



SIYANAKEKELA

A BOOK FOR CAREGIVERS OF
CHILDREN AND ADOLESCENTS
LIVING WITH HIV

WITH SUPPORT
WE STAND
STRONG

ABOUT THIS BOOK

This booklet has been developed by caregivers and young people living with HIV. It is designed to help you understand more about HIV and what you as a caregiver can do to support the children and young people you care for. We hope it provides you with the information and answers to your questions as well as stories and experiences from other caregivers.

Caregivers play such an important role in the lives of young people living with HIV. We know that supportive and loving caregivers can help children to grow up as happy, healthy young people by helping them to adhere better to their medication, cope with stigma and feel positive about their future.

The booklet was developed by asking caregivers what questions they had and what more they wanted to know. They also shared their own experiences so that this could help other caregivers. Based on this we have included information on HIV testing, disclosure, adherence and support.

We hope you find it useful.

Zvandiri caregivers and young people



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Project Coordination: Kate Iorpenda

Layout and Design: Baynham Goredema

Email info@zvandiri.org | www.africaid-zvandiri.org

CONTENTS

1. HIV testing	5
2. Talking to your children about the test	7
3. Receiving an HIV positive test result	8
4. Coping with your children's reactions to a positive HIV test	9
5. Knowing your own status	11
6. Sharing your status with your children	12
7. Disclosure to siblings and other family members	13
8. Coping with stigma	15
9. Starting treatment	16
10. Understanding ART	18
11. Finding your support	21

1. HIV TESTING

Testing your children for HIV can be a worrying decision to make. You may be concerned about the test itself and what happens, or afraid of the results, the stigma, or you might feel it is better not to know.

Many parents worry. Sometimes it is because they are HIV positive themselves, or some feel guilty about passing the virus to their children and don't want the children to know. Others are not sure how their children will cope with the HIV test result. But if there is a chance that your child could be HIV positive, then taking your children for testing is the most important thing you can do, even if there are no signs of sickness. Testing for HIV is the only way to know for sure.



I was so worried about my children since I had tested positive to HIV. I kept thinking that this will be a great favour I will do for my children if I take them for an HIV test. I then gathered my courage and took all my children to the nearest clinic for HIV testing. Two of them were found to be HIV positive.

At first, I did not have any fear about the test because my grandchild was never sick and I thought HIV can only be contracted by having multiple sexual partners.


I didn't want to test my child. I believed there was no hope for people living with HIV

It is normal to feel concerned about the result and what that would mean for your family but understanding how the test is done and how results are given can help with some of that fear.

When HIV enters the body it takes time before it is detected in your blood. This is known as the 'window period' - the time from the point of infection until the time when you can take the test. This will vary depending on the type of test that you take. Some tests can only give an accurate result if it has been three months since you acquired HIV, but other newer tests can give you a result just weeks after. Your healthcare provider will tell you what the window period is for the test you take. However, don't wait to go for a test if you think you or your child has been at risk. Go straight away.

The test will involve a discussion with a counsellor to prepare you for the test. They will explain the process and discuss your reasons for testing. A nurse will take a small amount of blood from your child. This is usually just a finger prick. The results should be available within an hour. A counsellor will meet with you again to prepare you for the results and to talk through what happens next. If you like you can take someone with you for support. Also, like adults, it is now possible for adolescents who are 16 years and above to 'self test' for HIV. This is an oral test which is used to screen for HIV but if the test is positive, the adolescent must go to the clinic for a confirmatory test. Ask at your clinic to find out more.

It can take a lot of courage to go for a test and feelings of fear, anxiety and worry are normal.



At first I was scared but I changed my mind because it was best for us to know our child's status

I felt very anxious and concerned when I took my child to get tested

I discussed with my child though it was difficult but I had to do it because I had received counselling on the importance of having my child know their status.

2. TALKING TO YOUR CHILDREN ABOUT THE TEST

Often, we believe that our children are not at risk, so there is no need to talk to them about HIV and testing. Other times we feel embarrassed or ashamed to talk about HIV in the family and some people will even test children without explaining the test to them.

