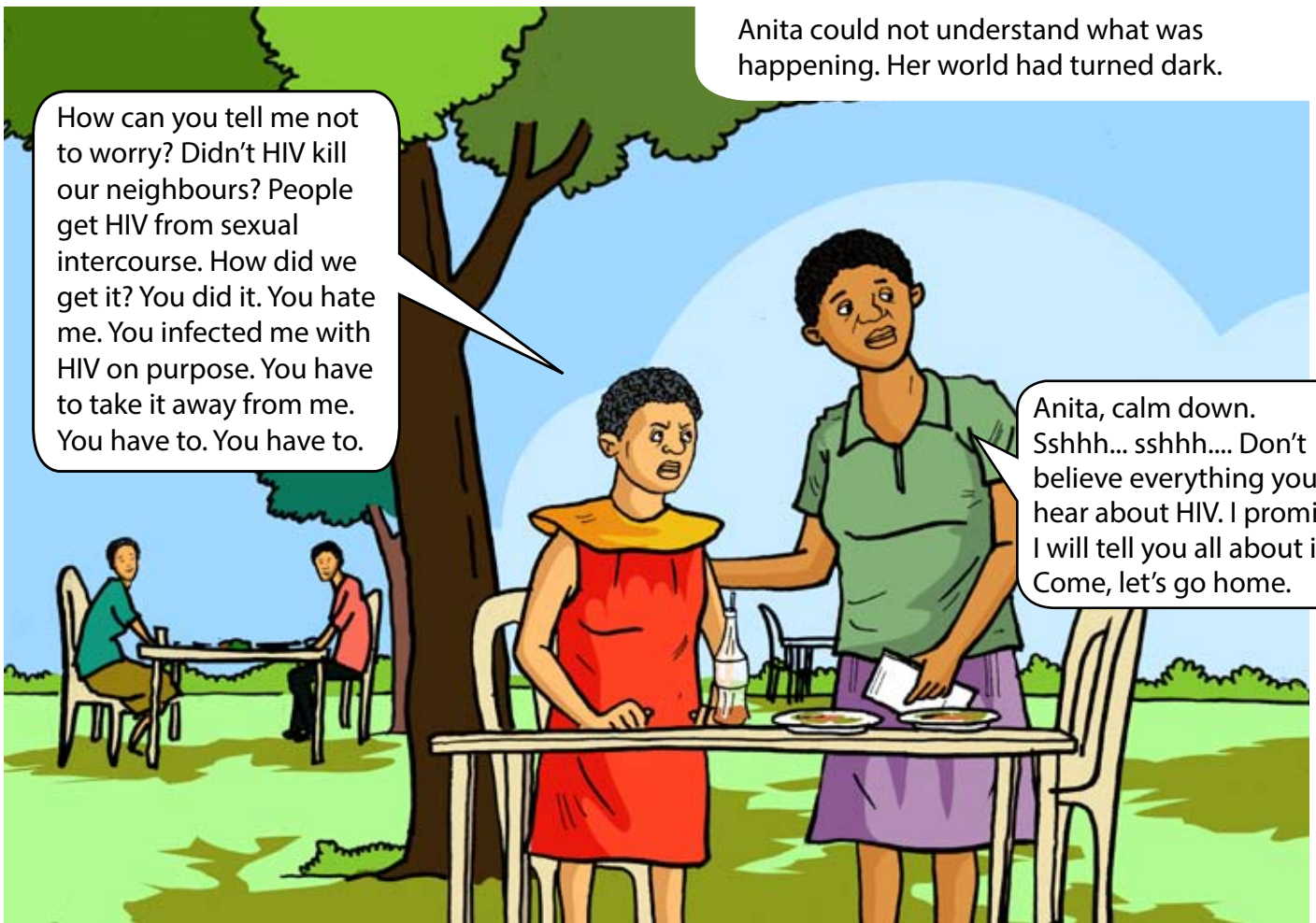
But Anita's happiness soon turned to anger.



What? But Mama, you said I had a heart problem. Why didn't you tell me you took drugs too? I don't understand what you're saying. You mean we both have HIV?

My daughter, you know that I love you very much. You know I would do anything for you, so please don't be angry. I think it is time for me to tell you that I also take drugs every day, just like you. That's because we are both sick. We both have HIV.

Yes, Anita. But don't worry. If we take our drugs regularly we will live.

