

My mum has HIV



A book for parents living with HIV and their children,
written by members of the Treatment Advocacy &
Literacy Campaign (TALC) in Zambia.



The story, and experiences, of the characters in this book are fictional but are based on the real life experiences of HIV positive parents.

The *My mum has HIV* book was developed from a group project organised by the Treatment Advocacy & Literacy Campaign (TALC), where parents and children were brought together to talk about issues of HIV disclosure.

In the experiences of all participants, both parents and children felt that disclosure of the parent's HIV status was very important and improved relationships and treatment support within the family.

While every family is different, the participants involved in this project strongly encourage HIV positive parents to use this book as a tool to help them disclose their status to their children.

Participants felt that parents should disclose when they felt the child was mature enough to understand basic facts about HIV. They also believe that sharing information about HIV is considered an important first-step in the process of disclosure.

To learn more about TALC, HIV and treatment access in Zambia please contact the Treatment Advocacy & Literacy Campaign using the details in the back of this book.

**Thank you and
keep living positively**

Foreword

When people discover they are HIV positive one of the first things they have to decide is whether to tell their children, family and friends. The fear and uncertainty about how these people will react makes disclosure difficult.

Fear of stigma and discrimination also prevents many people from even finding out their HIV status, which has negative impacts for voluntary counselling and testing programs.

In 1994 at the Paris AIDS Summit, 42 national Governments - including Zambia's - declared that the principle of Greater Involvement of People living with HIV (GIPA) was critical to ethical and effective national responses to the epidemic.

However, to date, it is mostly those very people living with HIV that have most strongly embraced this concept by coming out in the open about their positive status and giving a human face to the epidemic. It is those same parents who have been at the forefront in producing this book.

What has become clear from this process is that the children need and want to know about their parent's HIV status. They have a right to know. But the big question is how and when disclosure should occur. This book, full of the emotion from both parents and children, is a clear illustration of the positive effects of disclosure and it provides a guide to disclosure of one's status. This book is in a unique class of its own.

As the adage goes, 'a problem told is a problem solved'. Disclosure shows courage, maturity, responsibility and love to those surrounding you and is appreciated by the opportunity to live longer through adherence to treatment and responsible, positive behaviour. I therefore encourage every Zambian to first know his or her status and to be brave enough to disclose it to their family members, especially to their children.



Felix Mwanza
Programmes Manager, TALC

This book has been produced and printed by the Treatment Advocacy & Literacy Campaign (TALC) a Zambian NGO formed to advocate for proper access to treatment, care and support for people living with HIV.

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Illustrations by Caleb Chisa



My name is Mulenga.

I am a 12-year-old girl and I live in Mtendere compound in Zambia.

I live with my mother and my two brothers.

My elder brother, Chansa, is the first born. He is 15 and will be sitting for his Grade 9 exams at school this year.

My younger brother, Mundia, is the last born. He is 10 and he only thinks about football.

My mum has a small shop in the market where she sells some vegetables, small packets of sugar and salt and cooking oil. One of her brothers lives in England and he sometimes helps us with some money for school.

We live in a small house with three rooms. There is a small kitchen, a living room where we have an old television and the bedroom. Our toilet is outside in the yard and we share it with our landlord and her family.

My favourite food is nshima with ifisashi.



Yesterday my Uncle Chris came to visit us from Kitwe in Copperbelt province.

He is the brother to my mother. It has been a long time since he has visited us.

When he arrived my mother told me, "Go outside and play, we have some adult issues to talk about."

But I wanted to know why Uncle Chris was visiting, so I sat outside the house and listened through the open window.

"Please my sister, I need your help," Uncle Chris told my mother.

I could hear him crying and he seemed upset.

"I am HIV positive and I don't know what to do. I tested positive last year and now the Doctor has put me on treatment," my uncle said.

"My CD4* count is back up to 290, but now I am taking the ARVs* everyday the children are starting to ask me questions. They are asking why I am taking the medicine and I don't know what to tell them... especially the first born, he is going to be sitting his Grade 12 exams soon and I don't want to upset him."

*CD4 count is the measurement of the number of CD4 cells in a sample of blood. The CD4 count is one of the most useful indicators of the health of the immune system and the progression of HIV. When the CD4 count falls below 200 a person living with HIV should start treatment with ARVs, or antiretroviral drugs. ARVs are the medicines used to manage the levels of HIV in the body and maintain good health. ARVs are provided free by the Government of Zambia.



