WITH SUPPORT
WE STAND STRONG
ABOUT THIS BOOK

This book was first written in 2006 by the founding members of Zvandiri in Harare, Zimbabwe. We were fourteen children and adolescents who were just learning about our HIV status and what this meant for us. At that time, paediatric and adolescent HIV testing services, treatment and care were only just beginning to be available. We knew there was very little information for our peers who were also living with HIV. So, we decided to help them by sharing our story with them.

Now, our stories remain the same, but we wanted to update our book, because there are new stories to share now that HIV testing, treatment and care have moved on so far. We needed to make sure that the new issues for young people are also captured in our book.

We wrote this book for you. We want to share our experiences, our story, our journey with you - to help you understand more about what it means to be living with HIV, to help you to stay strong and to look positively towards your future. We also hope that adults reading this book will understand more about the way we feel, our worries, our questions, what we need to know and how they can help to support us on our journey growing up with HIV.
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1. How did we feel before we were told we have HIV?

We were all different ages when we found out we have HIV. For many of us, life had been difficult.

I used to always get sick. I would go to the clinic for medicine which made me better for a while but not for long. I soon got sick again. People used to tell me my blood was weak. No one would play with me because I was always sick.

In the beginning, I wasn’t happy because no one was telling me what was happening and why I was sick. I couldn’t play with my friends.

Before I was told that I was HIV positive, I felt very sick. I had lots of skin problems and I was feeling very embarrassed.

Before I knew that I had HIV, I just felt sick now and again. I went to Doctors to get treated. They gave me treatment and I got healed but after a very short period I started feeling sick again. Then there came a time when I started coughing. I was taking cough syrups but it wasn’t showing any change. Then I went to my Doctor. He discovered that I had TB and he put me on TB treatment for six months. I completed TB treatment and it was confirmed that I no longer had TB. But I kept on feeling sick which made me confused, wondering what the real problem was in my life and with my health.

I wanted to be at school with my friends, but I had to stop school as I was always sick.

My life was normal. I never got sick. I was just like anyone else. Of course, I knew about HIV but I always thought it was something that affected other people, not me.
All things started when I was born. I was feeling so sick with headaches, problems with my eyes and my legs. I couldn’t help myself. When I was 10 years old, I was suffering with a heart problem. My legs started to get sore when I was doing Form One. Sometimes I could not go to school because of my legs. I was feeling that soon I was going to drop out of school because of my illnesses.

When I was in Grade Three, my uncle came in to my room and he raped me. I couldn’t tell anyone at that time. I was well and didn’t really get sick. But I used to worry what if he had HIV. Did he give it to me? How could I find out? He seemed well but I heard sometimes you can’t tell if someone if HIV positive or not. So I just kept quiet.

I used to be sick here and there with coughing, vomiting, diarrhoea, loss of weight and all sorts of diseases. Sometimes I would feel very lonely because many friends, especially in the community, did not understand me well. Usually, I would spend the whole day sleeping due to illnesses which were continually in my body. One of my relatives told me that I was going to die and there is no life for me at all because he had already seen with his naked eyes that I was positive before I was tested. I spent the whole day crying, wishing to die and never see the light again.
Before I was told that I had HIV, I felt sick and helpless but I did not know what it was. I had big lymph glands and I felt lonely when people laughed at me.

I never knew I was positive because I hardly fell sick and I had never had sex.

Sometimes, I would spend a whole week without going to school because of continuous illnesses.

I’ve always been well but when I started to have sex, we didn’t use condoms. So I started worrying a lot. What if I am HIV positive?

Before I was told that I had HIV, I thought all the sickness events I had were just caused by something else. I thought I was suffering from malaria most of the time.

My life was a world of sickness and I was treated for lots of diseases like herpes, TB, a bad chest and heart problems. And I had a big stomach and I was not growing tall. Other girls thought I was pregnant. My stomach gave me problems when breathing. Sometimes I coughed for at least 5 minutes without stopping and it caused difficulties in breathing and chest pains.
2. HOW DID WE FEEL WHEN WE WERE TOLD WE HAVE HIV?

Most of us found it very difficult when we first found out we have HIV but it gradually got better...........

The very first day I was told that I am positive, surely, I was shocked indeed. I felt great pain and I cried.