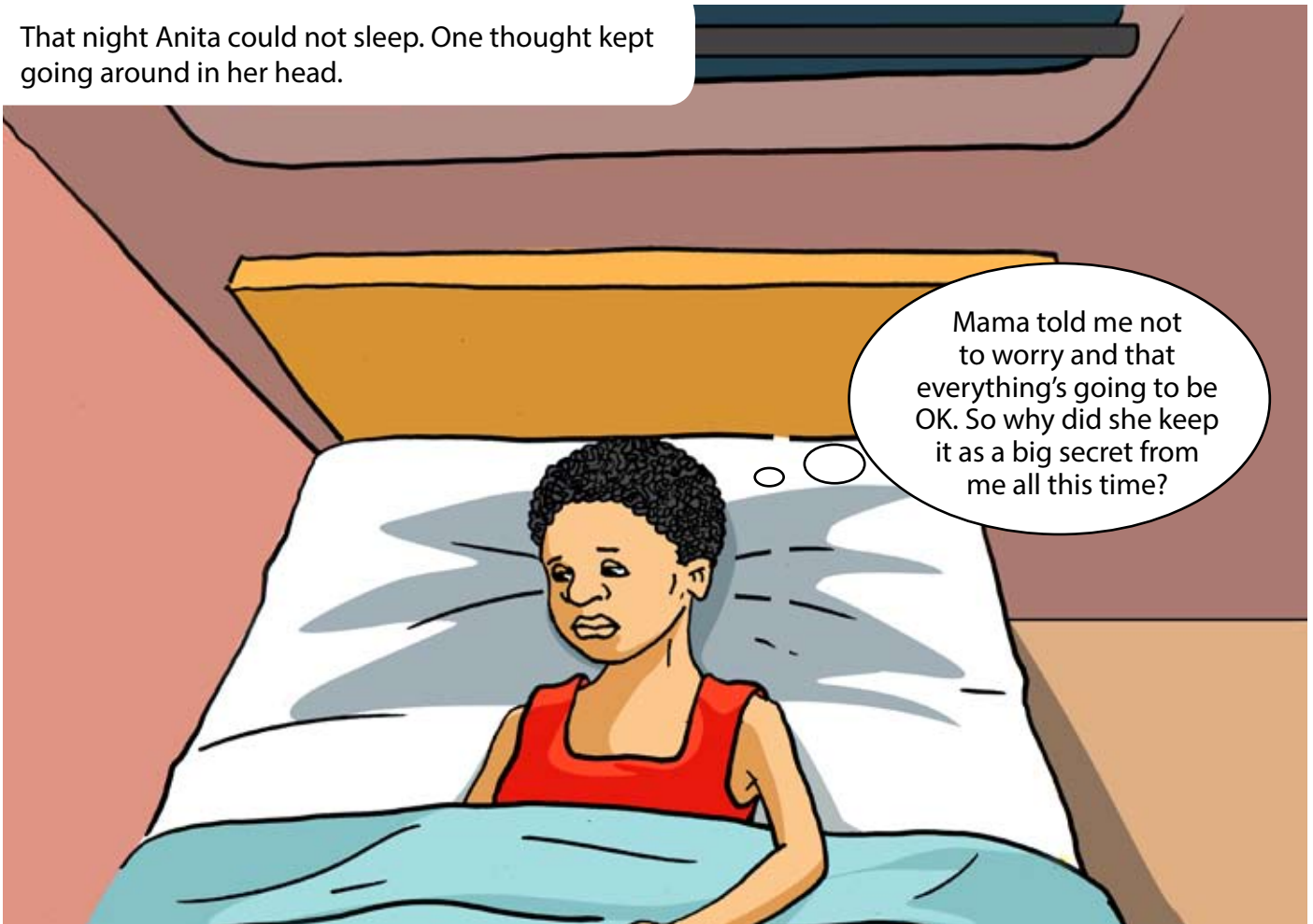


Anita could not understand what was happening. Her world had turned dark.

How can you tell me not to worry? Didn't HIV kill our neighbours? People get HIV from sexual intercourse. How did we get it? You did it. You hate me. You infected me with HIV on purpose. You have to take it away from me. You have to. You have to.

Anita, calm down. Sshhh... sshhh.... Don't believe everything you hear about HIV. I promise I will tell you all about it. Come, let's go home.

That night Anita could not sleep. One thought kept going around in her head.



Mama told me not to worry and that everything's going to be OK. So why did she keep it as a big secret from me all this time?

Anita's mother was also upset, but she remembered that children living with HIV met each other at SAVA on one particular day every month.



My poor Anita. She is so unhappy. I think I will take her to SAVA tomorrow. It will help her to understand that there are many children like her. I hope it will make her feel less unhappy.

