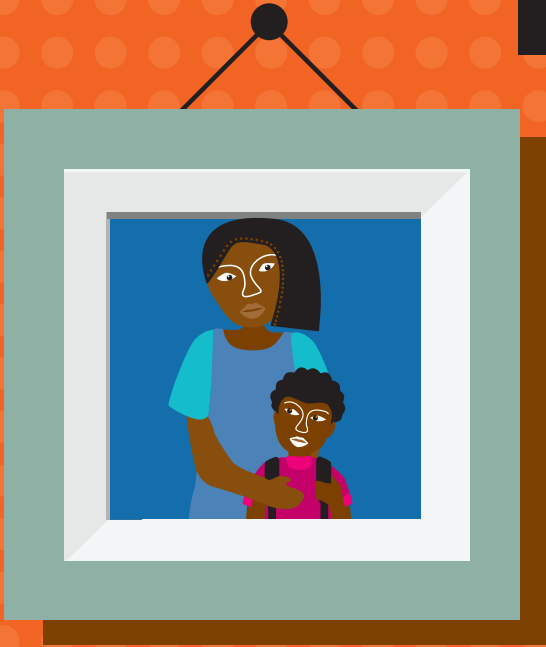


Caregiver Stories



This booklet has been developed from the stories of young people and families in the READY+ programme. Stories have been gathered from eSwatini, Tanzania and Zimbabwe to share the experiences of caregivers caring for children and young people living with HIV.

We hope it provides parents and caregivers with information and ideas to support conversations with children and young people about HIV.

These stories are followed by questions to start discussions and help caregivers think about their own experiences. There are also information pages that offer guidance on how to support children and young people to talk about HIV when they are ready.

The stories have been gathered through READY+ partners and we would like to thank the families who shared their experiences with us and all the story gatherers.

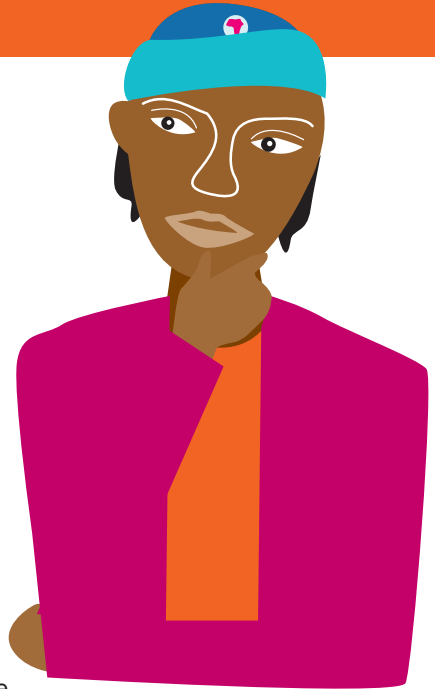
We have changed the names to protect the identities of individuals, but the stories are based on real lives of young people living with HIV.

This booklet can be used by individuals, or by groups as part of a support group session.

DUMI

Dumi is 23 and works as a community adolescent treatment supporter (CATS) supporting children and young people living with HIV. He lives with his mother Nobantu, his stepfather and a cousin who is nine years old.

Dumi was a very sickly child who was constantly in and out of hospital, but the doctors did not know what was wrong with him for many years. He found out he was living with HIV when he was 14 years old and in an unexpected way. Dumi had gone for circumcision with a group of boys from his school. The circumcision was arranged by a local organisation and they invited boys and their parents to attend the health facility where the circumcision would take place. Dumi was tested for HIV before undergoing the procedure and he and his mother were called into the testing room shortly after. The counsellor said, “The test can be positive or negative. How would you feel if the result comes out positive?” Nobantu can’t remember what she said but she listened as the counsellor told her that Dumi had tested positive. They asked Nobantu if she knew her own status. She felt emotional and confused and didn’t answer. She tried to think back to when she could have become HIV positive. Dumi sat quietly in the corner. Nobody spoke to him.



He was confused about HIV and afraid of what it meant

Dumi and Nobanti were referred to the hospital. Dumi was quickly started on ART treatment. However Nobantu was reluctant to test and start treatment immediately. She delayed testing, and did not start treatment until her CD4 count was very low and she was quite ill.