My mother told Uncle Chris that she is also HIV positive and that she is taking ARVs, the drugs that keep them both healthy.

“My three children also know about my HIV status,” she told him.

“The worries you have are normal. When you test for HIV you go through feelings like denial, guilt, anger and depression before you move to acceptance. I think the children experience some of the same when they find out their parent is positive, but it doesn’t take long for them to accept it.”

My uncle seemed surprised to hear my mother being so open, but he also seemed happy to know she had been through the same experience with us. He stopped crying at least.

“But how did you tell the children? I just don’t think mine can cope, I don’t want them to be ashamed of me,” Uncle Chris said.

My mother started telling Uncle Chris about the time she told us about her status. “I had wanted to tell the children for some time,” she said.

“I’d joined a support group for people living with HIV and I was starting to be more open in the community about my status, as a way to help others.”



“But I knew from my friend in the support group that I needed to tell the children myself, before they learned my HIV status from someone else. That is what happened to my friend and her children were very hurt that she had not told them herself,” my mother explained.

My mother went on to tell Uncle Chris that she had been raising the issue of HIV with us over some months to make sure that we had proper information before she told us about her HIV status.

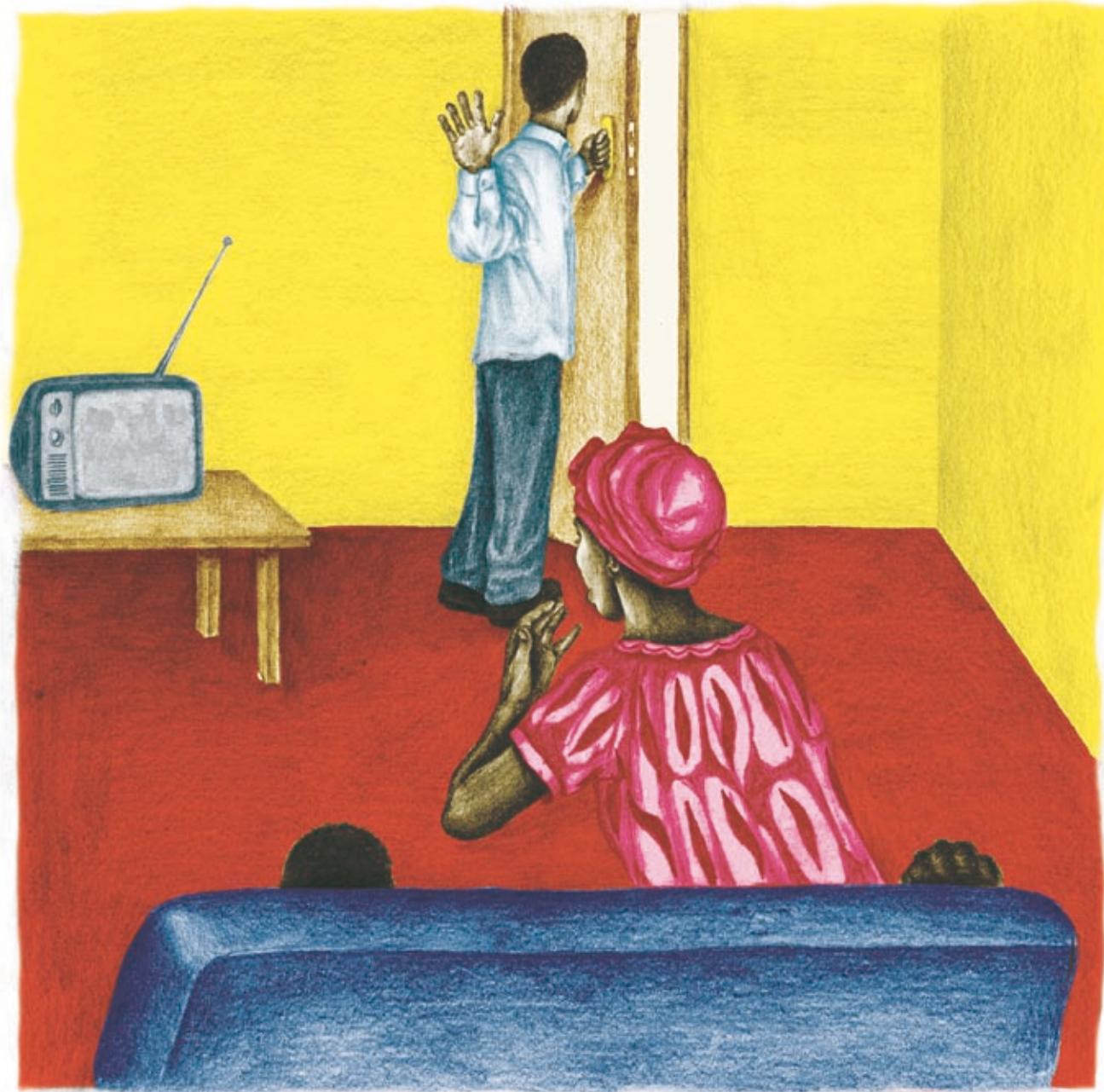
“I went to the clinic and picked up some brochures. That is also where I found out about a support group for people with HIV. And then I just took an opportunity when it came up,” she said.

