



Disclosure Process for Children **AND ADOLESCENTS LIVING WITH HIV** PRACTICAL GUIDE



HIV Disclosure in Children — A Practical Guide

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Introduction

HIV Disclosure in Children — A Practical Guide is a resource for you, the healthcare worker. It provides guidance on supporting caregivers to discuss with their HIV-infected children — between the ages of 5–13 years old — their HIV status. Although caregivers are responsible for disclosing to their children; your role as the healthcare worker is to provide information and guidance on when and how to begin disclosure discussions with children. During the disclosure process, you will provide emotional and informational support to caregivers, and share medical and clinical information.

Disclosure of HIV status to children should be an ongoing process. Early conversations about medicines, clinical visits or the child’s health will begin as soon as the child is old enough to ask questions — at two or three years of age. Explanations may begin by responding to questions then moving on to general discussions of health before disclosing HIV status. Disclosure of the child’s HIV status may occur between 8–11 years, and should begin when the child starts asking specific questions about their illness and why they have to attend the clinic more often than other children their age. Disclosure discussions do not end after disclosure of HIV status — children need ongoing support and will likely have more questions as they mature.

Many caregivers are uncomfortable speaking with their children about HIV. Always assess the caregiver’s level of comfort with disclosure and provide needed support accordingly. Refer caregivers to community resources, such as community health workers and support groups that can provide additional support for the disclosure process. If there are no support groups in your area, consider starting one!

Practical Guide

This *Practical Guide* is meant to be read and studied in advance as it provides background information to support you to understand the process of disclosure and provide you with a checklist of key points to cover with each caregiver. This *Practical Guide* is divided into three sections — partial disclosure, full disclosure (see box to right) and post-disclosure.

Partial disclosure refers to telling the child only some information about her or his illness, for example, the fact that she or he is sick and must take medicine. With partial disclosure, the term “HIV” is not shared with the child. This approach is often taken with young children who may not be able to grasp the full meaning of their illness. Partial disclosure also protects the child and family from unplanned disclosure.

Full disclosure means naming and giving more HIV-related details, for example, how it is transmitted, how the child might have contracted it. Families and caregivers must decide at what point full disclosure is necessary. An important indication that full disclosure should be considered is when the child starts asking specific questions about her or his illness — for example, how did she or he get the sickness — and no longer seems satisfied with the responses previously received.

Each of the three sections of the *Practical Guide* begins with guidance for you and then scripts for the counselling session for each of the three phases — partial disclosure, full disclosure (see box to right) and post-disclosure. The script focuses on how to empower caregivers to disclose to their children. You can, and should, change the words and/or language as needed depending on the caregiver’s situation and level of understanding.

The scripts include an “Objective” column and a “Script” column. The objectives provide a brief summary of what to say, for the healthcare worker who is familiar with the scripts. The script is meant for healthcare workers who may not know the content well, and therefore provides word-for-word guidance. Try not to read the script, instead, become familiar with it in advance.

Using the Cue Cards and booklets

This *Practical Guide* should be used with the *Cue Cards for Healthcare Workers* and companion booklets that cover the following topics:

1. *How to Keep _____ Healthy* (booklet and *Cue Cards* to support partial-disclosure)
2. *Knowing about Myself* (booklet and *Cue Cards* to support full-disclosure)
3. *Living a Life of Health* (booklet and *Cue Cards* to support post-disclosure)

Each of the three booklets was designed as a story book for caregivers to read to their children to guide the discussion in the home. Each of the booklets is complemented by *Cue Cards*, which are for the healthcare worker. The *Cue Cards* and the *Practical Guide* include the text from the booklets as well as key points for the healthcare worker to discuss with the caregiver when presenting the booklets. The assumption is that you will use the *Practical Guide* to study the content of the disclosure session in advance, but take the *Cue Cards* into the session as a job aid to assist with remembering key points. You may want to read the text of each page of the booklet using the *Cue Cards* while the caregiver follows along in their own booklet.



The description of the booklets that appears in both the *Practical Guide* and *Cue Cards* are divided into:

- “Booklet Content”: which includes the image and text that appears in the booklet
- “Objective of this page is to.... Possible discussion points”: which provides additional information about the objective and the purpose of each page. It also includes questions commonly asked by children.

The booklets should be given to caregivers one at a time, as their child is ready for them, starting with the first one. Caregivers may take months, even years, before they are ready to move from the first booklet to the second and then to the last one.

You should be aware that some caregivers may not know a lot about HIV. It is important that you be patient and use this process as a learning experience not only for the child, but also for the caregiver. Each caregiver and child is different. It is important that you use your knowledge of the family, the family’s wishes and the child’s health to assist the caregiver in the disclosure process.

General Guidance for Disclosure

- Disclosure should not happen immediately after the family has learned about the child's status, the family needs time to come to terms with the child's diagnosis.
- Support the caregiver(s) to consider if the child would, if disclosed to, be able to keep her or his HIV status private. If knowledge of HIV status would be a burden to the child, then delay full disclosure until the caregiver is relatively sure that the child can keep the information private — if that is what the caregiver(s) want.
- Biological parents often feel shame/guilt and grandparents may feel overprotective. These factors may make it challenging to talk about disclosure, highlighting the importance of ongoing discussions with caregivers to ensure that disclosure takes place when appropriate.
- In some families and perhaps in some cultures, it may be a grandmother or other family member who is assigned the role to disclose, rather than the mother or main caregiver. If this is the case, it would be helpful if both the caregiver and other family member are present during clinic discussions.
- Encourage disclosure to brothers and sisters of the child living with HIV; they can be a very important source of support for the child.
- HIV may affect the child's memory, ability to pay attention, and to learn. Make sure that the caregiver is aware of the child's ability to understand the information that is being shared.
- There are only a few situations in which full disclosure, without first having partial disclosure conversations with the child, may need to happen. These include:
 - ♦ The child, who is old enough to understand their HIV status, is hospitalised and there is a good chance that the child might accidentally find out that she or he has HIV
 - ♦ The child, who has overheard someone talking about her or his status, wants to find out the truth from the caregivers
 - ♦ The teenager who has been raped/sexually abused

Ideal circumstances for disclosure:

- Discussions are held in a safe, comfortable environment.
- Discussions are between a caregiver and a child who have a good relationship based on regular communication.
- Information about HIV status is shared as part of an ongoing discussion; a natural next step from the previous conversations about health — it should not seem like a special event.

Situations in which full disclosure should possibly be delayed:

- If it will have a negative effect on the child's will to live
- If the child has suffered multiple stressors, i.e. sexual abuse, death of parents etc., and is not able to cope with information about HIV at the present time
- Specific and realistic fears that the child/family will suffer from stigma/discrimination
- Child has difficulty keeping a secret
- Parental guilt or denial (healthcare workers should in this case continue talking to parents about the importance of eventually disclosing to the child)

What may happen to child if she or he is not told:

- The child may have frightening or incorrect ideas about HIV.
- Silence about HIV may keep the child from getting the support they need.
- If the parent dies, it robs the child of the chance to talk about their illness with the parent.
- The child may learn about HIV in a situation that is not supportive, for example at school.
- The child may find out from someone other than the caregiver — setting the stage for the child to not trust or feel the caregiver has lied, and providing a barrier to future discussions about HIV.
- The later a child is told about their status (ideal ages are between 8–11), the more difficult it will be for the child to accept.