I had no need to discuss such a topic with my grandchild who was not sexually active because I believed that HIV was for those who were sexually active

I did not discuss with her since she was very young and I could not tell her something she would never understand

I did not think about it. All I thought about was getting my grandchildren tested and that they get better.

It is important that you talk to your child about testing. What you say will depend on their age but they need to be prepared and can understand even when they are young, if it is explained in the right way. We know that children who are lied to or do not understand HIV testing and their own HIV status find it harder to deal with a positive result and harder to stay on their treatment. They also find it difficult to understand why they were not told earlier.



3. RECEIVING AN HIV POSITIVE TEST RESULT

There is nothing that can fully prepare you for an HIV positive diagnosis. But being informed and having time to discuss and reflect on things can help you and also help your children to accept their diagnosis.

Parents and caregivers often feel guilt and fear about HIV test results but there are others who feel relief and can feel grateful to understand things better and be able to access support.

It was hard to accept the reality but as a parent I had to calm the situation and explain to the child

I was very grateful that at least my children got the help that they needed and medication is free so that they continue to live a healthy life. I felt that I needed to know about this early so that my children would not die without any help

I was relieved because I was suspecting that it was going to be the case

Thank God for the health workers and the right information

I felt sorry for my child and I thought that it was the end of her life because by that time I did not have any information about HIV

Accepting an HIV positive diagnosis will not be something that will happen quickly but it is important that you find the right support so you can prepare to discuss the results with your child. Hiding it from them for any length of time can damage their ability to accept their HIV status. Also children often know that something is wrong and can sense the emotions of their caregivers before we think they do.



4. COPING WITH YOUR CHILDREN'S REACTIONS TO A POSITIVE HIV TEST

Children will react in different ways to being told they are HIV positive. It will depend on their age, their understanding of HIV, but also how they have been told and how they are supported to discuss and learn about HIV and their ability to express and share their emotions.

As a caregiver, your role is crucial in how well they understand this diagnosis. You are the difference between them feeling shame or fear and them feeling strong, loved and able to cope with what comes next.

At first my children acted as if they had accepted but I later realised that more counselling was needed as they showed signs of being bitter

I felt that she was too sick to understand her status. I decided that I am going to tell her later when she gets better

My child went quiet and I got confused

He was angry, mad and asked a lot of questions

I felt like it was my fault because I had not told him when he was younger



Explaining things honestly is important but it is also important to emphasise the support that they will get, the people that will be there to help them and the opportunities ahead of them to live healthy and happy lives.

They will take from you the meaning of this diagnosis, so it is important that you feel prepared and able to have this discussion and answer their questions as best you can. You may want to have someone to support you in answering some of the questions and prepare yourself for the emotions that are likely to be expressed by your child – confusion, fear, sadness, anger, denial.

You are likely to feel quite emotional yourself. Seeing a child struggle to understand and accept can be distressing but remember that this is only the beginning of their acceptance. They will need time to talk and reflect and you will need support with your own reactions and emotions.

I asked the counsellor to help me prepare how to tell my daughter that she is HIV positive. She used the soldier game so that both of us could understand more about HIV. I later managed to disclose my status to my child. With time she understood

It was really hard but telling them was the only way to go

He had questions on why he was the only one infected in the family. This was difficult for me to explain but with support from the clinic, he later understood and this made life easier for us and the PC even played the game with my child and with time she understood

5. KNOWING YOUR OWN STATUS

For many parents and caregivers, they are aware of their own status and this is why they take their children for HIV testing. Others may not yet know their own HIV status. It is important that as parents and caregivers, you also know your own HIV status so that you can be started on treatment and receive the care and support you need for your physical and mental health. Also, if you plan on having more children, women who know they are living with HIV can prevent transmission of HIV during pregnancy, child birth and pregnancy when they take ARVs.