I was afraid that people wouldn’t touch me but now I know that is not true.

I was scared of my status. I was frightened and I felt so alone, like I am going to die. I thought everybody would know about my status. I wasn’t feeling comfortable. All my thoughts were about dying. I didn’t realise that I was going to live for more years.

At first, I felt so relieved to know my status as I was worried what was going on in my life. Then, on second thoughts, I knew my HIV was a deadly disease that is incurable. Suddenly I thought it was the end of me, I am going to die any time soon. While I was wrestling with my thoughts my doctor came to my aid - he reminded me what we had discussed before he revealed my status to me.

At first, I didn’t understand as I had never slept with anyone ever before. But then my nurse told me that there are many ways of contracting this disease. She explained that children can be born HIV positive if their mother is living with the virus.

I felt very angry with my mother as she had not told me before.
When I was told I was positive I thought my life had ended. It took me quite some time to accept it and to come to terms with the fact I had contracted HIV from my boyfriend. But now I am realising it is not the end of my life. I am glad I am still alive.

Before I was told I was HIV positive, I felt so safe from the virus because I had been abstaining from sex. I was living a normal life and I was at ease. So, when I was told I have HIV, I was shocked, as if I am on the death list.

Knowing my status was like a big success in my life because, ever since I was born, I have not enjoyed even a single day. It was sickness after sickness. No time to play with other teenagers. Sometimes I would get seriously sick. That made me think I was being bewitched. Knowing my status made me realise what my future holds for me. It has also helped to know how to live positively and to take the medication very seriously.

I was shocked and had a long pain but the pain is subsiding. I wish my parents had told me earlier when they were still alive. I am now at ease and I am happy with the help being given by my doctors and nurses.

When I was told that I was HIV positive I was very shocked, and it scared me that I was going to die because that’s what many people say about it. This issue made me cry for a long time, thinking from deep down in my heart, “Where did I actually get this disease?” but I did not have an answer. I did not sleep with any women in a single day of my life. This made me feel depressed and stressed at the same time. I was expecting to be negative. The counsellor told me not to worry but I didn’t have any time to listen to her because I was thinking that she was lying to me. So, she waited for me to stop crying. Now, I am feeling good and fine. I don’t feel depressed because I accepted it as it is. I am expecting to live a long time and learn well at school without any disturbances of sickness. I just urge some teenagers out there to go and get tested early so it won’t kill any more.
It was important to be told my status because now I know the right ways of living. I am now living positively, and I can teach other people about this disease. I now know the right way to follow. I have removed the stigma which was in me of shyness. I do what the doctor has told me to do to make my body strong. And I am happy that no one knows my status unless I tell him.

Finding out my status was so painful. I had always abstained from sex, but I was sexually abused. Now I had to live with this HIV. It took me a long time before the pain stopped. But now I have met other people like me and together we share our experiences. I know I’m not alone. I thank God for the support and counselling I received.
If you are ill, that’s where you clearly see who loves you and who does not. My late aunt whom I was living with did not allow me to eat with the same plates or drink from the same cups with her and her children. I had my own cup, plate and spoon for my own use because I was told that I could pass the virus through the utensils. It pained me too much, especially if I think about it deep down in my heart, tears start to fall. This was what we call discrimination, but those days they did not understand anything about this disease. As for me too, I understood nothing.

I was very pleased to know my status early, it helped me to know how I can live. Before I was told, I used to eat any food which I came across. But now I know that eating fruits is healthy and I can also be able to live for a long time. It is also important because now when I am sick I know that I am supposed to be at the clinic early. Even if it is a fever or coughing which is troubling me, I must go to the clinic and get treatment, rather than letting the illness get worse. Now I go to get treatment to reduce the virus in me. If I keep myself on the safe side and always have peace of mind, I know that I can live as others are doing. To know my own status is as good as being told that you have passed exams. I urge each and every one to go and get tested because if you do not want the virus to spread. I don’t want people to die without knowing. It’s good to know what’s troubling you and control it early. As for me, I was encouraged to go and test. Now I know that I am in control and can defend myself from anything that is against me.
3. THE IMMUNE SYSTEM AND HIV

The Immune System

The Immune System is the part of the body which protects us from illnesses.

It is made up of different ‘cells’ which work together to protect us and keep us strong and healthy.