Partial Disclosure – Booklet 1 *How to Keep Healthy*

Guidance for Healthcare Workers to Pass on to Caregivers

- Find a comfortable, safe place to share the booklet with the child.
- Make the child feel comfortable. It is possible she or he will be worried or frightened at the beginning of the conversation.
- Let the child know that you are here to answer questions and that she/he can ask anything they want; ask if there are any questions before you start.
- Use words that the child will understand.
- The caregiver should show their child through their own behaviours and words that she or he is open and want to hear what the child is thinking.
- Encourage caregivers when going through to the booklet to pay attention to the child's reactions while she or he is talking. If necessary, slow down or ask how the child is doing as they go through the booklet together.
- Younger children, particularly if they are sick, are more interested in what will happen to them in the near future — they need additional comfort and assurance.



Guidance for Healthcare Workers

The following table includes a script to help you in counselling caregivers who are beginning disclosure discussions with their children living with HIV. You should feel free to adapt this script to suit your style and respond to your client's unique needs.

Objective	Script
Introduce yourself and the discussion.	<ul style="list-style-type: none"> ▪ Hello. My name is _____. Thank you for coming in today. ▪ I would like to discuss with you how you are going to talk with your child about HIV.
Make the caregiver feel comfortable.	<ul style="list-style-type: none"> ▪ If I say anything that you do not understand, please ask me. ▪ My goal today is to help you to talk to your child about her/his sickness¹, so it is important that you understand

¹ In the first two booklets, HIV is referred to as a “sickness” or “illness”. Although the caregiver will likely understand that “sickness” is a code word for “HIV”, the child may misinterpret “sickness” as suggesting that they are sick. If necessary, explain to the child that “sickness” does not mean that they are ill, particularly as they probably feel quite well much of the time. “Sickness” refers only to the fact that they have a virus that can sometimes make them feel sick.

Objective	Script
	<p>what I tell you so that you can talk about these things with your child once you get home.</p>
<p>Enquire if the child has asked about their illness.</p>	<ul style="list-style-type: none"> ▪ Has your child asked any questions yet about their sickness? ▪ If yes: What has she/he asked? ▪ Children will normally start asking questions about their medicine, the clinic or their illness by the time they are about 7 or 8 years old. This is normal. ▪ How have you answered these questions? ▪ What is important is for you to answer their questions as honestly as you can. If you do not know the answer, you can tell them that you will ask the nurse the next time you go to the clinic.
<p>Ask about discussions to-date.</p>	<ul style="list-style-type: none"> ▪ Have you tried to talk to your child about HIV? ▪ What kinds of things have you talked about with your child?
<p>Provide an overview of the disclosure process.</p>	<ul style="list-style-type: none"> ▪ What we will do today is to help you answer questions your child may have about HIV, but without telling your child specifically that they have HIV. ▪ It is important that your child has some information about their illness. But they may not be old enough yet to understand everything about their sickness. ▪ This is why we first talk to them about things that they can understand, like why they have to take their medicine. ▪ When they are older, that is when we will talk to them about having HIV. I or another healthcare worker will talk with you about this, and about when it might be time to tell your child she/he has HIV. ▪ We will have this discussion when you feel comfortable doing so.
<p>Summarise how to get the discussion started.</p>	<ul style="list-style-type: none"> ▪ Your child may normally start asking questions about their sickness. If they have not started asking questions by about age five or six, it may be helpful for you to give explanations to your child about why they have to go to the clinic and take medicines. ▪ When you start talking to your child about these things, it is very important that the conversation is very natural. For example, you can start talking about these things while you are giving your child medication, or while you are walking to the clinic, or while you are doing things in the home, like cooking or cleaning.

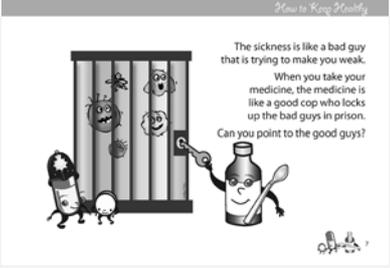
Objective	Script
	<ul style="list-style-type: none"> ▪ When you do this, it makes the conversation more natural and less frightening for your child. ▪ Do you think you would feel comfortable doing this?
Introduce the picture booklet.	<ul style="list-style-type: none"> ▪ When you and your child are comfortable talking about their sickness in general, you may then want to use the picture booklet that we will give you. ▪ The picture booklet can provide an excuse to carve out time to discuss your child’s sickness with her/him. It was provide guidance for the discussion and a forum for your child to ask questions. ▪ I am going to go over the picture booklet now.
Review the cover page.	<ul style="list-style-type: none"> ▪ The booklet is called, <i>How to Keep _____ Healthy</i>. You can see there is a space on the cover to write your child’s name. ▪ We can do that now.
Review the message for caregivers.	<ul style="list-style-type: none"> ▪ On the next page we explain that you should try to read this booklet to your child when nobody else is close by. ▪ This booklet should seem to be part of your normal conversations with your child. ▪ It is to be used with children 5–9 years old. ▪ When you are reading the booklet — and at other times — encourage your child to ask questions. ▪ The way you manage the talks with your child will set the stage for future discussions and help her/him to be more comfortable living with the sickness. So it is important to be gentle and to listen to your child.

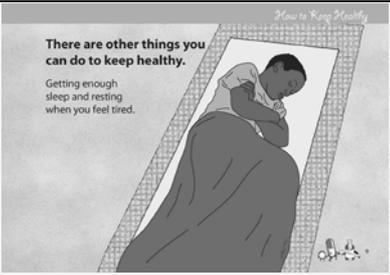
Instructions for Healthcare Workers

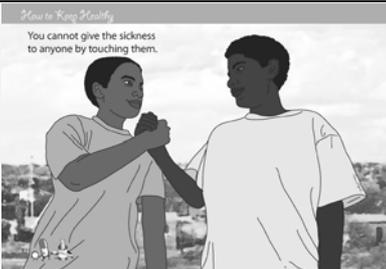
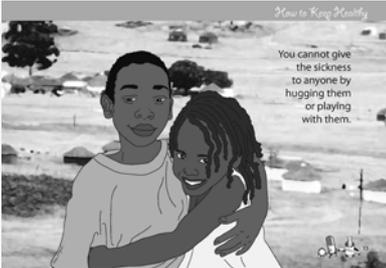
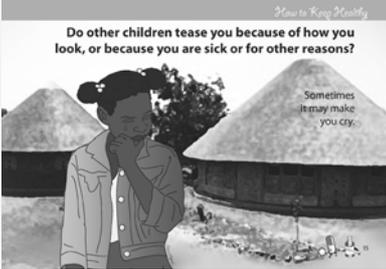
Each page of the booklet is re-printed in the column entitled “Booklet content” along with the text on that particular page. The column on the left, entitled “Objective of this page is to.....Possible discussion points” summarises the objective of each page along with possible discussion points and common questions from children.

When you are going through the booklet with the caregiver, read all of the words to make sure that the caregiver understands and will be able to read the story to the child.