Dumi managed his treatment well at the beginning but it was discovered that he also had TB, so he had to take TB medication as well as his ART which was very difficult. Dumi had a hard time accepting his status, he was invited to join a support group, but he refused to attend. He looks back at this and remembers he was still

confused about HIV and afraid of what it meant. He didn't feel able to talk to other people. He realised that the counselling he was given was not adequate as he did not understand how he had got HIV and why he had to take the treatment every day. Nobantu didn't talk about HIV with Dumi. She was afraid to bring things up and wasn't clear how to help Dumi. She says her biggest challenge was her own guilt, that she had not been able to protect her child. Dumi has never blamed her or given her a hard time but she just didn't feel able to talk.

Dumi did well with his medication and was given the opportunity by the clinic to train with the READY+ programme to be a community adolescent treatment supporter (CATS). He was chosen to support children starting on treatment at the clinic and to visit them at home to discuss the difficulties they face and to help them understand HIV.

Dumi feels he only started to understand HIV properly when he trained as a CATS and when he had the chance to meet other young people living with HIV. He realised that if he had chosen to attend the support group he was offered when he started treatment he could have got this help earlier.

Since he became a CATS Dumi has been able to talk to his mother and their relationship has got stronger. They support each other and other members of the family who are living with HIV. Dumi encourages young people to reach out for support and to find peers to talk to in a support group. Nobantu feels the support that Dumi has received has helped him open up and she encourages all parents to start talking. "It isn't easy, but it can give you and your children so much strength."

Questions:

- What challenges did Dumi face?
- What helped Dumi?
- What made things difficult for Dumi?
- What are some of the feelings Nobantu had?
- What are things that could have been done differently to help Dumi and Nobantu?
- How can this story help others?



TENDAI

Tendai is 18 years old and lives with his mother Rufaro. For years Tendai took tablets each day and believed he was taking them for an allergy. He had asked his mother many times about the medication, but she would just tell him to continue taking his tablets or his health would deteriorate. Tendai did not trust the story his mother had told him, and he would often not take his medication. His mother checked up on him, but he always managed to convince her that he had taken his tablets.

What Tendai didn't know was that stopping his medication led to a very high viral load and the nurses were wondering the cause for this. They asked him questions while trying not to reveal what the tablets were for, as requested by his mother but he told them he was taking them well. Despite all the problems and visits to the clinic, his mother continued to hide information from Tendai. Every day she thought about how difficult and painful it would be to explain to Tendai that he was living with HIV and it would stir up trauma around the death of her husband, which was the last thing she needed.

All the questions from the nurses made Tendai confused and curious about his health so he decided to go for an HIV test with his

**He came back furious
and wanted answers**



friends. He came back furious and wanted answers and his mother was left with no option but to disclose. He blamed her and demanded to know how he got infected with HIV. He also wanted to know why his siblings were not infected and he was the only one. She felt humiliated being asked so many questions and felt he was so disappointed with her.

The relationship became very difficult. Tendai spent long periods of time without talking to Rufaro and when things were bad, he attempted to take his own life. This devastated his mother and she broke down and told him the whole story. With the help of CATS and health care workers she was supported with information and ways to talk to Tendai and they helped him get some support from a psychologist. They have begun to rebuild their relationship. Rufaro has been able to apologise to Tendai for not telling him earlier and explain to him all the worries and fears that stopped her from being open. Together they now want to talk to Tendai's siblings support and explanations.

She felt humiliated being asked so many questions



Together, they now want to talk to Tendai's siblings

Questions:

- What challenges was Tendai facing?
- Why do you think he didn't trust the story his mother gave him about the allergies?
- What do you think could have been done differently to support Tendai?
- What have Tendai and Rufaro learnt that could help them speak to the other children in the family?
- How can this story help others?



NEEMA, IMANI & IMARA

Neema lives with her twin daughters Imani and Imara. The girls were healthy and happy for many years but when she was 10 years old Imani started to get sick, she had rashes and lost nails from her fingers. The family attended the clinic and tested for HIV. Imani and her parents tested positive but Imara was negative. The girls were not told about the tests but Imani and Neema were started on treatment. Neema's husband refused to accept the result and would not start ART. He died within a year.



After some time Imara started to ask a lot of questions about HIV. She had learnt about the signs and symptoms of HIV at school and recognised her sister had many of them. It was then that Neema decided to visit the clinic and ask for help with talking to her daughters about HIV. The doctor counselled the girls and retested them both so that he could share with Imani about her HIV status properly.