It made me start remembering back to the time last year when she told us....

...We had just finished eating nshima and relish and we were watching the news on television. An advertisement came on the TV about everyone in Zambia being infected or affected by HIV.

Chansa, my elder brother, started complaining. “Ah this HIV, I’m so sick of hearing about it at school. They are even now talking about it at church. I don’t think it’s even real.”

Then my mum said, “I have HIV.”



I was shocked. At first I thought she was joking, just to scare my brother for saying HIV wasn't real - even though we learn about it in school.

But then I looked at my mum's face and she looked so sad. I knew she was telling the truth. I was scared. What did this mean?

I remember thinking, 'What was going to happen to our family?' My Dad had died three years ago... who would take care of us?

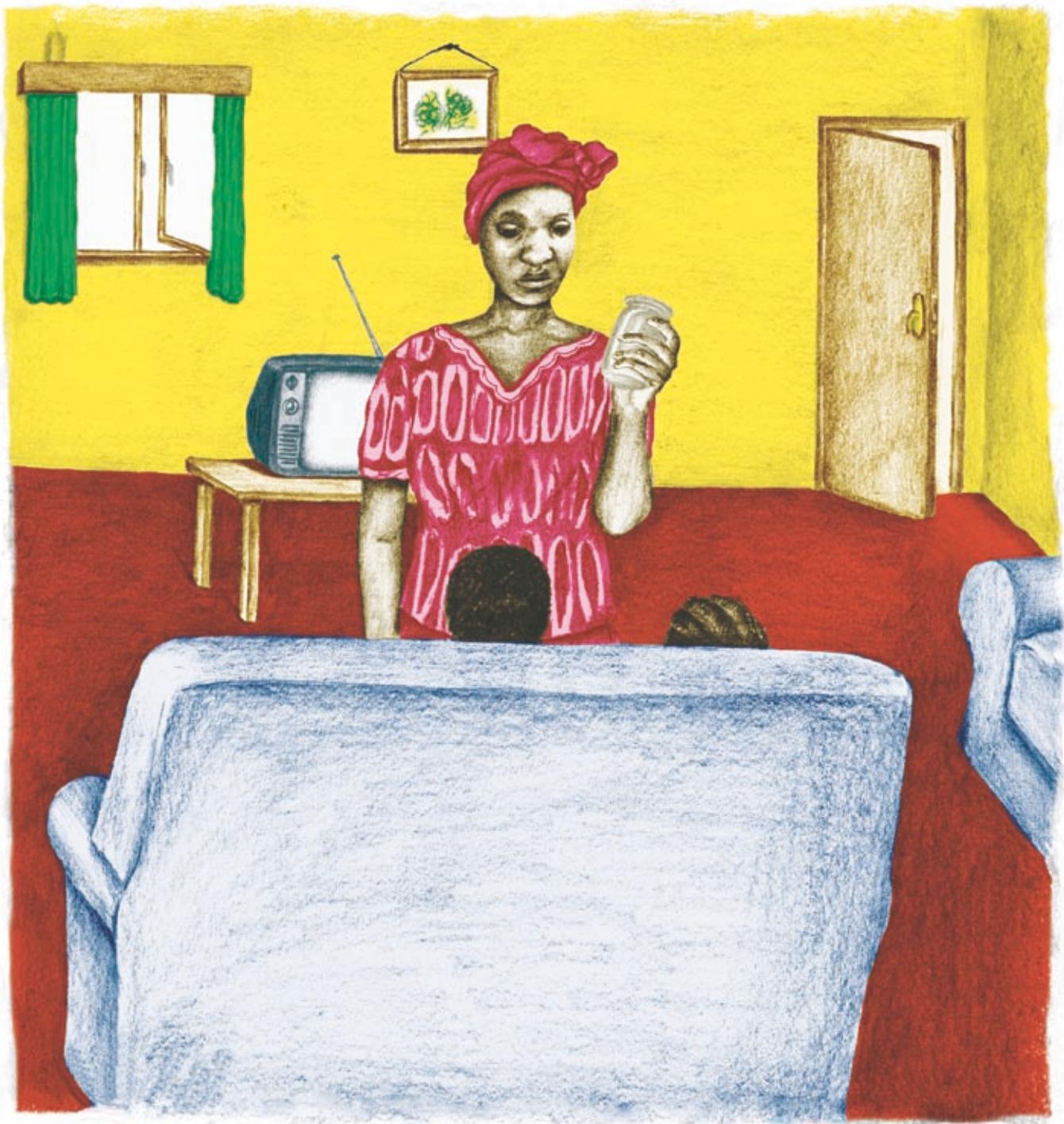
Chansa, my elder brother, was the one who said something first. "Are you joking?" he asked.