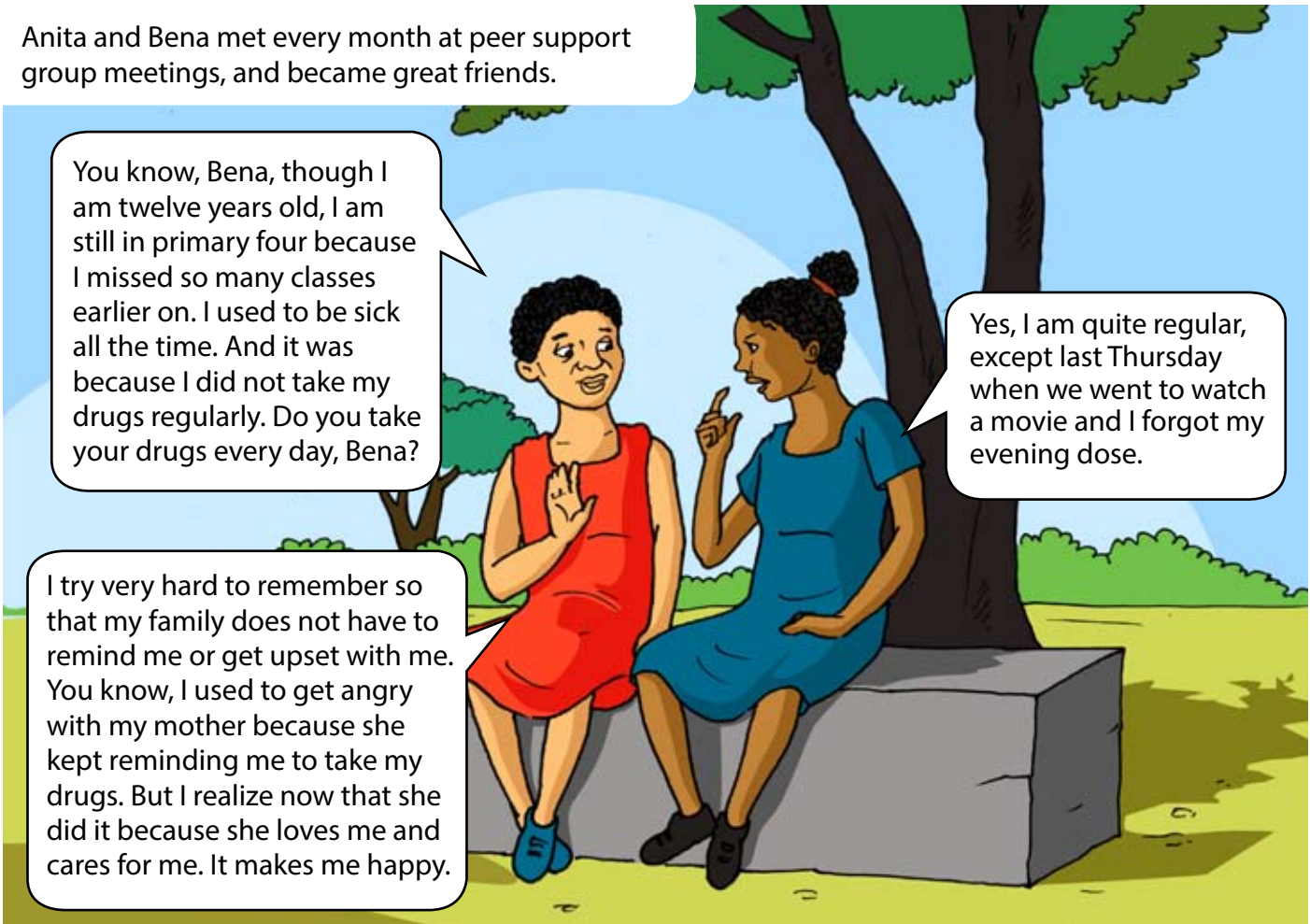
The next morning Anita's mother took her to SAVA. Anita was still upset.



It turned out to be one of the happiest days of Anita's life.



Anita and Bena met every month at peer support group meetings, and became great friends.



You know, Bena, though I am twelve years old, I am still in primary four because I missed so many classes earlier on. I used to be sick all the time. And it was because I did not take my drugs regularly. Do you take your drugs every day, Bena?

Yes, I am quite regular, except last Thursday when we went to watch a movie and I forgot my evening dose.

I try very hard to remember so that my family does not have to remind me or get upset with me. You know, I used to get angry with my mother because she kept reminding me to take my drugs. But I realize now that she did it because she loves me and cares for me. It makes me happy.

Every day, Anita's mother would tell her something about her illness. Soon Anita began to understand that getting HIV was not intentional.



I am so glad that Mama talks to me about HIV. I feel a lot better about myself and her. I know we are not the only people with HIV and I can live with it. It does not upset me any more.



Anita is now happy. She understands her illness and knows that she has to keep taking her drugs regularly. And she is not angry with her mother any more.

You know, Bena, I don't want to have HIV, but I am learning to live with it. At least now I am not alone and can talk about it with Mama and you. Poor Mama. I know now that life has not been easy for her. My father left us when I was quite small. He does not even know that Mama and I have HIV. Luckily none of my brothers has HIV. Mama still has to remind me sometimes about taking my drugs, but I know she does it because she loves me. She also buys me whatever I need to be able to take my treatment. I love Mama very much. She is my best friend.



