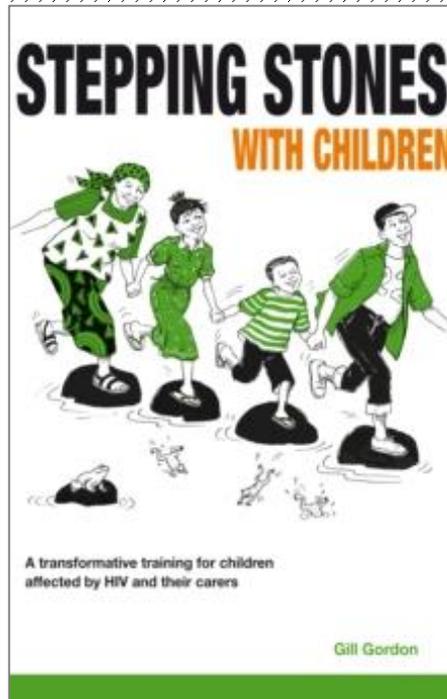


Handouts for *Stepping Stones with Children*



This *Handout for Stepping Stones with Children* is to be used with the *Stepping Stones with Children* training manual published by Practical Action Publishing, 2016.

You can download this handout for free for use with this training manual from the www.stepsstonesfeedback.org website.

On this website there are also many other resources to support you with this training manual and the original *Stepping Stones* training manual.

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TESTING FOR HIV AND TALKING ABOUT IT

1. What are our rights regarding HIV testing?

- We decide whether to have an HIV test or not: it is voluntary. No-one has the right to force us, or our children, to be tested. In most countries, caregivers need to give their consent for their child to have an HIV test, and the child gives their assent (agreement). Sometimes, older children can give their consent without their caregiver.
- We have counselling before the test (to help us decide whether to have the test) and after the test (to help us cope with the results, whatever they may be, and get support).
- We are offered support after testing, including care and treatment if we need it.
- The test and results are kept a secret unless we say we are willing to tell others. No health worker should tell our partner, children, family, or colleagues about any of our health issues without our consent.

2. About HIV testing

A **positive result** shows that HIV has got into our blood. We may be well, because HIV has not yet harmed our immune system. We may stay well for a long time without treatment, or start to get sick more often. Or we may already have signs of low immunity, such as frequent sickness and the illnesses associated with AIDS.

Once it is known we have HIV, doctors monitor our health and our number of CD4 cells, and advise us when to start taking ARVs. The ARVs reduce the amount of HIV in our blood so we start to feel well again.

A **negative result** usually means that we do not have HIV. However, it can mean that we are in the 'window period'. This is a time of about 3 months when we have recently acquired HIV and the test cannot yet detect it. During the window period, we can have HIV in our blood and share it with others, even though the test shows negative. If someone has a negative result, but may have been in contact with HIV recently, they will be asked to retake the test in three months.

Occasionally a test result is **inconclusive**. This means the result is not clear and we will be asked to repeat it.

3. Talking with children about having an HIV test

- Explain how having an HIV test can help them and the family, and ask for their views and questions. If they feel that the test will help them, they will manage much better.

- Give information suitable for their age and level of understanding. Be attentive to how they respond and support them if they get upset.
- Secrecy around HIV can make children feel fearful that they have been bad and HIV is their fault. For children over 12 years old, especially, we encourage you to discuss HIV openly, so you can support them to understand. The more normal you make HIV, the more your children will be able to feel normal about HIV.
- Many children fear having an HIV test because they believe a positive result means they will become sick and die young; they are afraid they will be stigmatized and will not be able to study, work, marry, or have children. Reduce their fears by explaining how treatment can keep them healthy and allow them to have babies free from HIV.

4. Telling your child that they are living with HIV

- Prepare your child by giving them information in small chunks. Begin with simple information about viruses and how the immune system protects us.
- Choose a time and place where you will not be rushed or disturbed. Make sure that the child cannot run into the street, or get lost if they are upset.
- Tell someone whom the child likes and trusts what you plan to do, and ask them to be available.
- Be prepared with basic facts: how HIV is transmitted; the difference between HIV and AIDS; and how support and treatment can keep people well for many years.
- Check what they think they know. Give correct information as needed.
- Do not make it a big thing. Say “You have HIV, it’s a virus that makes your immune system weak, so it is harder to fight off infections. You can take medicines that make your immune system strong again, so you can do the same things as other people”.
- Ask them to tell you any questions they may have, at any time. Find out the answers to questions you are not sure about.
- Tell them it is important to think about who to tell about having HIV. It is not a secret; but personal information is best kept with trusted relatives, friends, and health workers, because some people may not understand.
- Link them with supportive people such as family and friends, an HIV support group or counsellor.