"No," my mum said. "I have HIV." We were all silent for a while, then mum continued talking. "Your father also had HIV, for him the HIV led to AIDS and he died before he got treatment. But I started on treatment early and now I am healthy."

"But..." said Chansa. "But how can this be true?" Then he got up from the couch and walked out of the house.

My mum started to follow him, but by the time she reached the front gate he was gone.

Mum came back into the house to talk with me and my younger brother.



“How are you feeling?” she asked.

“I’m scared,” I told her. “What is going to happen to us?”

Then mum explained to us that being HIV positive means you have a virus in your body. She said there is no cure for the HIV but you can live a healthy life, even if you have the virus inside you.

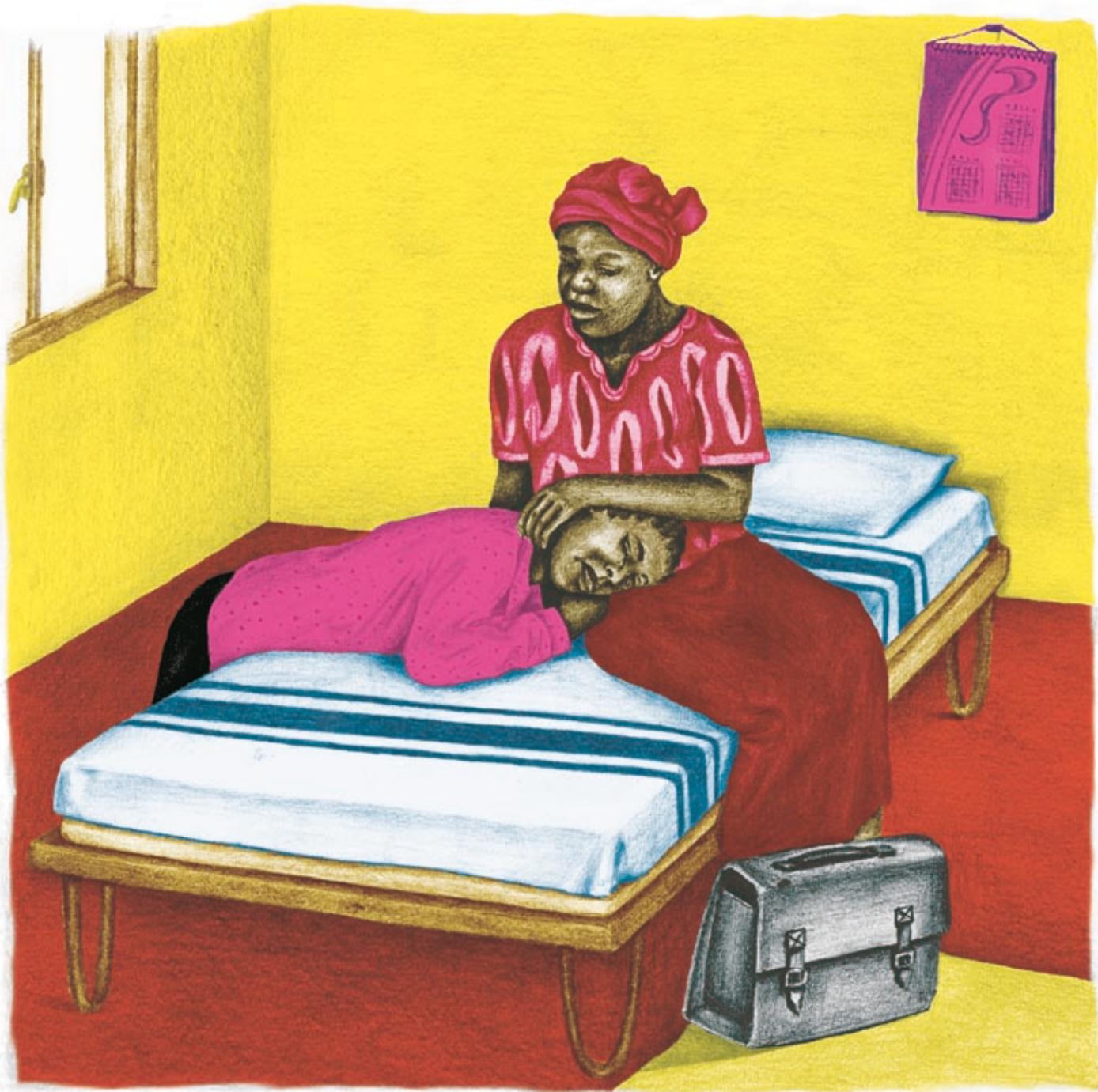
Mum said people with HIV need to take certain drugs called ARVs for the rest of their lives, but that some people had been taking the drugs and living well for more than 20 years.