These cells are found in the blood and in other parts of the body. They are extremely small – they cannot be seen with our eyes.

The scientific name for these cells is CD4 cells but we find it helpful to think of these cells of the immune system as like ‘warriors’.

The warriors (or CD4 cells) work together to fight off infections.

The number of CD4 cells in a sample of blood is called the CD4 count.

If there are lots of strong warriors (CD4 cells) in the blood, the immune system is said to be strong.

This means that the body can fight off infections.
HIV Damages the Immune System

Unfortunately, when HIV enters the body it uses the **warriors** (CD4 cells) to make more HIV, and this damages those warriors (CD4 cells). The warriors become **weak** and few in number. The CD4 count gets lower.

**As time passes** the amount of HIV in our bodies becomes more.

The amount of HIV in a drop of blood is called the **viral load**. Without treatment, the amount of HIV, or the viral load, continues to increase and the number of warriors (CD4 cells) in the body becomes less.

The immune system therefore becomes weaker and weaker.

When the immune system is **weak**, the body cannot fight off infections known as opportunistic infections (OIs)

This is why people with HIV become sick.

In some people, the HIV damages the warriors very quickly. These people become sick soon after being infected with HIV.

For example, some babies who are born with HIV get sick before their first birthday.

For other people, the warriors get damaged more slowly and so it takes longer before they get sick.

For example, some children born with HIV may have HIV for many years before the immune system becomes weak and the child gets sick.

As well as being sick, many children and adolescents with HIV often do not grow well. This is because all their energy is going in to staying well and fighting off infections.
What is AIDS?

As a person with HIV gets sicker and sicker, the infections they get become more serious.

When someone living with HIV gets really sick, this is called AIDS or Acquired Immune Deficiency Syndrome.

At the moment there is no medicine which can cure or remove HIV from the body.

In the past, very little could be done to stop people with HIV from getting so sick and developing AIDS so millions of people all over the world have died.

Did You Know

Now HIV is a different illness as there is medicine to help people with HIV to stay healthy. Unfortunately, there is still no cure for HIV, but if you read on, you will find out what can be done now to help people with HIV.
There are different ways through which people ‘get’ or ‘become infected’ with HIV.....

4. HOW DID WE GET HIV?

- Through unprotected sex with a person who is already infected with HIV (this could be through sex where two people agree or consent and also through sexual abuse).
- Through cuts with sharp objects (e.g. razor blades, needles, knives which have cut someone who is infected already).
- From a mother with HIV to her child during pregnancy, birth or breast feeding

If the HIV virus enters our bodies in one of these ways, the person is said to be “HIV positive.” Or some people may say “positive” or “infected with HIV” or “living with HIV” but it all means the same thing.
Our advice to you now is....

Medication
Take your medication regularly to stay healthy
(Read more about ARV medicines on Page 21)

Attend Clinic
Your Doctor, Nurse, Counsellor and CATS can help you to understand more about how to look after your health and live positively. You need to go to clinic so you can have your health checked, be weighed, get your medicines and have viral load tests. This helps you to know whether HIV is under control. Other blood tests are also taken to check that your kidneys and liver are working well. The clinic team can also give you information you need and assist you with problems you may be experiencing.
Think Positively

Remember, now with ARV medicines, you can grow up just like others. We advise you not to be stressed about your HIV status because this stress is not good for you or your mental health. We want to give you support and encourage you. We encourage you not to be afraid of anything because this is who you are now and you must accept it. And do not think it is the end of life. NO. Focus on your dreams, your future. This is all possible.

Find Out More!

The best way to take care of yourself is to get the information about your body, HIV and your medicines. Then you can take control of your own health. It is easier to understand and cope with this illness if you know the facts.

Eat Well

You need to eat a diet which includes the following foods: fresh fruit and vegetables, carbohydrates (e.g. sadza, bread, cereal, rice, and pasta) and protein (meat, chicken, fish, beans, eggs, nuts). This may not always be possible but if you can manage this, it will help to keep your body strong.
**Exercise**

It is good to get exercise, like walking and running. Playing different sports is also good for you e.g. soccer, netball, athletics. This will help you to become fit, healthy and strong. It is also good for your mind to exercise and play with friends.

