



# Disclosure Process for Children **AND ADOLESCENTS LIVING WITH HIV** PARTICIPANT MANUAL



## **THE SOUTH TO SOUTH PARTNERSHIP FOR COMPREHENSIVE FAMILY HIV CARE AND TREATMENT PROGRAM (S2S)**

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South Africa has the largest HIV burden of any country in the world, with an estimated 5.7 million people living with the virus. Women and children remain at the centre of the pandemic in terms of transmission, vulnerability and potential for impact.

To continue to build on the existing successes of South Africa’s antiretroviral (ARV) program, the capacity for HIV disease management must be enhanced. It is essential that HIV disease management transition from an individual case management to a family-centred and chronic-care approach targeting and prioritising pregnant women and children. Enrolling pregnant women and children into HIV care and treatment early and regularly can prevent new HIV infections and reduce morbidity and mortality, effectively sustaining the quality of life of mothers, their children, and their families.

The scale up of effective prevention of mother-to-child transmission (PMTCT) and paediatric ARV care and treatment programs are crucial in the fight against HIV but are challenged by many factors including perceived complexity of treating pregnant women and children, inadequate paediatric and PMTCT knowledge and clinical skills, lack of psychosocial and adherence support, delays in integrating PMTCT services with antenatal and child health management systems, and gaps in referral systems.

The South to South Partnership for Comprehensive Family HIV Care and Treatment Program (S2S), a collaboration between the Department of Paediatrics and Child Health, Stellenbosch University, Cape Town, and the International Centre for AIDS Care and Treatment Programs (ICAP), Mailman School of Public Health, Columbia University, New York, aims to address these gaps in support of quality HIV care and treatment services. This is accomplished through the provision of comprehensive technical, programmatic, capacity building and systems support for healthcare workers at public health care facilities throughout South Africa by integrating and strengthening PMTCT, paediatric HIV and adherence and psychosocial (APS) programs.

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### **ACKNOWLEDGEMENTS**

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The “HIV Care and Treatment Training Series”, serves as a comprehensive collection of training material for members of the multidisciplinary team caring for women, infants and children living with HIV and their families in South Africa.

Module 6: Disclosure Process for Children (3 to 18 years of age living with HIV), was developed by the South to South (S2S) team, in collaboration with and with support from the International Center for AIDS Care and Treatment Programs (ICAP) of Columbia University Mailman School of Public Health.

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## **DISCLAIMER**

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# MODULE 6

## Disclosure Process for Children 3 to 18 Years of Age Living with HIV

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### DURATION

9 hours (10 hours with panel presentation)

\*The 10 hours required to teach this module is not inclusive of breaks. It is recommended that this material be taught over the course of at least two or more days and that the practical follow the two days of classroom study.



### LEARNING OBJECTIVES

By the end of this module, participants will be able to:

- Develop an understanding of the disclosure process as one that progresses over time with the increasing maturity of the child.
- Identify values and opinions healthcare workers hold regarding talking about HIV with children and caregivers.
- Describe the difference between partial and full disclosure as it applies to children.
- Discuss the benefits and challenges, including parental disclosure and stigma, of the disclosure process.
- Discuss the role of the healthcare worker in facilitating the three stages of the pre-disclosure phase.
- Discuss how to support caregivers to move to the next stage/phase of readiness to disclose.
- Review and practise age and developmentally appropriate approaches to disclose HIV status to children.
- Discuss client support needs after disclosure and how to ensure these needs are met.



### CONTENT

- 6.1 Introduction to the Disclosure Process (2 hours 30 minutes)
- 6.2 Benefits and Challenges in the Disclosure Process (1 hour)
- 6.3 Pre-Disclosure Phase (2 hours 30 minutes)
- 6.4 Beginning the Disclosure Discussion (2 hours)
- 6.5 Ongoing Disclosure, Clarification and Support (1 hour; 2 if optional exercise is included)



## SESSION 6.1: INTRODUCTION TO THE DISCLOSURE PROCESS



### SESSION LEARNING OBJECTIVES

- Develop an understanding of the disclosure process as one that progresses over time with the increasing maturity of the child.
- Identify values and opinions healthcare workers hold regarding talking about HIV with children and caregivers.
- Describe the difference between partial and full disclosure as it applies to children.