I realised then that Mum was telling the truth, I had noticed her taking medicines every morning and night. I’d asked her what they were for, but she’d never mentioned HIV.

That night I went to bed and I cried and cried.

The next morning my brother still had not come back home. Mum said she got a message on her phone from Aunty Carol in Kamwala to say he was staying with her.

I didn’t want to go to school. I told mum I didn’t feel very well. Mum looked sad and I could tell she was worried about us. I felt bad for her. She told me I could stay home from school. I cried the whole day while mum was at the market.



After school, my best friend Chisola came to the house.

“Where were you today?” she asked. “How come you stayed away from school?”

I told her I felt sick. I wanted to tell her about mum but I couldn’t. I was scared that she might run away.

That night my brother didn’t come home from school and Aunty Carol sent another message to say he was still with her.

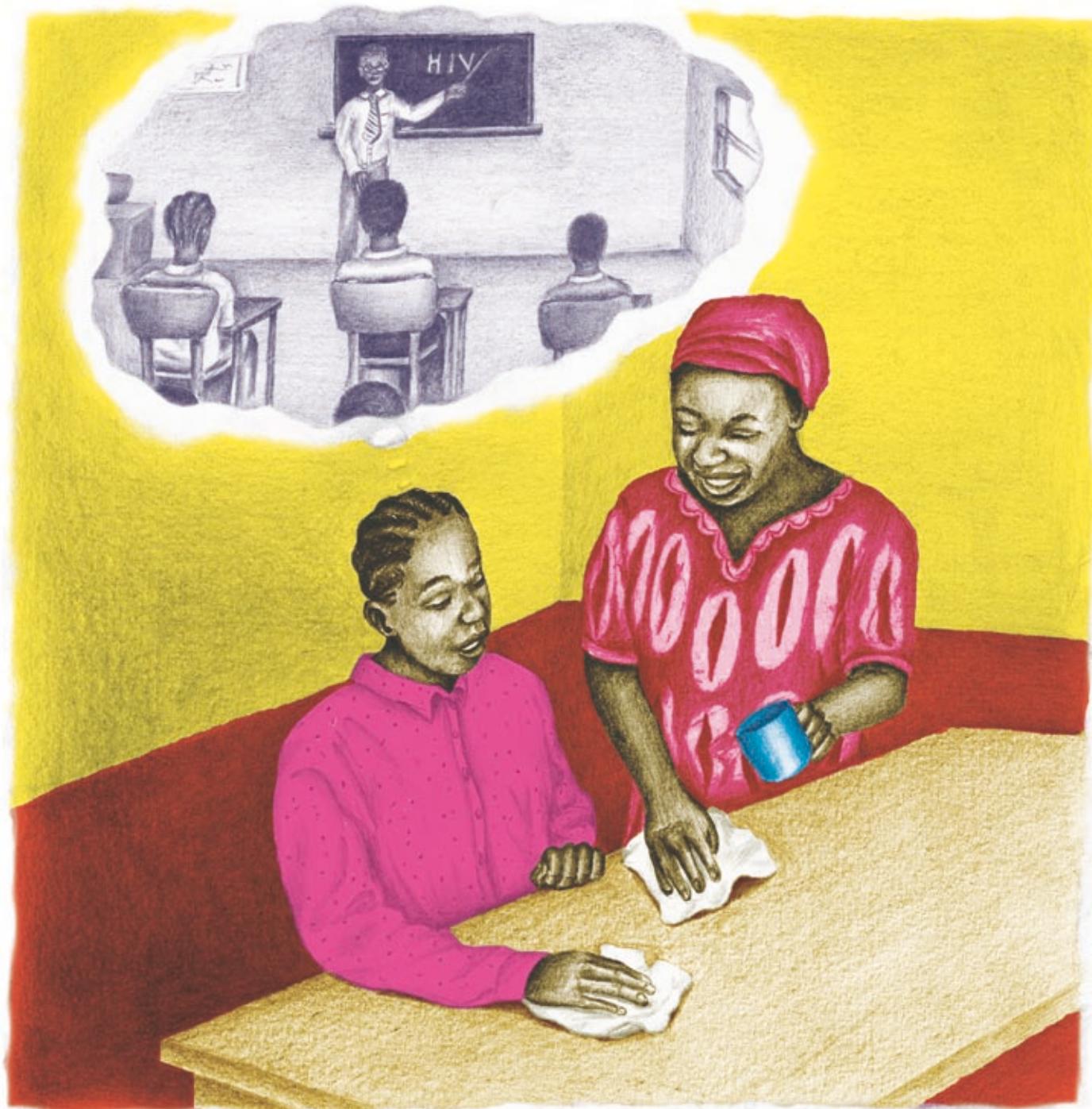
Mum was looking more worried than ever. Mundia was just sitting on the couch playing with his football.

The next day the same thing happened. I told mum I was sick and I stayed in bed and cried.

That night, after the market closed, mum came in and sat on the bed next to me.

“What is wrong?” she asked. “Tell me why you are crying.”

I was scared and I couldn’t think of the words to say. I didn’t say anything. I just kept quiet.



As mum was cooking dinner I came into the kitchen to help and we started talking. "Remember when your dad died?" mum asked.

I nodded. "Remember how I looked then?" she asked again.

"You were very thin, and you were always feeling sick," I said.

"That's right. And I was so sick I couldn't keep the market stall open. But look at me now, I'm not sick any more. Being HIV positive doesn't have to mean I look or feel sick, it just means I am living with a virus that I need to control by taking ARVs everyday."