Neema had been so afraid to tell Imani about HIV but that moment at the clinic changed everything. Imani was able to tell her sister Imara about her diagnosis and Imara now supports her mother and sister, reminding them to take their medication. Imani attends a support group and safe space where she meets with other young people living with HIV. Talking to others who have had many struggles living with HIV she realises she is healthy and doing well on her medication.

Questions:

- Why do you think Neema didn't tell the girls that Imani is living with HIV?
- What might be the challenges of having siblings who are both HIV positive and HIV negative?
- How did the support from the clinic help Neema?
- How can this story help others?



Peter fell ill when he was 8. He had a terrible cough and his mother Glory took him to the hospital and he was given medication but there was no improvement. After trying different medicines, the nurses encouraged Peter's mother to take him for an HIV test. She was hesitant but knew she had to, and she decided that they would get tested together although she was not ill. They both tested positive and were started on ART.

Peter was not told about his HIV diagnosis but each time they visited the clinic they would see so many children critically ill and Peter would ask what was wrong with them. Glory told him it could be HIV. The questions Peter asked helped her to explain the modes of transmission and ways to avoid illness. One day Peter asked his mother if he too was HIV positive. Despite all their discussions and visits to the clinic Glory decided not to tell him the truth. At 8 years old she felt he was still too young.

One day at the clinic while Peter and Glory waited to be seen a child passed away. Peter asked Glory about the cause of the death and it was then that she decided to tell him he too was HIV positive and how important it was to take his medication. To see a young child the same age as Peter lose his life, she knew she needed to explain things. Glory told him she did not know how they both contracted HIV. All she could tell him was that it happened when he was born. Peter understood what Glory told him and she realised that he had been aware of much more than she thought. She had been afraid of what his response would be, but he coped well.



At 8 years old she felt he was still too young

Peter began to realise that people knew or suspected he was living with HIV when other children did not want to play with him. Glory

explained to him that he was privileged to know his own status early and that he just had to continue taking his medication so that he remains strong.

She realised he had been aware of much more than she thought

For Glory she has learnt the importance of being open with children even if it seems difficult.



Questions:

- What encouraged Glory to talk to Peter about his HIV status?
- What were some of the things that might have prevented Glory from speaking to Peter earlier?
- What challenges did Peter face after he had been told about his HIV?
- What helped Peter deal with the challenges?
- How can this story help others?



RUMBI

Rumbi grew up being a precious little princess after her elder sister had passed away. All Rumbi was told about her sister's death was that it was heart failure. When Rumbi got sick her mother was careful to get medical care as soon as possible. When Rumbi's father passed away, Rumbi began to ask questions. She wanted answers as to why her father had been so ill. Her mother assumed she was too young and avoided discussing things with Rumbi. What she didn't know was that Rumbi understood much more than she thought and was asking to clear her own mind.

She realised that Rumbi was failing to cope with her HIV status

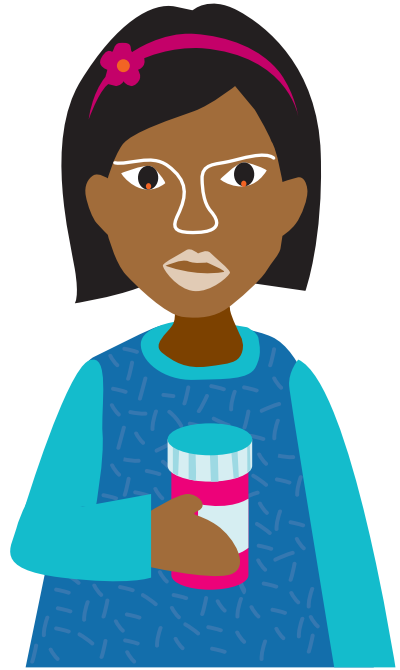
When Rumbi turned 11 she started suffering from severe headaches and the doctor decided to carry out an HIV test. Rumbi's mother knew what the results of the test would be, so she asked the doctor to tell Rumbi whilst she sat outside, but when the doctor talked to Rumbi her mother could not stand the loud screams of her daughter and ran into the room. The doctor and the nurse gave Rumbi counselling and Rumbi's mother shared her own status with her.

Rumbi's mother knew she had to support Rumbi to start taking her medication, but she was worried about other children who lived in the house finding out. She told Rumbi that she had to take her medicine each day. Rumbi seemed fascinated with the pink container that the medicine came with but not the contents. Rumbi hated going to the clinic and waiting in long queues and being with so many other people. She did not want to go for check-ups and only took her medicine when her mother stood over her. At times her mother found pills in between the cushions of the couch or undissolved pills in the bathroom. That is when she realised that Rumbi was failing to cope with her HIV status. She would constantly ask why she got infected and whether she was going to die like her sister. This broke her mother's heart. "Nothing I said helped the situation, she would throw tantrums or lock herself in her room. I ignored her moods as I felt I was to blame for everything that was happening."