## MODULE INTRODUCTION

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The process of disclosure of HIV diagnosis is an important component of the care of children living with HIV. Although research about paediatric HIV disclosure in Africa is limited, this module pulls together available knowledge and experience to assist healthcare workers to increase their skills and become more comfortable in providing disclosure counselling and support for caregivers and children.

Disclosure should be an ongoing process, one that takes account of the readiness of the caregiver and family and the developmental level of the child, along with input and guidance from the healthcare worker, as appropriate and as needed. Disclosure should not be seen as a one-time event; rather it is a process that begins before the child knows the term “HIV” and continues with ongoing support even after full disclosure of HIV status has occurred.

As initial steps to increase understanding and skills related to the process of disclosure, it is helpful for healthcare workers to:

- Briefly discuss current knowledge and practices about disclosure in individual practice settings. Questions may include:
  - *How do you deal with cases of disclosure in your setting?*
  - *Have specific members of your staff been given the responsibility of conducting disclosure discussions with caregivers and children?*
  - *Have you or anyone at your facility received training on disclosing to adults or children?*
- Consider their own opinions about disclosure and communicating with children. Sample questions may include:
  - *Do you think it should be the responsibility of caregivers only to disclose to their children?*
  - *Do you think young children should know their status?*
  - *What is your opinion about children speaking up and questioning adults?*

Throughout the module, it is important for participants to discuss and share information about tailoring content to meet the needs of children and caregivers from different cultures and communities.

<b>Exercise 1: Values clarification</b> <b>Large group: participants stay in large group</b>	
<b>Purpose</b>	<ul style="list-style-type: none"> <li>To encourage participants to recognise and articulate the values that they hold around child HIV and disclosure</li> </ul>
<b>Duration</b>	40 minutes
<b>Introduction</b>	<ul style="list-style-type: none"> <li>Participants will read through the six statements in the box below, and take 4–5 minutes to rank on a scale of 1 (Disagree), 2 (Neutral — neither agree nor disagree), or 3 (Agree).</li> <li>Next, the same statements will be read aloud and participants will be asked to get out of their seats and stand under the “Agree” sign if they agree with the statement or stand under the “Disagree” sign if they disagree. Those with feelings in between should position themselves somewhere between the signs. <ul style="list-style-type: none"> <li>A few participants at each end of the room will be asked to state why they feel that way about the statement.</li> </ul> </li> <li>After different points of view have been shared, participants will have the option of changing their opinion on the statement and thus changing where they are standing. Those who moved will be asked to explain why.</li> </ul>

Statement	Disagree	Neutral	Agree
Communicating with children is difficult.	1	2	3
A child must know his or her HIV status by the age of eight years.	1	2	3
A caregiver is the best person to tell a child about his or her HIV status.	1	2	3
The best place to tell a child about his or her HIV status is at home.	1	2	3
A child does not need to know how he or she got HIV.	1	2	3
Healthcare workers should encourage caregivers to disclose to the child soon after learning the child’s HIV status.	1	2	3

## **INTRODUCTION TO DISCLOSURE AND THE PROCESS OF DISCLOSURE**

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South Africa is a nation of many cultures and many beliefs about health, the need for disclosure and the impact of disclosure, particularly on children. Many studies have been conducted on the issue of disclosure, however, very few among children in South Africa. To date, there is little agreement amongst authorities on how disclosure should be dealt with among children living with HIV. This module therefore is meant to be a guide for

healthcare workers in this process and to be used in conjunction with what is acceptable at the local level and with an individual caregiver and child.