"The ARVs protect my body from getting infections like TB, because those are some of the infections that could make me sick. But more important than the ARVs is to have your support, without your support then I could die."

I went to bed that night thinking a lot about what mum had said.

I wanted my mum to be around for a long time and I knew she was right. I had to support her and love her, the same as always.

I knew enough about HIV from my school to know that people with HIV, like my mum, need love, care and support.



The next morning it was Saturday and there was no school. While we were eating breakfast my brother, Chansa, came back to the house.

I could tell mum was happy to see him, but she seemed nervous like she didn't know what to say or do.

Then my brother came to her and gave her a hug.

"I'm sorry," he said. "I was scared. But I talked to Aunty Carol and I know it will be okay."

Mum smiled. I could tell she was happy. Mundia and I also gave her a hug. I started to feel better. Then Chansa said, "Today we start positive living." This made mum laugh....

...."And that's how it happened for us," I heard mum telling Uncle Chris through the open window of the house.

"Although it took Mulenga and Chansa some time to adjust, it was just a few days. And Mundia has accepted it without a problem."

....I'd been daydreaming about that time when mum told us she was HIV positive. It all seemed like such a long time ago now, almost like it didn't really matter now...



“But I don’t think it can be so easy for me,” I heard Uncle Chris say to mum.

He told her he wasn’t sure if his children were old enough to understand.

“You need to make sure they have some good information about HIV first,” mum told him.