Rumbi became very stubborn and her schoolwork suffered. One day she wrote a letter to her mother blaming her and threatening to run away from home. Rumbi's mother decided to take her to one of her friends who was a professional counsellor. The counsellor engaged Rumbi in youth activities that changed everything. Rumbi

The counsellor engaged Rumbi in youth activities that changed everything

became a leader in all these groups, she became an advocate and now speaks openly about her status to her peers and advocates for other parents to disclose to their children. Rumbi now reminds her mother to take her medicine and she has an undetectable viral load and is well and happy. For Rumbi's mother talking to



children about HIV is so important. She says “Let the children grieve so that healing takes place in a natural way. Encourage them to join support groups and other related activities as they helped bring my daughter back to me.”



Questions:

- Why do you think Rumbi’s mother didn’t tell her about her HIV status?
- What are some of the feelings that Rumbi’s mother might have felt?
- What are some of the feelings Rumbi might have experienced?
- What could have been done differently to support Rumbi?
- How can this story help others?

SALMA

Salma is a mother of twins, Rahma and Rahima who are 15 years of age. The twins are both living with HIV and Salma told them about their status when they were 7 years old when they began asking questions about the medication they were taking. They would complain every morning about taking the tablets and at times refused until they were forced. Salma noticed when she was away that they wouldn’t take the medication at all and they would lie to her when she returned.

Salma and her husband decided they needed to explain to the girls about living with HIV in the hope it would improve their adherence to medication. On a Saturday evening Salma made a delicious dinner that she had never prepared before and after they had all eaten, she asked Rahma and Rahima to sit down in the sitting room.

Salma asked them if they knew why they were taking medicine and both girls replied “No”. Salma explained that they had a problem with their immune system called HIV and that all the other people they see at the clinic have the same problem.

Salma explained that they had a problem with their immune system called HIV

**Be open and honest
with your children.
Don't hide the truth.**

The girls cried for a while and asked questions about how they got HIV. Salma was honest and explained that the HIV was transmitted through breast feeding and at the time Salma did not know that this could happen. She had not known she was HIV+ until Rahma had been sick when she was a baby and they were all tested. Salma told them that

living with HIV is a disease just like any other disease and life goes on.

Salma felt sad and emotional while explaining and answering their questions but since that night things for the girls have changed. They now take their medicines even when Salma is not around, and they remind each other. They are happy in attending the clinic and support group and meet with other children and share experiences. They have a better understanding of HIV and show no signs of loneliness and sadness. Salma says she feels peaceful, relieved and happy with her children. She is free from any sort of fear and has hope for the future. She advises other caregivers "Be open and honest with your children. Don't hide the truth. Telling your children about HIV is not an option it is a must. Only the truth will help them cope."

Questions:

- Why do think Rahma and Rahima avoided taking their medication?
- What did Salma do to make telling the girls about HIV as successful as possible?
- How can this story help others?



**They now take their medicines
even when Salma is not around.**



INFORMATION TO SUPPORT DISCUSSIONS



Children living with HIV

Children who aren't told they are living with HIV can feel confused and scared. It is important that children learn about HIV early on and are supported to talk about their experiences and feelings. Children from the age of 6 can understand information about HIV and what they need to do to stay healthy. Research suggests that children who are told when they are young are better able to manage their treatment in the long term. All children should be told by the time they finish primary school but by the age of 9 is recommended. Lying or hiding information from children can create problems later. Children can feel they have been betrayed and they might feel less able to trust the adults around them. It is also important that a child knows about their HIV so they can take up the different support on offer such as medication, counselling and support groups where they can talk to others and discuss their feelings.

Younger children are often more able to accept that HIV is a condition they can live well with as they are less likely to have had the experience of other people's negative attitudes. This is another reason for telling children early. Waiting until children are older into their teens is not only a difficult time for them but also it is likely they will be much more aware of the stigma that surrounds HIV.