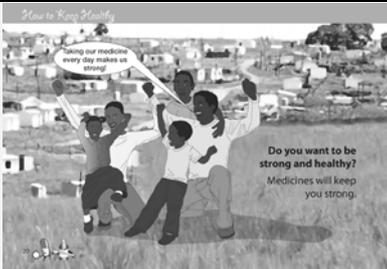
	Booklet content	Objective of this page is to.... Possible discussion points
Page 3	<p>This book is about how to keep you healthy. I want you to be as healthy as you can be. And the nurses, doctors and counsellors at the clinic also want you to be well. Do you want to be strong and healthy?</p>	<p>Summarise the goal of this booklet.</p> <p>Discussion points:</p> <ul style="list-style-type: none"> ▪ Rather than focusing on the negative side of having a sickness, instead talk about how to stay (or get) well. ▪ A focus on wellness also introduces the concept of “Positive Living”, a philosophy that will help them cope with a chronic disease throughout their life.
Page 4	<p>We go to the clinic to check your health.</p>	<p>Discuss going to the clinic.</p> <p>Discussion points:</p> <ul style="list-style-type: none"> ▪ We start the discussion with the clinic visit, as this is a safe starting point — a place that is, by now, familiar yet associated with health.
Page 5	<p>The nurses and doctors take your blood and check to see that you are well.</p>	<p>Discuss what happens at the clinic.</p> <p>Common questions:</p> <ul style="list-style-type: none"> ▪ Why do they take my blood? (See Table 1 for possible response to this question.)

	Booklet content	Objective of this page is to.... Possible discussion points
Page 6	 <p>You have a sickness in your blood. Some children were born with the sickness. Some children got the sickness in other ways. Sometimes the sickness gets strong and makes you feel bad.</p>	<p>Explain the sickness.</p> <p>Common questions:</p> <ul style="list-style-type: none"> ▪ How did I get this? ▪ How could I have gotten this before I was born? <p>(See Table 1 for possible responses to these questions.)</p>
Page 7	 <p>The sickness is like a bad guy that is trying to make you weak. When you take your medicine, the medicine is like a good cop who locks up the bad guys in prison. Can you point to the good guys?</p>	<p>Discuss the importance of medicines.</p> <p>Discussion points:</p> <ul style="list-style-type: none"> ▪ Allow your child to get distracted by the animation in this picture. Give them a moment to pick out the “good guys” (note the cop on the left and the bottle of medicine on the right) and the “bad guys” (who are behind prison bars). ▪ Ask what questions they have. Younger children may ask if their sickness really looks like that. Explain that it doesn’t really, but we can pretend that it does as a way to start understanding how the sickness works.
Page 8	 <p>Sometimes you may not want to take your medicine. But if you do not take the medicine, the bad guys will get out and try to make you sick. Do you take your medicine all the time?</p>	<p>Discuss what happens when medicines are not taken.</p> <p>Common questions:</p> <ul style="list-style-type: none"> ▪ What happens if my mum forgets to give me my medicine? (Response: give the child permission to remind her/his caregiver that when it is time to take medicine; stress the importance of shared responsibility.)

	Booklet content	Objective of this page is to.... Possible discussion points
Page 9	 <p>There are other things you can do to keep healthy. Getting enough sleep and resting when you feel tired.</p>	<p>Talk about the importance of sleep.</p> <p>Common questions:</p> <ul style="list-style-type: none"> How does sleep keep me healthy? (Response: It gives your body time to heal.)
Page 10	 <p>Eating healthy foods like fruit, vegetables and milk. And going to the clinic.</p> <p>What other healthy foods do you like?</p> <p>Can you think of other things you can do to stay healthy?</p>	<p>Talk about the importance of eating well and going to the clinic.</p> <p>Common questions:</p> <ul style="list-style-type: none"> What if I am too sick to eat? (Response: some days you will not feel like eating, and that's OK because on other days you will be very hungry and eat more than usual.) <p>Discussion points:</p> <ul style="list-style-type: none"> If appropriate, this page may present an opportunity to discuss healthy eating, eating enough, eating even though you may not be hungry (for children who are underweight), and making healthy food choices. Exercise also helps me stay healthy.
Page 11	 <p>There are many other children just like you who live with the sickness. They all have to go to the clinic and take medicine too.</p>	<p>Explain that the child is not the only one with the sickness.</p> <p>Common questions:</p> <ul style="list-style-type: none"> Who else has this sickness? (Response: we don't really know exactly who has this sickness. The government has told us that millions and millions (nearly six million) of South Africans have HIV, and many of them are your age.) <p>Discussion points:</p> <ul style="list-style-type: none"> If your child wants to know more about who has HIV, feel free to use this opening to discuss confidentiality — whether we have HIV or not is information that belongs in the family, it's not discussed outside of the house.

	Booklet content	Objective of this page is to.... Possible discussion points
Page 12	 <p>You cannot give the sickness to anyone by touching them.</p>	<p>Explain that this sickness is not transmitted through touch.</p> <p>Common questions:</p> <ul style="list-style-type: none"> Can I give it to anyone by sneezing or coughing on them? (Response: no.)
Page 13	 <p>You cannot give the sickness to anyone by hugging them or playing with them.</p>	<p>Explain that it is not transmitted through hugging or playing.</p> <p>Common questions:</p> <ul style="list-style-type: none"> Can I give it to anyone by kissing them? (Response: no)
Page 14	 <p>You cannot give the sickness to anyone by eating from the same plate.</p>	<p>Explain that eating from the same plate does not transmit the sickness.</p> <p>Discussion point:</p> <ul style="list-style-type: none"> The main message on this and the preceding two pages is to communicate that people with HIV can do just about anything that people without HIV can do (if the child is older, she/he will need to know that they are responsible for ensuring that they do not transmit HIV to anyone else; but younger children don't need to know this just yet).
Page 15	 <p>Do other children tease you because of how you look, or because you are sick or for other reasons? Sometimes it may make you cry.</p>	<p>Open a discussion about teasing.</p> <p>Discussion point:</p> <ul style="list-style-type: none"> After reading this page, pause for a moment to give your child an opportunity to think about times when they were teased and how this felt. Encourage discussion.

	Booklet content	Objective of this page is to.... Possible discussion points
Page 16	<p>Sometimes it may make you angry. But you can handle the bad feelings in different ways. What do you do when other children make you cry or make you angry?</p>	<p>Ask what the child does when teased.</p> <p>Common questions:</p> <ul style="list-style-type: none"> What should I do? (Response: Let's read the next page to see how this boy dealt with being teased.)
Page 17	<p>Make friends with other children who like you just as you are. Who at school is nice to you? Talk to someone when you have bad feelings, like an older sister, grandmother or teacher — someone you can trust.</p> <p>Make friends with other children who like you just as you are. Who at school is nice to you?</p> <p>Talk to someone when you have bad feelings, like an older sister, grandmother or teacher – someone you can trust.</p>	<p>Discuss what to do when teased.</p> <p>Discussion point:</p> <ul style="list-style-type: none"> Consider asking your child, for example, “What else do you think this boy should do if he’s teased?” What should he say to the boys and girls who are teasing him?
Page 18	<p>Can you think of someone you can trust? Let's talk together about who you can tell about your sickness. Always know that you have family and friends who love you.</p> <p>Can you think of someone you can trust? Let's talk together about who you can tell about your sickness.</p> <p>Always know that you have family and friends who love you.</p>	<p>Talk about who the child can trust.</p> <p>Discussion point:</p> <ul style="list-style-type: none"> The main message of this page is for the child to recognise that she/he does have someone in whom he can confide, even if he does not want to discuss a particular issue with his caregiver.