“Maybe you should take some of these brochures back to the Copperbelt. You should also ask at the clinic for some more information and then you can just leave it in the home where the children will find the information and you start talking that way.”

“When you feel they have enough information then you can find a time to tell them.”

“I think, like me and my friends in our support group, you’ll be surprised about how supportive the children are,” my mum said.

“Chansa is now so worried about my positive living that he won’t let me leave the house without a sweater when it’s cold, and he makes sure I have healthy eating habits. I find I’m cutting back on drinking wine and I am living more positively for my children.”



“It is so much easier now the children know, they even remind me when to take my medicine and take Care not to stress me too much,” mum added.

Mum and Uncle Chris kept talking and I started thinking again....

...It seemed strange to think about mum being HIV positive now, I realised I hadn't really thought about it much at all.

Mum's ARVs and our positive living had just become a normal part of life. We didn't even really notice that HIV was in our home.

I realised I was happy, mum had told us about her HIV and that things were somehow okay.

I'd even gotten the courage to tell my best friend Chisola about mum. Chisola had come over to play and she saw mum's ARV bottle in the kitchen.

“Whose are these?” she asked. “They are my mum's,” I said.

“But these are ARVs, these are for people with HIV,” she said.

“I know, my mum has HIV.” As I said the words I was worried, but Chisola just gave me a hug and told me not to worry.



“My aunty also has HIV,” Chisola said. “I think it’s true what they say that every family in Zambia is affected.” We smiled...

...When Uncle Chris left Lusaka the next day I gave him an extra big hug. I was hoping to give him some courage to tell his children as soon as possible.

Knowing about mum’s HIV status had been a good thing for our family.

Even though I cried and my brother went to my aunt’s for a few days, things turned out okay soon enough. And my younger brother has been learning more about HIV in school, so he also understands... although mostly he just thinks about football.

This book was inspired by the HIV positive members of TALC who have found ways to talk to their children about their status. The following parents shared their stories to help make this book possible and they hope that other parents can take courage and inspiration from their experiences. All of the parents can be contacted through TALC and are happy to provide advice and support to other people living with HIV.



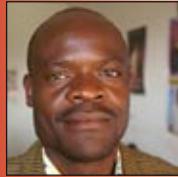
Amadi Ferdinand is a HIV positive father of 2 children. He lives in Makeni.

"I found out I was positive in 2000, and I told my girls about it in 2005. Telling them about my HIV status has brought me closer to them. I'd been pretending that I wasn't positive, but after disclosing I realised that pretence is also a disease. Contact me at New Start (YWCA) or TALC offices or on 0977 941 132 or 0977 254 190."



Victor Asani is a HIV positive father of 6 children. He lives in Chazanga.

"I tested positive in 1996, since then I have been living positively. Before, I thought that when one is HIV positive he is dying soon, but that is not the case. I encourage other people to go for VCT and learn to be open to family members in order to receive some support. I have learned more on HIV from TALC and my support group. Please call me on 097 889 1928."

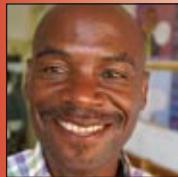


Chris Hang'ombwa is a HIV positive father of 4 children. He lives in new Jack extension, Plot 406/28.

"Disclosing my status to my children was a bit difficult as I went on television without consulting them, but eventually it worked - hence the production of *My mum has HIV*. I'm pleased to be in touch for more information. My contact number is 0966/0955 433 914 and email is: chrishang004@yahoo.com".



Judith Phiri is a HIV positive mother of 4 children. She lives in Chelstone.



Moses Mazyopa is a HIV positive father of 2 children. He lives in Lilanda.

"I use my status to educate my children and others about the dangers of HIV."

Sifamwelwa Masialeli is a HIV positive mother of 5 children. She lives in Chilbolya, House No. 52/05.

"As parents we have to look at our children and which ones we disclose to, there are some who can discriminate you. Its better you look at the ages of the children, before you disclose. I can be contacted on 0978 402 727."



Harrison Mwima is a HIV positive father of 7 children. He lives in Chazanga.

"I'm very open with my status, people should feel free to contact me on 0979 419 337 for support. I am proud that my children are all HIV negative."



Carol Maimbolwa is a HIV positive mother of 2 children. She lives in Woodlands.