We also know that children supported by a caregiver living with HIV who is adhering to medicine do better at their own adherence. Caregivers can be wonderful role models for healthy behaviours, eating well, sleeping well, talking about feelings and adhering to medicines

I did not know about my own HIV results. I felt that I am now old...why should I get tested?



6. SHARING YOUR STATUS WITH YOUR CHILDREN

Parents who are living with HIV often feel guilt about passing on HIV to their children. Shame and fear of rejection can prevent them from discussing with their children about their own status. Some parents worry that talking about their status will mean they then need to talk about how they contracted HIV and this may involve talking about sex or abuse.

Remember secrecy and shame around HIV is learnt behaviour and if your children see and feel your shame and you keep things hidden this is what they will learn to do. Try to be honest with your children about your status, share your own thoughts and feelings about it. This will support them to accept both yours and their status.

At that time , I did not share my status with anyone, particularly my daughter because she was too young to understand and it was going to be a disgrace to our family

Yes I had to explain my own status so that they get to understand where they got it from



7. DISCLOSURE TO SIBLINGS AND OTHER FAMILY MEMBERS

Many families keep secrets about HIV even amongst themselves. Often a child's status is kept hidden from siblings. This may be done to protect the child living with HIV, to ensure they are not stigmatised or to prevent siblings disclosing the child's HIV status to people outside the family. This is a genuine concern but we also know that siblings often can sense there is a problem before you say anything, they experience anxiety about unspoken secrets and they often feel excluded or isolated. A child living with HIV can also feel they are treated differently and they too can feel excluded when there are secrets.

I shared with the family so the child could get support from them and avoid discrimination

I did not tell them as I felt that they will tell the whole community and we will be isolated in participating in the activities organised by the community

I disclosed to family members because I needed a strong support system for my child



Sharing within a family is something you will need to decide on but it is important you think about how best to do this so that everyone can feel supported, included and cared for. Explaining to younger children may need less detail but even young children can understand about HIV and also about the importance of not discussing things outside the family, if it is explained properly in a way they can understand.

We also have to consider sharing with other adults, spouses, in-laws, extended family. This can sometimes be harder than sharing with children, as adults have deeper prejudice and greater fear of HIV. Their lack of knowledge or experience can make them very scared. This type of disclosure can also expose issues within a family, such as people who have been hiding their status and infidelity. As with any disclosure there are important things to consider about, if and when you decide to do it. Remember for children living with HIV in a family it is so important that they feel included, loved and cared for by everyone and not different, not ashamed or expected to hide the truth.



I told my husband about the positive result since he is the one who gave us the virus. I no longer wanted to stay with him. I cried when I was telling him that he messed up our lives and that of our daughter

I told my husband because I could not hide it forever

At that time I could not tell my husband. It was more of a sensitive issue for me and the children

I did not disclose to him since he does not know that I am HIV positive as I feared rejection too

8. COPING WITH STIGMA

Of course, telling people about HIV is never easy and we never know what their reactions will be. That is why it is important you have taken time to accept your status or the status of the child before sharing with people more widely. You need to be strong in your understanding of HIV so you can challenge any misconceptions or fears and you can be clear in how you want this information to be used once it is shared. You can also be clear about the support you want from others.

It is possible that sharing this information will lead to someone rejecting you or your child. Despite providing information some people are still unable to understand HIV, the risks, the implications and what people living with HIV need. Some people can be irresponsible with this knowledge and can try to harm you through discriminating or sharing with others. Think carefully about who you share with.