**Join a Support Group**

You must also get involved with support groups because that’s where you can learn from your peers who have gone through the same experiences as you. Support group is a safe place for us to learn to be strong and not to think about anything else, but to accept who you are.

**Support Your Peers**

There are so many other young people who need your support. Supporting others can help you to feel good about yourself, that you have helped a friend to do well, that you can be part of the change you hope to see for you and other young people.

*I don’t tell my friends at school, but I have lots of friends at support group who are my peers and experienced the same things. We all have HIV so it’s OK.*
6. What Can you Expect for the Future?

We want you to know this is not the end...

If you follow all this above, I know you will live a long time because it’s the same as other chronic illnesses like BP, asthma or diabetes. So there’s no need to fear.

Once you have tested positive, there is no need for you to stress yourself. I see myself having a long life, living positively and looking healthy.

Some give up and say they will die. They are wrong. You can get treatment to live a normal life.

Trying to be a better self is my only ambition. I look in the mirror every day and see a greatness. I never let HIV be a barrier to my dreams. I always rise up to the challenge.

I have known my status for a year. I am not in a departure lounge, but I am HIV positive.

It is important you know your status because you can now get a good treatment and you know what the problem is in your body. You should go for counselling because it can help you to know a lot of things about how to live positively. You must take care of yourself. I would like to comfort you - We are in the same boat.

This is who I am and this is who I choose to be. Being HIV positive is not a death sentence but a new reason and purpose to live. Do not discriminate against yourself.
I am getting much stronger and stronger everyday with the support from my family, my CATS and my HIV clinic where I get my treatment. I feel so happy I know my status. There is nothing better in this present life we are living than to know your status. Honestly speaking I felt so happy in my life because I am getting the help and medication that goes hand in hand with my HIV status.

Sometimes when people find out that they are HIV positive, some of them could kill themselves because of that. But when I found out that I am HIV positive I was happy because I know I could take my ARVs and take care of my health. Being HIV positive does not mean it is the end of your life.

HIV is only a virus which can be reduced when it appears in your body, that’s all. You don’t even have to worry about it because it can be controlled.
Once HIV enters the body, it multiplies, making more and more HIV. The viral load increases.

The warriors (CD4 cells) become less. The CD4 count drops.

The immune system becomes weak and it is therefore difficult to fight infections.

But the good news is that there are now medicines which fight against HIV.

These are called antiretroviral medicines, or ARVs.

ARVs control the HIV virus, making it difficult for it to multiply.

So, the amount of HIV in the body becomes less. The viral load reduces.

With less HIV in the body, the warriors (CD4 cells) are therefore protected and can become strong and plenty in number again.

This keeps the viral load low. When the amount of HIV is so low in the blood, it is said to be undetectable.

The immune system is stronger and it is possible to fight infections again.

These medicines are very clever but unfortunately, at the moment, they cannot remove HIV completely from the body.

They are not a cure for HIV.

This means that someone taking ARVs still has HIV, but it is in very low levels.
It also means HIV is much less likely to damage the immune system, or to be transmitted during sex, pregnancy, childbirth.

If the immune system is strong again, the body can fight off infections again. The medicines can only work well if they are taken properly. This is called **adherence to the medicines**

This means you must:

- Take every single dose
- At the right time
- The right way
- For life

**Urgent**

If you are worried about taking ARVs or any other medication, go to your clinic to talk about it.

Do not decide to stop the medication yourself as this could make problems for you.

If you stop the tablets, miss doses or take the tablets late, there is no control over the HIV for that time.

This means that the HIV can start multiplying again, making more HIV in your body.

Then it starts to damage the warriors (CD4 cells) again.

The **immune system will then become weak again** and you will get sick again.

Also, if the medicines are not taken properly, the HIV virus starts to change. This is called mutation and this means the medicine can’t work. The virus becomes resistant to ARVs and they stop working. This is called **treatment failure**.
It means that even if you start taking the medicines well again, they will not be able to control the HIV any more. If this happens you may have to change to a different combination of ARV medicines. This is called 2nd line treatment. If 2nd line medicines stop working, there are now 3rd line medicines available. But these medicines get more difficult, so the best is to adhere well so that you stay on the 1st line medicines.