Sharing your own HIV status with your children

It can be very difficult to talk to your children about your own HIV status, there are often concerns about the questions they might ask or the emotions that may be stirred up. However, children living with family members who are living with HIV should be told. Children often know there is something they are not being told and this can create anxiety

and worries. For children who are also living with HIV, being told can help them feel included and supported in managing their own HIV. It also means they have people who are important to them who can listen to their concerns and feelings, people who understand. Adults can act as role models around staying healthy and adults and children can work together to support each other.

There is no single right answer about when you should tell your children you are living with HIV. It may depend on whether they are also living with HIV, what age they are or what else is happening in their life, for example, traumatic or stressful events or stages such as puberty. The key guidance is to prepare for it, so that it is not revealed unexpectedly, and you need to make sure you keep discussing it and answer the child's questions until it becomes something they are comfortable to talk about.

Don't forget siblings:

Some families worry about talking to other family members about HIV. Often siblings are not told about their brother or sister's HIV diagnosis and they can feel confused or excluded. Working as a family to share information with siblings when they are old enough is important, and is a gradual process, sharing the information according to their age and capacity to understand. Remember they may have their own questions, worries or concerns and could also benefit from counselling or support groups.



Support groups

Offering your children the opportunity to attend a support group with other children and young people who are living with HIV can be very beneficial. Support groups can offer safe spaces where children can ask questions, learn about HIV, express their feelings and receive support from those who have had a similar experience. Sometimes caregivers are reluctant to let children take part as they worry about privacy and other people finding out about they are living with HIV. Talk to the organisers of the support group to understand how they ensure confidentiality and learn about the benefits of the groups for children and young people.

Asking health workers for support

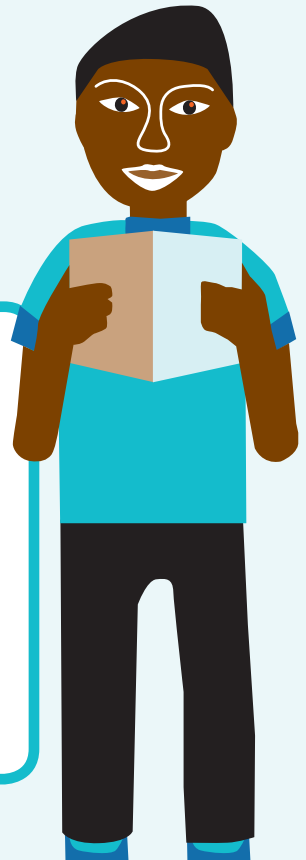
It is generally believed that talking to children is best done by those adults that matter most to them, such as family and caregivers. However, this can be a difficult and emotional task for caregivers alone. Doctors and counsellors can help you plan and practise talking to your children. They can provide information about HIV for you to share and they can help you find the words and explanations to use when you talk to your children. In some cases, they can be with you when you talk to your children.

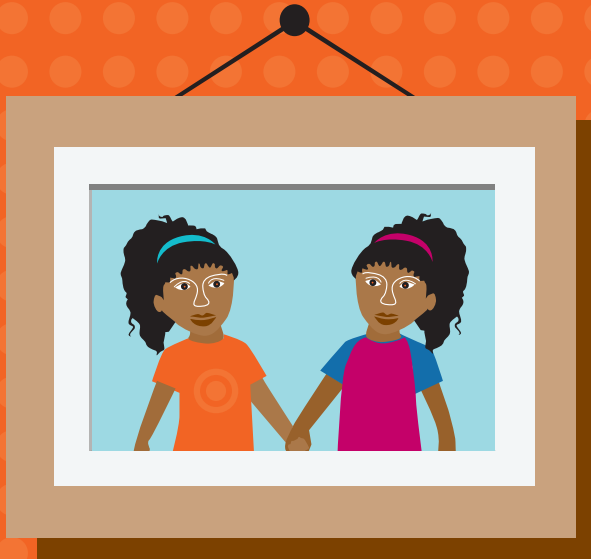
Leaflets for children and young people

READY+ has produced leaflets that you can share with your children to help understand more about living with HIV and to support them when they want to share with someone else that they are living with HIV.

You can find them here:

<https://frontlineaids.org/resources/>





READY+ aims to advance sexual and reproductive health and rights (SRHR), psychological wellbeing, care and treatment with, by and for 30,000 adolescents and young people living with HIV in Mozambique, eSwatini, Tanzania and Zimbabwe. The programme is being implemented by an innovative and multi-disciplinary consortium of youth, SRHR, HIV and communication partners.

READY+ is one of a portfolio of projects being implemented under the READY programme. For more information, visit <https://frontlineaids.org/our-work-includes/ready/>



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