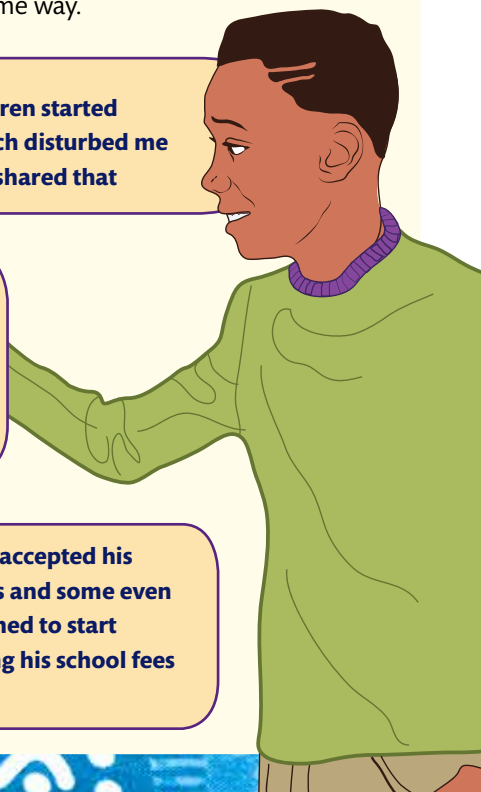
Others will surprise you. The acceptance and love that they can offer can give great strength, not everyone will react in the same way.

Some of my grandchildren started discriminating her which disturbed me and I regretted having shared that

They accepted her status. Others also concurred that since the parents died with unknown diseases, they suspected that she got it from her parents

They just supported my daughter when she was not well

They accepted his status and some even vouched to start paying his school fees



9. STARTING TREATMENT

Once a child receives a positive HIV test result, the child will be prepared by the clinic to start Antiretroviral medicines, or ARVs. It is now known that if medication is started early, then people living with HIV do better. But the most important thing is that they are ready before starting. So take time with your child to prepare for this.

When children start their ARV treatment their responses can be different. Some children do well very quickly and adapt to their medication well. Others struggle with taking medication every day at the right time. Some may have reactions and side effects such as dizziness, headaches, abdominal pain and skin rashes. Until they start, we don't know how they will be. It is important that you are ready for them to start and you have learnt about what the medicines are doing inside the body and what might change for the child. It is important you understand how medication needs to be managed and who can support you to support the child. If you are also taking ARVs you will be able to understand taking treatment but remember it might be quite a different experience for your child.

I was not very sure of what was going to happen but I decided for my child to start medication as the nurses had said.

I was somehow convinced that they would help my child

I was very eager for my grandson to start medication because I wanted him to quickly get better and I had very high hopes in these medications

At first I was afraid of the side effects of the medication but I was told what to look out for and when to go to the clinic and my child was fine

I was not ready for both me and my child to be put on ARVs as I knew it would cause trouble at home with relatives. I was also fearing that the ARVs would cause complications like what I have heard from other people. I just accepted the meds because the nurses had told me to.



I felt complications could arise as I had little knowledge about treatment. That is when the counsellor explained the importance of starting treatment early. I decided for her to start medication so that she can improve.

I learned that my grandchild can live longer and have as many children as she wants. I wish my child was alive so that she could have benefited from these ARVs.

10. UNDERSTANDING ART

The most important thing to prepare a child for ART and to help them adhere to their medication is to help them understand how HIV works in their bodies and how ARVs control the virus.

Understanding how the treatment work is important for you to explain to your child what the medicines do. At Zvandiri we use a story to explain this to children.

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**.

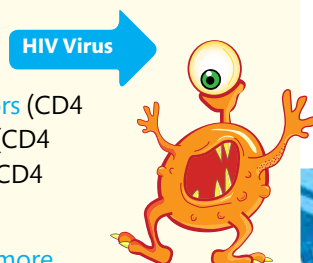
This means that the body can fight off infections.



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.



19

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

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.



Did You Know

ARVs can make life much, much better by controlling the HIV virus.

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**

Supporting your child

The greatest support you can offer your child is encouragement, love and honesty. Give them space to ask questions and express how they feel. They are likely to go through periods where they feel sad and struggle with medication, with stigma or with staying healthy. But being there for them can help them see the opportunities and the benefits from medicines that will keep them healthy and will support them to have loving relationships and have families in the future.