	Booklet content	Objective of this page is to.... Possible discussion points
Page 19	 <p>Do you have any questions?</p> <p>If you have any questions I cannot answer, we can talk with the nurse, doctor or counsellor at the clinic.</p>	<p>Ask if there are any questions.</p> <p>Discussion point:</p> <ul style="list-style-type: none"> If questions come up that you, the caregiver, cannot answer, be sure to write them down so that you remember to ask them during the next clinic visit. This will show that you take your child's concerns seriously.
Page 20	 <p>Do you want to be strong and healthy?</p> <p>Medicines will keep you strong.</p>	<p>Stress the importance of keeping healthy and taking medicines.</p>
Page 21	 <p>Good Things in My Life (write or draw)</p>	<p>Provide the child with an opportunity to express positive things in her or his life.</p>
Page 22	 <p>My Thoughts (write or draw)</p>	<p>Provide the child with a way to express how she/he feels.</p>

Objective	Script
Ask if there are any questions.	<ul style="list-style-type: none"> ▪ What questions do you have? ▪ Was there anything I told you that was not clear? ▪ We can talk about this the next time you come back to the clinic. ▪ Do you think you will feel comfortable talking to your child? ▪ What plans do you have to start this conversation? ▪ What can I do to help?
Refer for support.	<ul style="list-style-type: none"> ▪ Tell the caregiver about any support services in your area, for example a support group for mothers or children who are living with HIV.

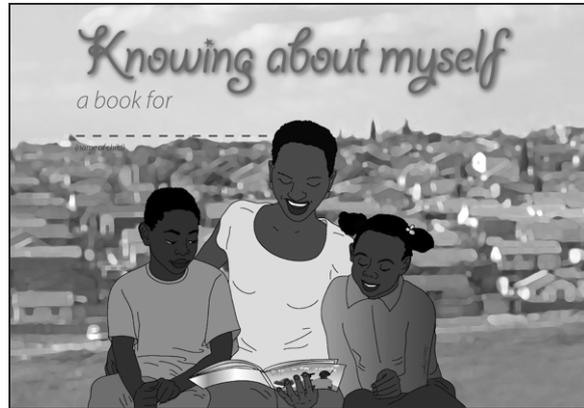
Table 1: Suggested answers to common questions.

Additional anticipated questions from children	Suggested answers
Why do I have to see the nurse?	So that she/he can check your blood.
Why does the nurse take my blood?	So that she/he can make sure that you stay well.
Why do I have to go to the clinic?	The nurses and doctors at the clinic are there to help keep you well.
Why do I need to take this medicine?	There is a sickness in your blood that is like a bad guy trying to make you sick. If you take your medicine every day, the medicine is like a good cop who catches the bad sickness and locks it away in prison. Then you can keep being healthy.
Why am I sick? How did I get this sickness?	<p>You were born with something in your blood.</p> <p>You got the sickness through the blood that you got at the hospital.</p> <p>You got the sickness through breast milk.</p> <p>You got the sickness when a bad person hurt you.</p> <p>That is why you have to take your medicine every day so that the medicine can keep you well.</p>

Full Disclosure – Booklet 2: *Knowing about Myself*

Guidance for Healthcare Workers to Pass on to Caregivers

- Healthcare workers and caregivers will know it is time to start thinking about full disclosure when children start asking more specific questions — e.g., about why they are taking medicines, why they have to go to the clinic so often — and the normal responses no longer seem to be enough for the child.
- Children typically ask these types of questions sometime between 8–11 years of age.
- Some children may even ask, “Do I have HIV?”
- Try to make HIV seem as normal as possible — as just another long-term illness.
- Some children may be overwhelmed by hearing that they have HIV, and unable to listen to the information that follows. Encourage caregivers to pay attention to the child’s emotions and reactions, to ask if the child has any questions or if there is something she/he does not understand. It may be necessary to continue the talk at another time when the child is more able to listen to the remaining information.
- Common reactions to disclosure include anger, fear, rejection, sadness, worry, crying, and withdrawal, among others. Regardless of the child’s response, caregivers should let their children know that these feelings are normal and that they should talk to someone who they trust when they have these feelings.
- Most children experience a range of emotions after finding out they have HIV, but then start to feel “normal” once again. If the child’s behaviours and emotions do not return to normal after about three to six months, efforts should be made to provide the child with additional support.



Guidance for Healthcare Workers

The following table includes a script to help you in counselling caregivers who will begin full disclosure discussions with their children living with HIV. You should feel free to adapt this script to suit your style and respond to your client's unique needs.

Objective	Script
Introduce yourself and the discussion	<ul style="list-style-type: none"> ▪ Hello. My name is _____. Thank you for coming in today. ▪ I would like to discuss with you about how you are going to tell your child she/he has HIV.
Make the caregiver feel comfortable.	<ul style="list-style-type: none"> ▪ If I say anything that you do not understand, please ask me. ▪ My goal today is to help you to talk to your child about HIV, so it is important that you understand what I tell you so that you can talk about these things with your child once you get home.
Ask if the child has asked about their illness.	<ul style="list-style-type: none"> ▪ Has your child asked any questions yet about their sickness? ▪ If yes: What has she/he asked? ▪ Children will normally start asking questions about their medicine, the clinic or their illness by the time they are about 7 or 8 years old. This is normal. ▪ How have you answered these questions? ▪ What is important is for you to answer their questions as honestly as you can. If you do not know the answer, you can tell them that you will ask the nurse the next time you go to the clinic.
Ask about discussions to-date.	<ul style="list-style-type: none"> ▪ Have you tried to talk to your child about HIV before? ▪ What kinds of things have you talked about with your child?
Introduce the second booklet.	<ul style="list-style-type: none"> ▪ You may have gone through the first booklet <i>How to Keep _____ Healthy</i>. When you feel the child is mature enough to understand what it means to have HIV, then it will be time to read the second booklet to her/him: <i>Knowing about Myself</i>.
Review the cover page.	<ul style="list-style-type: none"> ▪ You can see there is a space on the cover for us to write your child's name. ▪ We can do that now.
Review the message for caregivers.	<ul style="list-style-type: none"> ▪ On the next page we explain that you should try to read this booklet to your child when nobody else is close by. ▪ This booklet should seem to be part of your normal conversations with your child.

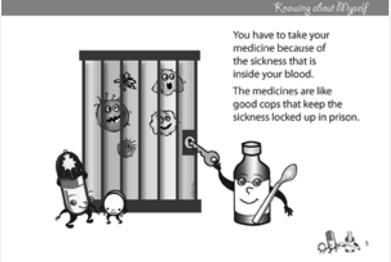
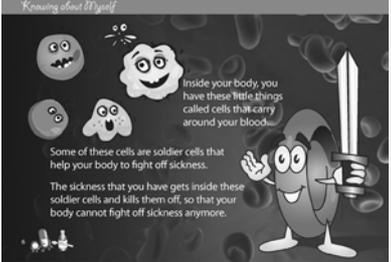
Objective	Script
	<ul style="list-style-type: none"> ▪ It is to be used with children over eight years old. ▪ You should try to make sure that your child is old enough to understand how to keep information about HIV private, if that is what you want. ▪ When your child hears that she/he has HIV, she/he may become frightened, angry or very quiet. All of these feelings are normal. ▪ Take a break when you feel your child needs one, go back to the booklet at a later time or day. ▪ Remind your child over and over again that HIV is not anybody's fault. ▪ When you are reading the booklet — and at other times — encourage your child to ask questions. ▪ The way you manage the talks with your child will set the stage for future discussions and help her/him to be more comfortable living with the sickness. So it is important to be gentle and to listen to your child.

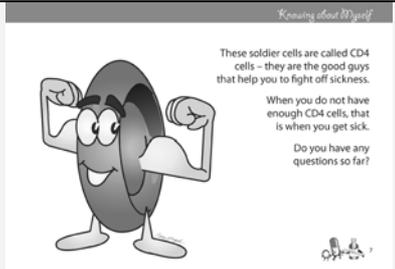
Instructions for Healthcare Workers

Each page of the booklet is re-printed in the column entitled “Booklet content” along with the text on that particular page. The column on the left, entitled “Objective of this page is to.....Possible discussion points” summarises the objective of each page along with possible discussion points and common questions from children.