Studies have shown that in South Africa, family disclosure is more likely to occur when community support is available, for example HIV support groups or community health workers for outreach to those living with HIV. Reasons for not disclosing differ for each family. Not disclosing has been associated with:

- The belief that children are too young to know their HIV status
- The belief that disclosure would be too painful for children
- The assumption that children who know their HIV status may experience stigma
- Not knowing how to address the issue of disclosure

If healthcare workers are asked to assist with the process, it is important that they make an effort to understand family resources and challenges before advising a particular course of action.

Another important issue in the process of disclosure is time. Studies in Africa have shown disclosure is more likely to occur when a greater length of time has passed since the individual learned his or her status. This fact suggests that parents of children living with HIV need time to accept and become more comfortable with their own and their children's HIV diagnosis before they should be encouraged to disclose to children.

## **THE IMPORTANCE OF DISCLOSURE FOR CHILDREN LIVING WITH HIV**

Today, as HIV in South Africa has moved from an acute, fatal disease to one that can be managed with medication, more and more children will grow up living with HIV as a chronic disease. Thus it is important for children to learn about their disease in a way they can understand so that they can take an active role in their treatment and care. According to the Children's Act, every child has the right to "...have access to information regarding his or her health status [and]...have access to information regarding the causes and treatment of his or her health status.... Information provided to children... must be in a format accessible to children, giving due consideration to the needs of disabled children."<sup>1</sup>

### **The South Africa Convention on the Rights of the Child gives children the right to:**

- Have access to health care.
- Have control over their body.
- Not be subjected to procedures that would be medically or psychologically detrimental to their well-being.

In a study among healthcare workers in South Africa, there was agreement on the need for disclosure to children.<sup>2</sup> Most of the healthcare workers felt that it was most important for caregivers to disclose to children, but with the support of healthcare workers. They indicated that the role of the healthcare worker in disclosure discussions might include educating caregivers and children about the medical aspects of HIV, providing emotional support, and guidance on

when and how best to approach the issue with children.

## **THE PROCESS OF DISCLOSURE**

The process of disclosure has always had an integral place in the psychosocial care of children living with HIV. The disclosure support needs of children and families will vary based on:

- Age at diagnosis

- Health status of the child: For example, symptomatic children, particularly those requiring hospitalisation, should be informed of their HIV status sooner. The likelihood of children inadvertently learning about their status in a hospital setting is high.
- Mode of transmission
  - **Mother-to-child transmission:** Perinatal transmission brings up disclosure issues with respect to both the parent’s and child’s HIV status.
  - **Transmission via sexual abuse:** In situations where a child is infected by means of sexual abuse, the disclosure process is largely the same except that research has suggested that children who contract HIV through abuse have a greater need for ongoing counselling and support (than those who were perinatally infected) to help cope with the emotional impact of the abuse. For children infected through abuse, healthcare workers may have a greater role to play during the disclosure process, as the healthcare workers themselves may have been the ones to initiate HIV testing (see Session 6.2 for more detail).

Many people think about disclosure as “telling” others that they have HIV. This may be true for adults who must decide with whom within their friend and family network they will share information about their HIV status. In clinical practice, children may be identified as having been disclosed to (know their HIV diagnosis) or not disclosed to (do not know they have HIV). However, this can be misleading since disclosure of HIV status, particularly in the case of children, is not — and cannot be — a one-time revelation.

The terms “partial disclosure” and “full disclosure” are used in practice and in research to distinguish between varying levels of information-sharing among persons living with HIV. Among adults, partial disclosure is understood to mean that only selected people have been told about one’s HIV status, while full disclosure is associated with telling most or all people in one’s network about having HIV. These definitions are somewhat different among children. Among children:

- **Partial disclosure** refers to telling the child only some information about his or her illness, for example, the fact that he or she 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, developmentally, may not be able to grasp the full meaning of their illness. Partial disclosure also serves as a means of protecting the child and family from inadvertent disclosure and the possible effects of stigma and discrimination.
- **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. It is generally recommended that children are fully disclosed to when they are developmentally ready to receive the information. A particularly important indication that full disclosure should be considered is when the child starts asking specific questions about his or her illness, for example, how did he or she get the sickness, and no longer seems satisfied with the responses previously received. Full disclosure the family will involve of what HIV means to the child over time.