My child also needed to know if there are any other children who had HIV and that was the time she started attending a support group in the community. This has helped a lot as she knows she is not the only one. They support each other and learn about living with HIV

He needed love and a lot of support so that he was not afraid to ask any questions about HIV. Now he is doing well on medication, his viral load is undetectable

At first, he needed support but as time proceeded he is now able to start taking his own medication. He even reminds me to take my ARVs

11. FINDING YOUR SUPPORT

Caring for a child who is living with HIV brings different responsibilities, worries and challenges. As a caregiver it is important you have support to share your feelings and get the information you need.

As adults, to see children ill or dependent on medication can make us feel very sad and guilty and this can weigh us down. We can feel quite hopeless or that we have let children down. Remember that you are such an important part of a child's life. You can determine how well they accept their HIV status and manage their treatment. Make sure you stay healthy and get advice and support from others to help you support the children in your care. The clinic can offer information and advice about treatment and refer you to organisations that offer support groups for children and carers. There are also government supports that you may be able to apply for to help with food, schooling, child care.

I received information on good adherence, importance of support groups and having viral loads collected as is required. My child is not sick anymore. He is healthy and doing so well at school.

I was referred for the other needs which my child required such as payment of school fees as I could not afford it.

I received information from nurses, counsellors and CATS who used to tell me the importance of disclosing early to my child. We now understand one another and support each other.

I was really helped to come to terms with my own status. I let go of the anger that I had for my husband and managed to get my husband tested and also put on medication. It also later empowered me to disclose to my daughter who is now in a support group and doing really well on medication.

Things to remember

- Children and young people living with HIV can grow up, finish school, get married, have HIV negative children just like others, but they need your love and support
- You are so important in the lives of your children and have the ability to support them to be happy, healthy and safe
- If you are living with HIV you are a role model for taking care of yourself and others
- Children do better adhering to medication when they are disclosed to early and understand their HIV status
- Taking care of yourself is as important as taking care of a child living with HIV. They need you to be healthy.
- There are people to support you with health, with talking about feelings and answering your questions.
- You are not alone, there are others facing the same challenges. Find people to share your experiences with.





OPPORTUNITIES
Fun
Love
Smile
Goals
Care
Hope
Trust
singing
Hospital
Support
patients
live
Dancing
our own books

PURPOSE
Well-being
Change
Treatment
Peace
Engagement
Support
Confidence
Safety

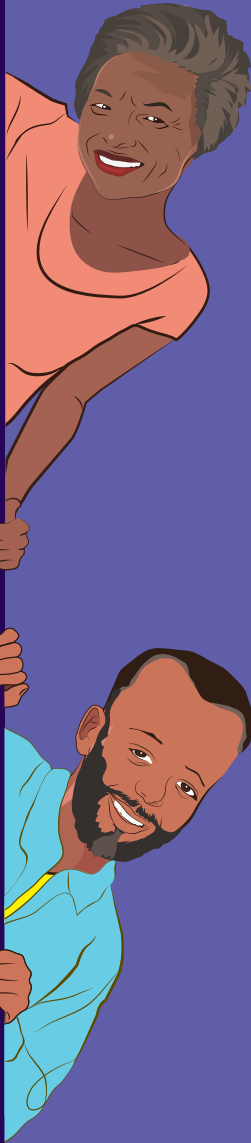
Fun
Care
Jobs
Happiness
Final
Trust
Skills
Dancing
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Viral
A voice
Pride
Access
Growth
Skills
Safety
Peace

HEARING AIDS
Shine
Peace
DREAMS
CARE
pill box fun fun joy

TRAINING
love
Medicines
SAFETY
DANCE
EDUCATION

Dental Care
Singing
HAPPINESS
Access to treatment & care



Africaid Zvandiri

- 📍 11-12 Stoneridge Way North, Avondale, Harare, Zimbabwe
- ☎ +263 242 335 805 📧 info@africaid-zvandiri.org
- 📱 Africaid Zvandiri 🐦 @zvandiri 🌐 www.africaid-zvandiri.org