When you are going through the booklet with the caregiver, read all of the words to make sure that the caregiver understands and will be able to read the story to the child.

	Booklet content	Objective of this page is to.... Possible discussion points
Page 3	<p>Today, we are going to talk about your health. Do you remember the things that you need to do to keep healthy? Eating healthy foods. Sleeping and resting when you feel tired.</p>	<p>Talk about keeping healthy.</p> <p>Common questions:</p> <ul style="list-style-type: none"> ▪ But what if you cannot eat enough healthy food because you feel too sick to eat? (Response: some days you will not feel like eating, and that is OK because on other days you will be very hungry and eat more than usual.) <p>Discussion points:</p> <ul style="list-style-type: none"> ▪ This page and the next two pages review content from the first booklet as a starting point to the discussion of full disclosure and to put the discussion in context of “living positively”.
Page 4	<p>It is very important to go to the clinic. And you must remember to take your medicines every day. Can you think of other ways that you can keep healthy?</p>	<p>Emphasize the importance of going to the clinic and taking medicines.</p>

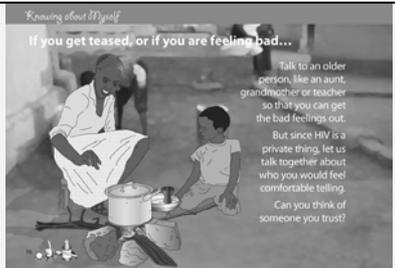
	Booklet content	Objective of this page is to.... Possible discussion points
Page 5	 <p>You have to take your medicine because of the sickness that is inside your blood.</p> <p>The medicines are like good cops that keep the sickness locked up in prison.</p>	<p>Discuss the importance of medicines.</p>
Page 6	 <p>Inside your body, you have these little things called cells that carry around your blood. Some of these cells are soldier cells that help your body to fight off sickness.</p> <p>The sickness that you have gets inside these soldier cells and kills them off, so that your body cannot fight off sickness anymore.</p>	<p>Discuss how the body fights the sickness.</p> <p>Common questions:</p> <ul style="list-style-type: none"> ▪ What if the sickness kills all of the soldier cells? (Response: you will get sick.) <p>Discussion points:</p> <ul style="list-style-type: none"> ▪ Similar to the previous page, your child may need some time to look at the animation. She/he may have questions such as “Why is the soldier cell carrying a sword?” Try to answer these questions, children need to feel they understand the concrete messages before they can focus on the message conveyed in words. ▪ Spend some time on this page. You may even have to read it twice and act out the scenario between the sickness and soldier cells.

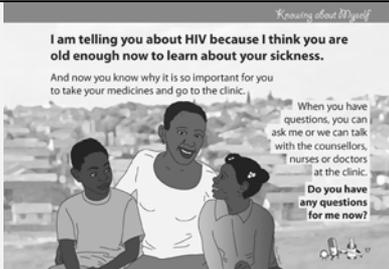
	Booklet content	Objective of this page is to.... Possible discussion points
Page 7	 <p>These soldier cells are called CD4 cells — they are the good guys that help you to fight off sickness.</p> <p>When you do not have enough CD4 cells, that is when you get sick.</p> <p>Do you have any questions so far?</p>	<p>Define CD4 cells.</p> <p>Discussion points:</p> <ul style="list-style-type: none"> Your child’s reaction to this page will probably be similar to that of the previous one. Again, take some time to help her/him understand. If your child is familiar with the term “CD4” because they have heard your or a healthcare worker talk about someone’s CD4 test result, then mention it.
Page 8	 <p>Your sickness is very strong, but we can fight it.</p> <p>Do you know the name of your sickness?</p> <p>You have HIV.</p> <p>Have you heard anything about HIV?</p> <p>Tell me the things that you have heard about HIV.</p>	<p>Explain what the sickness is.</p> <p>Common questions:</p> <ul style="list-style-type: none"> I have heard that HIV can turn into AIDS, is that true? Can people die from this? Will I die? (See Table 2 for possible responses to these questions.) <p>Discussion points:</p> <ul style="list-style-type: none"> Take your time with this page. Stop, wait for your child to react, even it means that there is silence for several minutes.

	Booklet content	Objective of this page is to.... Possible discussion points
Page 9	 <p>Sometimes when children hear they have HIV, they may get frightened, or angry, or sad. It is alright if you also feel this way.</p> <p>Hopefully we can keep talking about this until you understand.</p> <p>Should we take a break now, or do you want me to continue?</p>	<p>Encourage the child to identify how she/he feels.</p> <p>Discussion points:</p> <ul style="list-style-type: none"> ▪ It is very possible that your child may need some time to think about what she/he has heard. Take your time, even if it means that there is silence. ▪ The caregiver should watch for signs from the child that this information is too much and that a break is needed. ▪ If your child is feeling afraid or sad or angry, reassure her/him that these are normal feelings that any one would feel after hearing such news. ▪ If the child is silent, the caregiver might say something like: “Sometimes when children hear that they have HIV, they may feel frightened or worried or angry. This is very normal. I am here to talk to you if you decide later on that you want to talk with me.” ▪ You should feel free to stop here, the discussion can continue at a later time, even another day.
Page 10	 <p>Do you want to write down how you feel at the moment?</p>	<p>Provide the child with a way to express how she/he feels.</p>

	Booklet content	Objective of this page is to.... Possible discussion points
Page 11	<p style="text-align: right;"><i>Knowing about Myself</i></p> <p>Do you have any questions for me?</p> <p>HIV is a virus, just like a virus that causes colds, but it is a tougher virus and we need strong medicine to fight it.</p>  <p>The virus lives in your blood and it makes it hard for the body to fight off sickness, which is why you may get sick more often than other children.</p> <p>Do you have any questions for me?</p> <p>HIV is a virus, just like a virus that causes colds, but it is a tougher virus and we need strong medicine to fight it.</p> <p>The virus lives in your blood and it makes it hard for the body to fight off sickness, which is why you may get sick more often than other children.</p>	<p>Discuss the effect of HIV on the body.</p> <p>Common questions:</p> <ul style="list-style-type: none"> ▪ Why can't the body fight off illnesses if I have HIV? (Response: Remember when we talked about the "soldier cells", which are also called "CD4 cells"? Remember how the soldier cells protect us? Well when you have HIV you can have fewer of the soldier cells so your body can't fight off illnesses the way that some of your friends can fight illnesses.) <p>Discussion points:</p> <ul style="list-style-type: none"> ▪ Ask your child what she/he knows about HIV. Listen to the response carefully so that you can correct any misunderstandings.
Page 12	<p style="text-align: right;"><i>Knowing about Myself</i></p> <p>Children can get HIV in different ways.</p>  <p>Some children may have gotten it from their mothers when they were still inside their tummy. Some may have gotten it when they got extra blood put inside them at the hospital. Some children may have been abused.</p> <p>Children can get HIV in different ways.</p> <p>Some children may have gotten it from their mothers when they were still inside their tummy.</p> <p>Some may have gotten it when they got extra blood put inside them at the hospital.</p> <p>Some children may have been abused.</p>	<p>Discuss how children get HIV.</p> <p>Common questions:</p> <ul style="list-style-type: none"> ▪ So, HIV is in my blood? (Response: Yes, it is in your blood and we will discuss this further later in the booklet.) <p>Discussion points:</p> <ul style="list-style-type: none"> ▪ Ask your child what questions they have; depending on their experience she/he may find this page simply interesting or it may bring up painful memories. ▪ Some children will have questions about HIV transmission; others will be silent. Others may wait until this the booklet is read to them several times before they will be ready to ask how other children get infected. ▪ Children who have been abused may need additional support at this time.