To control the virus well, it is necessary to take a combination of ARV medicines. Your doctor will decide which medicine to give you, but it is normally three different ARV medicines. Fortunately, these are often combined in to one or two tablets so they are easier to take.

It is extremely important you carry on going to clinic so the doctor, nurse, pharmacist and counsellor can make sure the medicines are helping you properly.

The clinic will need to do blood tests every few months. These tests are used to count the amount of HIV in your body (viral load) and the amount of CD4 cells (or warriors). This will show if you are managing to control HIV and if your immune system is becoming stronger.

They will also weigh you and measure your height as the ARVs normally help you to grow well.

You may also need to take Cotrimoxazole which is an antibiotic which can prevent some opportunistic infections.

Like all medicines, ARVs do have some side effects.

For example, sometimes they cause headaches, stomach ache or skin rash.

These do not usually last long but you should let your relative know, then go to your Doctor, nurse, counsellor or CATS. They will reassure you and help you.

The important thing is to never stop your medicines unless your doctor tells you to do so. Your doctor, nurse, counsellor or CATS will always be very happy to listen if you have any worries, so that they can help you properly.
8. WHEN YOU TAKE ARVS, WHAT CAN YOU EXPECT?

All people living with HIV should start and stay on ARVs. It may seem difficult but this what they mean to us.....

If you have just found out you have HIV, don't panic. The world has not come to an end. You have to take your medicines correctly. They need to be taken at the right time and not to jump a day. If you take them and use them correctly your viral load will decrease and your CD4 will increase. The medicines help your warriors (CD4) to fight the virus. Starting ARVs was great because they are making my body strong. At the other hand, it was boring, knowing that you will have to take the drugs for the rest of your life.

ARVs are tablets which help you to boost your immune system to fight against the virus in the body. When I started on treatment, my viral load was over 200,000. I was sick all the time and in hospital. But I took my medicines and with the support of my clinic and CATS, I am happy to say my viral load is undetectable.

These tablets cannot heal completely HIV in your body but they can help you to reduce the virus and to boost your immune system.

I felt great about starting ARVs because I knew I was going to live longer.

I now feel very strong and my skin is now clear. I now feel like other normal children.

ARVs are helping me a lot. My life cannot go on without them. I thank God they are there.
Once you start taking these tablets you cannot stop taking them. You can see something changing in your body when you start taking these tablets. Some of us got side effects when we started like falling asleep, you can have a rash on your face and you can also vomit. But then you will start feeling better.

I feel like my wheel of life now begins to spin since the time I lost hope. I couldn’t imagine what was happening in my life. I couldn’t walk or play with other children. Now I feel like other children living without HIV. I can walk to the supermarket and back by myself. There is no more stress going on in my life these days. I think ARVs are the best tablets. I have gained strength, weight and also appetite to eat which was difficult to do.

YOU are in control of your illness. If you take your medicines well and attend clinic, you will help yourself to control your HIV and become strong again.

You must remember that if you drink ARVs you must stick to the time and the ARVs are for the rest of your life.

I expect to go to school and get a quality education. When I finish my education I want to get a well-paid job to prepare for my future and buy good food to stay healthy. I want to be treated like everybody else in the community. In my life I expect to get married and have my own family.

At first, I thought it was too much. I had to hide my medicines as I didn’t want others seeing them. But later I appreciated them because they worked well for me. I now feel great about ARVs because I have changed greatly.

I am now happy because the tablets are making me feel better and I can now play with other children.

YOU are in control of your illness. If you take your medicines well and attend clinic, you will help yourself to control your HIV and become strong again.

You must remember that if you drink ARVs you must stick to the time and the ARVs are for the rest of your life.
I feel very healthy and strong, the ARVs helped me very much. These medicines are very strong. Even to a person who is about to die, they can get up and walk as others. I am now feeling happy since I started these drugs. My health is back to normal because of these medicines. I didn’t have any warriors for my defence system but since I started these medicines all of them have risen up. Now I am fit and fine. I don’t have any side effects at all from these medicines. About these ARVs, you need to know they are strong enough to maintain your life. Also you must take them every day because if you don’t it will affect you. You also have to listen to the clinic. What they say is what you need to do at that time. If they say drink your pills and never jump any day you must do it. When you follow this you can expect good health.

Before, when I was sick, no one would play with me. But now I am well and have lots of friends. We play together all the time.