5. Tips for supporting children emotionally

- Try to stay calm and on your hub.
- Be ready to talk about the issue frequently and repeat the information.

- Give a lot of love and praise to reassure children that they have support, and to raise their self-compassion.
- Read their body language and listen to what they say and use your mindsight skills to understand how they are feeling.
- Use your compassion and empathy to help them cope with their feelings. Then help them to think about what is happening in a calmer way.
- Talk about the situation positively: how many people manage to live well with HIV; how medicine can keep us healthy, even with HIV.
- Explain why you did not tell them earlier. For example, "I didn't want to burden you, but now I know you are becoming mature and wise, we will use our courage and strength to cope with this together". If appropriate, apologise: "I'm sorry you are hurt. I did what I thought was best."

6. The Story of Martha and Mark

You may find this story useful to read with children or to share with friends.

Part 1

Martha finds life a struggle. Her husband died two years ago from an illness related to AIDS. She is bringing up her four children by herself. She often feels tired and sick. Last month she had an HIV test and found out that she has HIV. She worries about how she will find enough money to feed the children and send them to school. She does not feel ready to tell them that she has HIV, but wishes that her eldest son Mark, who is 12 years old, was more understanding. He is always asking for money for school stuff and sometimes gets angry when there is no food ready after school. Martha sometimes thinks it would be good if she told him that she has HIV. He would help her more and let her rest. The health worker says that she needs to rest and eat more to take her ARVs safely.



Mark is also anxious. He is afraid that his mother might have HIV. She seems so tired and is often sick. He sees her hiding pills and taking them when she thinks he's not looking. He thinks his father died of an AIDS-related illness. How would he and his siblings cope if his mother was not there? How would he look after them all? Might he or his siblings also have HIV? He wishes he

could talk openly to his mother about his feelings. Sometimes he feels bad because he gets angry and doesn't help his mother on the farm. He wishes that he and his mother could talk openly about what is really happening in their lives.

Part 2

Martha heard that there were some women in her community who had formed a support group for woman with HIV. Because the women in the group talked openly about having HIV, they were able to support and advise each other and seek medical help openly. Martha went to visit Anna, the group leader. Anna invited Martha to come to some meetings to help her decide whether she wanted to tell Mark and her family about her HIV or not. There were many consequences to think about, but she could choose who she wanted to tell, if anybody.



Part 3

Martha decided that she wanted to tell Mark that she had HIV. She wanted to prepare him for the future and she needed his help to stay healthy. She also needed to think about whether any of the children might have HIV. But she decided to go one step at a time. She prepared for telling Mark with Anna. She waited until Mark seemed ready. One evening he asked, 'Mum, Why are you so tired? I'm worried about you.' This was her opportunity to tell him.



At first Mark was very upset but then he said that he'd already guessed. He was glad to know the truth. Anna met with Mark and they talked about his feelings, and gradually he became calm. Mark then decided to ask if he had HIV too. She explained that it was unlikely that Mark had HIV, as he was 12 years old and rarely ill. Anna also had a son of her own, John, aged 14. She asked Mark if he would like to meet up with John. Mark agreed and met and talked with John also. Mark was surprised to realize that he recognized John from school. They played football together, which felt great.

Part 4

It is now a few months later. Martha's health is much improved. She is more relaxed because she is no longer trying to keep her HIV a secret. She goes to meetings with other women, which encourages her. The women support each other in getting treatment at the health centre. Mark is also now calm and feels happy that his mother decided to trust in him. He helps his mother on the farm so that they can eat healthy food. Mark also gets the younger children to help more about the house, so his mother can rest. He talks with his mother a lot. He also sees John regularly outside school. Mark is glad to see his mum looking so much healthier and happier. Martha is writing a memory book so that she and Mark can record past memories and plan for the future. She has written a will so that Mark will know about his inheritance. But for now, Martha feels very positive. She is getting stronger day by day, and Mark is feeling happier too because they can share their concerns and their minds are at ease. He also knows that John understands too and is his friend. There is song and laughter again in the house.



Question: Can you think about what might happen next in this story?