	Booklet content	Objective of this page is to.... Possible discussion points
Page 13	<p>Now that you know what you have, the most important thing is to take care of your health. That means taking your medicine every day. What other things should you do to keep healthy?</p>	<p>Initiate a discussion of “positive living”.</p> <p>Discussion points:</p> <ul style="list-style-type: none"> Encourage your child to provide at least two answers to the question (“What other things should you do to keep healthy?”). Possible answers include: eat healthy food, eat all of my meals, take exercise, get enough sleep, got to the clinic, take my immunisations without crying, etc.
Page 14	<p>You cannot give HIV to anyone by touching them, hugging them, eating from the same plate, or using the same toilet.</p> <p>The only way people can get HIV is –</p> <ul style="list-style-type: none"> When a baby is inside its mother. From breast milk. From blood. From sexual relations. 	<p>Discuss how HIV is — and is not — transmitted.</p> <p>Discussion points:</p> <ul style="list-style-type: none"> Encourage your child to ask questions about how HIV is transmitted. Ask what other people say about how HIV is transmitted. Correct any misunderstandings. This page brings up the issue of HIV transmission through sex. Younger children may allow you to gloss over this point without question. Children who are a bit older (age 10–12, maybe) might just giggle or feign disgust. For older children (age 12 and older), this page provides an opening to discuss relationships. Do not miss the opportunity to stress that even if you have HIV you can still have a boy/girl friend. Think about your own and your family’s values and the messages you want to give your older children around sexual relationships and HIV prevention. Regardless of your message, it is important that young people understand (maybe not immediately, but before they start dating) that HIV infection brings with it the burden of ensuring that the virus is not further transmitted to anyone else.

	Booklet content	Objective of this page is to.... Possible discussion points
Page 15	 <p>HIV is just like any other sickness that other children have.</p> <p>You did not do anything to get HIV. It is something that just happened and we will learn how to live with it.</p> <p>You are not different from any other child. You can play just like other children.</p> <p>You can have friends just like other children. You can go to school just like other children.</p>	<p>Stress that children with HIV are just like other children.</p> <p>Discussion points:</p> <ul style="list-style-type: none"> ▪ This page is a page that celebrates childhood and invites children with HIV to live normally. ▪ Be sure to tell your child — some may need to hear it over and over again — that having HIV is not her/his or anybody’s fault.
Page 16	 <p>If you get teased, or if you are feeling bad –</p> <p>Talk to an older person, like an aunt, grandmother or teacher so that you can get the bad feelings out.</p> <p>But since HIV is a private thing, let us talk together about who you would feel comfortable telling. Can you think of someone you trust?</p>	<p>Encourage her/him to identify a close friend or trusted adult whom she/he can share their feelings with.</p> <p>Common questions:</p> <ul style="list-style-type: none"> ▪ What if I do not feel comfortable telling anyone? (Response: would you feel comfortable telling me?) <p>Discussion points:</p> <ul style="list-style-type: none"> ▪ Some children will need time to identify a person in whom they can confide. Allow them to take time. Many children need time to adjust to their own diagnosis before they can discuss it with anyone else.

	Booklet content	Objective of this page is to.... Possible discussion points
Page 17	 <p>I am telling you about HIV because I think you are old enough now to learn about your sickness.</p> <p>And now you know why it is so important for you to take your medicines and go to the clinic.</p> <p>When you have questions, you can ask me or we can talk with the counsellors, nurses or doctors at the clinic.</p> <p>Do you have any questions for me now?</p>	<p>Summarise the key messages in the booklet.</p> <p>Discussion points:</p> <ul style="list-style-type: none"> ▪ Encourage the caregiver to create an environment in which the child feels comfortable asking questions whenever she/he feels the need to do so. ▪ Let the child know that there is always someone who can provide support, she/he will not be facing the future without this support.

Objective	Script
Ask if there are any questions.	<ul style="list-style-type: none"> ▪ What questions do you have? ▪ Was there anything I told you that was not clear? ▪ We can talk about this the next time you come back to the clinic. ▪ Do you think you will feel comfortable talking to your child? ▪ What plans do you have to start this conversation? ▪ What can I do to help?
Refer for support.	<ul style="list-style-type: none"> ▪ Tell the caregiver about any support services in your area, for example a support group for mothers or children who are living with HIV.

Table 2: Suggested answers to common questions.

Additional anticipated questions from children	Suggested answers
How did I get this virus?	<p>Your mother had the virus and so when you were inside her, you got the virus too.</p> <p>You might have gotten the virus from breastfeeding.</p> <p>You might have gotten the virus from blood that you received at the hospital.</p> <p>You might have gotten the virus from the person who abused you.</p>
Am I going to die?	<p>The medicines that we have for HIV are very strong. So if you take your medicines every day, that will help you to keep healthy. The nurses and doctors will do everything they can to make sure that you stay well.</p>
How did my mother get this?	<p>(If the child is old enough to understand.) Your mother may have gotten HIV when she was having sex with her partner, or if she received blood from the hospital or she may have come in contact with blood from someone who has HIV.</p> <p>(If the child is not yet old enough) We are not sure how your mother got this, because there are different ways to get HIV.</p>
What is HIV?	<p>HIV is a virus, which is like a bad germ that gets into your blood. It attacks the cells in your body that fight off sickness and makes them weak, which is why you might get sick often.</p>
Why am I sick?	<p>You were born with something in your blood.</p> <p>You got HIV when you were breastfeeding.</p> <p>You got HIV when you got blood at the hospital.</p> <p>You got HIV when someone abused you.</p> <p>That is why you have to take your medicine every day so that the medicine can keep you well.</p>
What does the medicine do?	<p>Taking your medicine makes your fighting cells (your “soldier cells”) stronger so that you do not get sick so often.</p>
How come so many people with HIV die or get so skinny?	<p>Many of those people are not taking their medicine or maybe they are not taking good care of their health.</p>
Why are people so mean to me?	<p>Many people do not understand what HIV is. They think they can get HIV just by touching you or being close to you. So they are afraid, and when people are afraid they sometimes say mean things.</p>

Post-disclosure – Booklet 3: *Living a Life of Health*

Guidance for Healthcare Workers to Pass on to Caregivers

For all children

- Children may seem to accept or understand the messages given during the disclosure discussion, but it is very likely that once they have time to think about the information, more questions will come to mind.
- The post-disclosure session should be more interactive than previous ones because it is likely the child will have more questions.
- It is important to be as honest as possible when you respond to their questions.
- In post-disclosure sessions, children may not want to talk about their worries, even though they may be feeling depressed, worried, or frightened. Find a way to make them comfortable talking about these feelings, or at least to make sure that they have others with whom they can share their feelings. Sometimes you can encourage your child to talk by saying, for example: “You seem worried (or frightened or depressed), do you want to talk about it?”
- Let your child know that other children also have the same feelings and that these feelings are very normal.
- Some children, particularly younger children, will react to disclosure by becoming become more attached to their caregivers, not wanting to be far away from them, or not wanting to go to school.
- Emphasize that HIV is not their fault.
- Post-disclosure counselling may not seem as important as the actual disclosure discussion, but it actually is even more important because it provides an opportunity to discuss emotions that they may not be able to manage on their own.
- How disclosure is handled will affect how the child will deal with their HIV infection. Present HIV as similar to other lifelong diseases that other children have, such as diabetes or asthma, and that they will learn how to live with it.