Starting ARVs was kind of weird to me. I could not believe the conditions underlying taking these tablets. Once I start taking this medication I must not skip or forget the tablets and this is for the rest of my life, even if I am not feeling sick. It has to be an everyday thing I must do forever in my life. However, I was so happy I started the medicines and without doubt I am going to feel better for the first time in my life after a long time of sicknesses without hope. Thanks to God for the ARVs.

ARVs are pills which help the weakened warriors of an infected person to get back to normal. They make us live a long time like other people because they will be protecting us in many ways such as the defence system from getting any other disease. My warriors now have many powers to defend me from any sickness. These medicines are encouraged for many people ARVs are there to make you rise up again.

ARVs can make you better. You can expect to live a healthier life. You need to have the confidence and strength.

I used to think I was dying. All I wanted was to go back to school. Now I have gained weight and am now healthy and strong and back at school.

ARVs are pills which help the weakened warriors of an infected person to get back to normal. They make us live a long time like other people because they will be protecting us in many ways such as the defence system from getting any other disease. My warriors now have many powers to defend me from any sickness. These medicines are encouraged for many people ARVs are there to make you rise up again.

Thanks to God for the ARVs.
So I don't need to fear about this news because I know that they are going to help me for good. Even though it is for the whole of my life, I did not mind at all. But in some ways, I have heard that it has got some side effects, but as for me I didn't get affected at all. No, not at all. I drank them with confidence because I know who I am now and be able to drink those pills. After time, you will get used to it.

ARVs boost the immune system and once you start taking them you can react to them but you will get used to them. You should expect to live positively and not to be looked down upon.

When I was told that I am going to start ARVs, I felt very happy because I knew that my life would now be in a good condition. My health is going to come back to normal.

The medicines are given according to the National treatment guidelines.
9. WHERE CAN YOU GET HELP?

You are NOT alone! Here are some of the people who could help you...

• **Your Family and Friends**

  You can get love, help and support from your own family, relatives and friends. It is important for you to identify someone in your family who can support you on your journey. You will know who the best people are to do this, but if you find this difficult, talk to a counsellor at your clinic to assist you.

• **Your Clinic**

  Your clinic is there to help you. The nurses, doctors, counsellors and CATS at the clinic will ensure you have the right medicines, the right care and support to look after your health. It is very important that you go to the clinic at the scheduled times, as well as other times if you need their help.

• **Zvandiri**

  Zvandiri is run for and by young people living with HIV. Services are provided in your clinic, home and support group to help you to gain the knowledge, skills and confidence to live happy, healthy, safe, fulfilled lives. With your permission, young counsellors known as Community Adolescent Treatment Supporters (CATS) can assist you with knowledge and counselling to support you.

• **Your Community**

  Not everyone needs to know your HIV status. But there are many people who understand and care about your needs and experiences. For example, some community volunteers and church members can support you with information, love and support.
• **Your Support Group**

When I was told that I have HIV I was horrified. By that time, I did not really know what that meant. I only thought it was the end of the world to me. I thought I was going to die. On the other hand, I was happy and I did not know what I was happy about. As time went by, I found out what I was happy about. I had met Zvandiri, in which I met other children like me and we discussed how to live positively. Now I am happy – I can live as a normal human being.

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10. **DON’T FORGET!**

We hope our book has helped you! Here are a few final things we want you to remember:

- Being HIV positive does not mean it is the end of your life.
- You should know your status first, and have a positive attitude and most of all, you should expect change when you start treatment and to live longer.
- Children and adolescents living with HIV can expect to grow up, get married, have their own families and to have babies who are not living with HIV. They can also expect to have good jobs.
- You must start and stay on treatment. This is extremely important if you want to control HIV and stay healthy. When medication gets difficult, talk to someone who can help you.
- Children, adolescents and young people living with HIV can get information, help and support from support groups, parents, guardians, doctors, nurses, counsellors and CATS.
- Take care of yourself, stay strong and SHINE!
Thank You

to all the members of Zvandiri – for inspiring, revising and updating this book and sharing their experiences in order to help others understand more and to cope better with the events in their lives.

Knowing my status together with being in the Zvandiri support group has changed my life. Being positive is not the end of life.

Vimbai, aged 16