"Many of us out there know, or suspect, we are HIV positive - but we are in DENIAL. We live fearful, lonely, tormented lives. It is such a heavy load to carry alone, right? And remember, denial will not take the HIV away. Information and disclosure sets you free - why don't you try it and live your life to the fullest and start helping others deal with their 'denial' issues?"



Fred Mwansa is a HIV positive father of 2 children. He lives in Matero.

"Disclosure is a process of treatment and positive living. People are free to contact me through TALC."



Mary Kabaso is a HIV positive mother of 6 children. She lives in Mtendere East.

"Natampilepo ukwibukishako abana bandi abanakashi babili, ibeli lyandi elyo nowakonkapo. Elyo panuma ya workshop intu twakwete pa TALC, elyo naishile sokolola HIV status yandi kabili kubana bandi bambi babili abaume. Aba bambi babili bachili utwaice nkabebukishako nga bakula nabo bene."



Danny Lungu of Chainama Hospital is a HIV positive father of 7 children. He lives in Mtendere, house C641.

"I've been living happily with HIV and educating others and I'm happy to be contacted any time for support. I live in Mtendere and can be called on 0955/0977/0966 682 098 and the email is: dannylungu@yahoo.co.uk".





Enock Danny Lungu



Rebecca Mutinta Hang'ombwa

By sharing their experiences and enthusiasm the following children and young people also made this book possible.

As young Zambians they strongly encourage parents to talk more openly with their children about HIV and to disclose their status.



Honor Maureen Nyirenda



Eddie M. Nyambe



Gloria Mulenga



Chengo Chewe



Chimwemwe Kalenga



Christabel Chishimba Mwima



Simon Miyoba Hang'ombwa



Judy Munsaka Lungu



Edward Mbewe
edward_mbw@yahoo.com

TALC

TALC is the Treatment Advocacy & Literacy Campaign. TALC is a Zambian NGO that exists to educate the community about HIV treatment, care and support and to advocate for improvements to treatment provision in Zambia.

My mum has HIV

This book was inspired by the courageous and honest members of TALC. Many members are people living with HIV, people that are also mothers, fathers, brothers, sisters and children. Their desire to be open and honest about their HIV status inspired this book. *My mum has HIV* is designed to be a tool for families to encourage openness and disclosure in the home.

Sharing and support

This is a book for all Zambian families living with HIV. Printing such a book is costly and so it is not possible to produce a copy for every family who needs it, but TALC is distributing this book through support groups, home-based care services, clinics and resource centres. If you use this book we encourage you to pass it on after you have read it and shared it with your family to support disclosure in other Zambia families. All of the HIV positive parents involved in this project are available to provide advice and support. They can be contacted through the TALC office in Lusaka.

Feedback

This book is the first of its kind produced in Zambia so it is important to TALC to hear any comments or feedback you may have about it. If the book is useful, TALC hopes to have it produced in other languages and may even produce similar books on other topics related to living with HIV. If you have any comments, questions or suggestions on *My mum has HIV* or anything related to HIV treatment, care and support in Zambia please contact TALC in one of the following ways:

Write to:
PO Box 31084
Lusaka, Zambia

Email:
info@talczambia.org

Phone:
01 236 278

Phone or SMS/text:
0977 565 644

For information about book distribution:

Joint HIV Resource Centre
Afya Mzuri/TALC/SafAIDS
Katopola Road, Lusaka
Phone: 01 250 261

Contact a TALC hub in your region:

Western
Kabanda Samba, 0955 887 750

Eastern
Daniel Mubanga, 0979 789 230

Central
Winter Musonda, 0977 631 464

Copperbelt
Jordan Kaisi, 0966 725 955

Note: New TALC hubs will open in Southern and Northern provinces by mid 2008.

Not-for-profit copying of this resource is encouraged.
After reading and learning from this book, please pass it on to someone else who may find it useful.

*“When I found HIV in our family I felt bad.
As time went on I felt good when I knew there were ARVs...
Friends, cousins and neighbours gave me some advice and that
helped me cope. What helped me understand is that mum
told me the truth and I felt good.”*

Comment from a Zambian child whose mum has HIV



The *My mum has HIV* book project was supported through the U.S. President's Emergency Fund for AIDS Relief (PEPFAR). It was also made possible through volunteer support from VSO and RAISA, the Regional AIDS Initiative of Southern Africa. This book has been produced by TALC for parents living with HIV. Not-for-profit copying of this resource is encouraged.