For teens

- Teens do very well if there is a group of other young people (e.g., a support group) like them with whom they can talk and share feelings. If possible, this sort of group should be organised.
- As teens mature, they want to show they are more independent and begin to take responsibility for taking their own medicines. Many teens go through a period when they do not want to take their medicines, this may be a way of exerting their independence, or to be more like other children who do not have HIV, or for other reasons.
- Healthcare workers and parents should expect this to occur and plan together on how to deal with this issue.

- Teens may or may not bring up the topic of boy/girl friends, marriage and sexual relationships. If the teen does not broach the topic, the caregiver should. In particular, teens with HIV need to recognise that HIV brings with it the responsibility of ensuring that they do not infect anyone else with this virus. Initiate the discussion about sex and safer sex before the teen starts dating.
- Some teens act out by turning to alcohol, drugs or sex to help them to deal with their difficult feelings. Let them know that it is normal to try to run away from difficult feelings, but give them ideas on how to better manage these feelings (join a support group, discuss feelings with a friend, write and perform music, join a theatre group, paint or draw, read a book, help others who are less fortunate by volunteering in a local clinic, etc). Again, young people entering sexual relationships have an obligation to take all precautions to ensure their partners do not get HIV, including practising safer sex.

Guidance for Healthcare Workers

The following table includes a script to help you in counselling caregivers who are continuing disclosure discussions with their children living with HIV. You should feel free to adapt this script to suit your style and respond to your client's unique needs.

Objective	Script
Introduce yourself and the discussion.	<ul style="list-style-type: none"> ▪ Hello. My name is _____. Thank you for coming in today. ▪ I would like to discuss with you how you plan to support your child, now they she/he know he has HIV. ▪ Now that your child knows her/his status, you may think that is all the information she/he needs. But children always have questions, and as they get older, they may have more questions to ask about things they do not understand.
Make the caregiver feel comfortable.	<ul style="list-style-type: none"> ▪ If I say anything that you do not understand, please ask me. ▪ My goal today is to help you support your child now they she/he knows he has HIV.
Encourage regular communication.	<ul style="list-style-type: none"> ▪ It is important for you to ask your child regularly how they are doing with school, with their friends and other parts of their life.
Ask about adherence.	<ul style="list-style-type: none"> ▪ How often is your child taking her/his medicine? ▪ Did she take her medicine today? How about yesterday? Out of the seven days in this past week, on how many of the seven days do you think your child took her medicine as she was supposed to? ▪ If adherence is less than perfect: What do you think the problems are? What ideas do you have to resolve this?

Objective	Script
Encourage child to take responsibility she/he.	<ul style="list-style-type: none"> ▪ As your child is getting older, it is also important to get her/him to take more responsibility for taking medicines.
Introduce the picture booklet.	<ul style="list-style-type: none"> ▪ When you think that your child is beginning to feel comfortable talking about HIV, you may want to use this, the third picture booklet. ▪ This booklet will support you to talk to your child about how she/he is feeling and to help her/him feel more comfortable living with HIV. ▪ I am going to go over the picture booklet now.
Review the cover page.	<ul style="list-style-type: none"> ▪ This booklet is called, <i>Living a Life of Health</i>. You can see there is a space on the cover to write your child's name. ▪ We can do that now.
Review the message for caregivers.	<ul style="list-style-type: none"> ▪ On the next page we explain that you should try to read this booklet to your child when nobody else is close by. ▪ This booklet should seem to be part of your normal conversations with your child. ▪ It is to be used with children over eight years old. ▪ When you are reading the booklet — and at other times — encourage your child to ask questions. ▪ After your child has learned that she/he has HIV, you may think that is the end of the story. But as your child matures and gets more comfortable living with HIV, she/he may have new questions. And sometimes she/he may ask the same things over and over again. This is normal — allow your child to do this. ▪ Your child's feelings and emotions about HIV may change from day to day. Sometimes happy, sometimes sad or worried. This is also normal. ▪ The way you manage the talks with your child will set the stage for future discussions and help her/him to be more comfortable living with the sickness. So it is important to be gentle and to listen to your child.

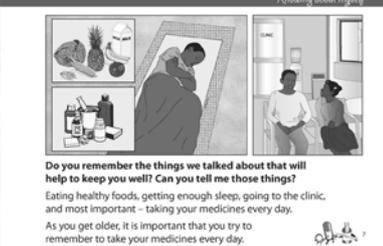
Instructions for Healthcare Workers

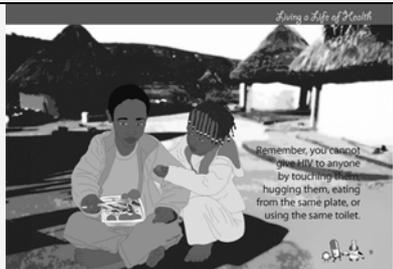
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When you are going through the booklet with the caregiver, read all of the words to make sure that the caregiver understands and will be able to read the story to the child.

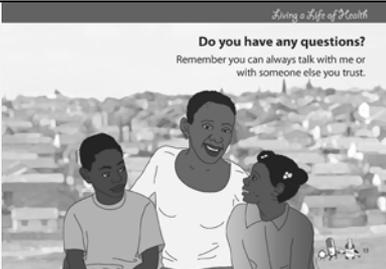
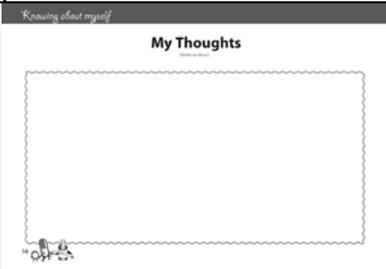
	Booklet content	Objective of this page is to.... Possible discussion points
Page 3	<p>I want to talk with you about how you are doing. Do you remember the talk we had about HIV?</p> <p>Do you have any questions on anything we talked about? Can you talk to me about how you are feeling?</p>	<p>Ask about what they remember and how they are feeling.</p> <p>Discussion points:</p> <ul style="list-style-type: none"> ▪ You will notice that this page, like others in this booklet, includes questions to encourage your child to talk about their feelings. ▪ This booklet provides the caregiver with a tool to encourage discussion. Take your time, go through the booklet at your/your child’s own pace. Give your child time to answer the questions, even if it means that there are periods of silence.
Page 4	<p>Sometimes when children hear that they have HIV, they get frightened or angry.</p> <p>Sometimes they may not want to talk anymore or play with their friends.</p> <p>All of this is ok. The most important thing is to talk to me or someone else you trust about how you are feeling.</p>	<p>Reassure the child that angry or frightened feelings are ok.</p>

	Booklet content	Objective of this page is to.... Possible discussion points
Page 5	 <p>Sometimes it may be hard to continue with school or other things after you hear about having HIV.</p> <p>But everything is just the same as before. The only thing is that now you know a little more about yourself.</p>	<p>Reassure the child that everything is the same.</p> <p>Common questions:</p> <ul style="list-style-type: none"> Why do I still have to go to school? (Response: For the same reason you had to go to school before you knew you had HIV and for the same reason that other children have to go to school — because you need to learn to read and write.) <p>Discussion points:</p> <ul style="list-style-type: none"> You might want to ask your child, for example, if she/he feels any different now that she knows she has HIV.
Page 6	 <p>Tell me, how are things going for you at school? How are things going for you with your friends? Remember you can always come to talk to me.</p>	<p>Ask about how things are going.</p>

	Booklet content	Objective of this page is to.... Possible discussion points
Page 7	 <p>Do you remember the things we talked about that will help to keep you well? Can you tell me those things?</p> <p>Eating healthy foods, getting enough sleep, going to the clinic, and most important – taking your medicines every day. As you get older, it is important that you try to remember to take your medicines every day.</p>	<p>Discuss positive living.</p> <p>Discussion points:</p> <ul style="list-style-type: none"> ▪ Again, encourage your child to live positively with HIV. People who live positively are more likely to take their medicines and more likely to live a relatively healthy and normal life than people who do not take care of themselves.

	Booklet content	Objective of this page is to.... Possible discussion points
Page 8	 <p>Remember HIV is a sickness that is very hard to pass on to other people.</p> <p>Do you remember those ways?</p> <p>When a baby is inside its mother. From breast milk. From blood. From sexual relations.</p>	<p>Discuss how HIV is transmitted.</p> <p>Discussion points:</p> <ul style="list-style-type: none"> Encourage your child to ask questions about how HIV is transmitted. Ask what other people say about how HIV is transmitted. Correct any misunderstandings. This page, like page 14 in booklet 2, brings up the issue of sexual transmission. Younger children may allow you to gloss over this point without question. But be sure to mention HIV transmission through sex in same way that is comfortable for you. The more comfortable you are talking about sex, the more likely your child is to come to you with her/his questions. These discussions are the foundation for communicating to your child your family values. Children who are a bit older (age 10–12, maybe) might just giggle or fake disgust. For older children (age 12 and older), this page provides an opening to discuss relationships. Do not miss the opportunity to stress that even if you have HIV you can still have a boy/girl friend. <p>Regardless of your message, it is important that young people understand (maybe not immediately, but before they start dating) that HIV infection brings with it the burden of ensuring that the virus is not further transmitted to anyone else.</p>
Page 9	 <p>Remember, you cannot give HIV to anyone by touching them, hugging them, eating from the same plate, or using the same toilet.</p>	<p>Discuss how HIV is not transmitted.</p>

	Booklet content	Objective of this page is to.... Possible discussion points
Page 10	 <p>HIV is a private thing, so we do not want to tell everybody about it. Sometimes it might be hard to keep this secret.</p> <p>Has it been hard for you to keep from telling your friends?</p> <p>There are some safe people who it is ok to tell. Tell me who you might feel comfortable with.</p>	<p>Encourage her/him to identify a confidant.</p> <p>Common questions:</p> <ul style="list-style-type: none"> Can I tell my best friend that I have HIV? How about my other friends? <p>Discussion points:</p> <ul style="list-style-type: none"> Discuss with your child who they can and should not tell about their HIV status. The child's willingness to disclose to others will depend on their own adjustment to their diagnosis, their feelings about HIV, and their confidence in dealing with their confidant's reactions and questions (all of which will change over time). If your child wants to disclose to a friend, be sure they are prepared to answer the friend's questions and deal with their reaction. If your child is a teen, you might even want to discuss when it is appropriate to disclose to a boy/girl friend. Some children will need time to identify a person in whom they can confide. Allow them to take time.
Page 11	 <p>Have you told anyone about your HIV?</p> <p>What did that person say when you told them?</p> <p>Some people will be helpful to you when you tell them. Some people may be angry. In any case, you can always come and talk with me.</p>	<p>Discuss disclosure to others.</p> <p>Discussion points:</p> <ul style="list-style-type: none"> See above.

	Booklet content	Objective of this page is to.... Possible discussion points
Page 12	 <p>Together we can manage your HIV infection. The best way to do this is to take your medicine, go to the clinic and eat healthy foods.</p> <p>I will help you to keep healthy and the nurses, doctors and counsellors will help too. Together we can make sure you stay well.</p>	<p>Summarise the key messages in the booklet.</p> <p>Common questions:</p> <ul style="list-style-type: none"> Why do I have to take my medicines every day, why not every other day? (Response: because the medicines stay in your body for about one day, then they disappear. If you take your medicines every other day, that means that every second day there would be no medicine left in your blood, so the HIV will have opportunity to regain strength and make you sick. If you take your medicine every day, you will make sure that there is enough medicine in your blood every day to fight HIV.) <p>Discussion points:</p> <ul style="list-style-type: none"> Again, take this opportunity to remind your child of the importance of living positively with HIV.
Page 13	 <p>Do you have any questions? Remember you can always talk with me or with someone else you trust.</p>	<p>Ask if there are any additional questions.</p>
Page 14	 <p>My Thoughts (write or draw)</p>	<p>Provide the child with a way to express how she/he feels.</p>

Objectives	Script
Ask if there are any questions.	<ul style="list-style-type: none"> ▪ What questions do you have? ▪ Was there anything I told you that was not clear? ▪ We can talk about this the next time you come back to the clinic. ▪ Do you think you will feel comfortable talking to your child? ▪ What plans do you have for this conversation? ▪ What can I do to help?
Refer for support.	<ul style="list-style-type: none"> ▪ Tell the caregiver about any support services in your area, for example a support group for mothers or children who are living with HIV.

Table 3: Suggested answers to common questions.

Anticipated questions from children	Suggested answers
How did I get this virus?	Your mother had the virus and so when you were inside her, you got the virus too.
Am I going to die?	The medicines that we have for HIV are very strong. So if you take your medicines every day, that will help you to keep healthy. The nurses and doctors will do everything they can to make sure that you stay well.
How did my mother get this?	(If the child is old enough to understand.) Your mother probably got HIV when she was having sex with her partner. (If the child is not yet old enough) We are not sure how your mother got this, because there are different ways to get HIV.
What is HIV?	HIV is a virus, which is like a germ that gets into your blood. It attacks the cells in your body that fight off sickness and makes them weak, which is why you might get sick often.
Why am I sick?	You were born with something in your blood. You got HIV through the blood that you got at the hospital. You HIV through breast milk.

Anticipated questions from children	Suggested answers
	<p>You got HIV when you were abused.</p> <p>That is why you have to take your medicine every day so that the medicine can keep you well.</p>
What does the medicine do?	Taking your medicine makes your fighting cells stronger so that you do not get sick so often.
How come so many people with HIV die or get so skinny?	Many of those people are not taking their medicine or maybe they are not taking care of their health properly.
Why are people so mean to me?	Many people do not understand what HIV is. They think they can get HIV just by touching you or being close to you. So they are afraid, and when people are afraid they sometimes say mean things.
Why do I have to keep this a secret?	Many people do not understand what HIV is, so they may say mean things or do things to hurt people with HIV. For now, this is something that you have to keep within your family.
How come other children are not sick or do not have HIV like I do?	There are a lot of other children with HIV like you. Maybe you don't see them at your school or in your neighbourhood, but they are all around you. Maybe there are other children with HIV who look very healthy, so you do not know they have HIV.

For inquiries regarding this manual, please contact:



STELLENBOSCH UNIVERSITY,
FACULTY OF HEALTH SCIENCES

3rd Floor, Wateride Plaza, South Gate,
Tyger Waterfront, Cecil George Drive, Bellville, Western Cape 7530
T: +27 21 918 4376 F: +27 21 918 4569 Toll Free: 0800 090 090
Website: www.sun.ac.za/southtosouth

For inquiries regarding this guide, please contact:



STELLENBOSCH UNIVERSITY,
FACULTY OF HEALTH SCIENCES

3rd Floor, Waterside Place, South Gate,
Tyger Waterfront, Carl Cronje Drive, Bellville, Western Cape 7530

T: +27 21 918 4376 **F:** +27 21 918 4389 **Toll Free:** 0800 050 050

Website: www.sun.ac.za/southtosouth