## **THE PROCESS OF DISCLOSURE: ONGOING SUPPORT NEEDS**

The disclosure process does not end when children are told they have HIV. It continues beyond this event to address the child’s understanding of his or her illness, feelings and ongoing support needs as he or she matures. It is important to talk to caregivers about

how children’s understanding and feelings about having HIV can change over time. For example, an 8-year-old boy who seemed to adjust quickly after diagnosis may have more difficulty as he enters his teen years. Age-appropriate support and therapeutic counselling will be discussed in a later session.

Giving the child information about HIV also provides an opportunity for caregivers and healthcare workers to work together to increase children’s understanding and active participation in their care. In this way, disclosure of HIV for children living with the disease is a part of their ongoing care as a person who is chronically ill.

### **EXPLORING ALTERNATE MODELS OF DISCLOSING**

In some cases, it may not be possible or acceptable for the mother or primary caregiver to be the person who engages in the disclosure process with the child. This may be due to a variety of reasons, for example, it may be culturally inappropriate to do so or the mother may be ill or unable to begin the discussions. In such cases, it is helpful for the healthcare worker to initiate discussion with the caregiver about who would be most appropriate to begin these discussions with the child. In some cases it may be the father’s sister or a grandmother, in others, perhaps a trusted church leader. The healthcare worker should be open to a range of possibilities and discuss with the caregiver the most appropriate means of disclosing for the child and family.

### **DEVELOPMENTAL APPROACHES TO DISCLOSURE**

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The concept “developmental approach to disclosure” is a cross-cutting one, a theme throughout the remaining sessions in this module. Decisions about when to start talking to the child about his or her health will be determined by the readiness of the caregiver, as well as by the developmental stage of the child. A child who is only five years old, for example, may ask why he or she must take medications or visit the clinic so often. A nine-year-old, on the other hand, may have heard things about HIV, been teased in school, and may have overheard adults talking about HIV, but does not fully understand the implication of having HIV. The approach taken in these two cases, assuming the caregiver is ready for disclosure discussions, will largely be based on how much the child is able to understand, which will be determined by the age and developmental level of the child. Therefore an overview of childhood development should support healthcare workers to help caregivers through the disclosure process.

Each phase of a child’s development from infancy, toddler, pre-school to early and late adolescence has characteristic features. Understanding a child’s developmental stage is vital to disclosure because children’s understanding evolves as their brain becomes more equipped to absorb complex concepts. Understanding how children develop will help healthcare workers and caregivers better guide the disclosure process for children, ensuring that appropriate information is presented when the child is able to cope with it.

### **DISCLOSURE AND DEVELOPMENTAL AGE**

Pre-school-aged children’s understanding is tied to what they can see and manipulate. They cannot understand a concept as abstract as a “virus”. They also relate things to themselves, so much so that they can easily blame themselves for things happening around them (e.g., “this happened because of what I thought”). Children develop the ability for logical thinking around the age of six years. It is at this time that they are able to begin to understand the concept of illness and what causes it; partial disclosure may

therefore be considered around this age, particularly if the child has started asking questions related to his or her health. At around age 10, children have a greater understanding of illness — that it is caused by something not working properly in the body; full disclosure should be considered around this age if the child is developmentally on target.

Interestingly, these ages correspond to the recommendations among South African healthcare workers about the appropriate time to begin to introduce discussions of illness generally (at age six), when children are mature enough to understand and when they are beginning school and therefore interacting more with peers. Healthcare workers recommended that specific information about HIV be discussed around age 10, when the child is able to understand some of the complexities surrounding the disease. These ages are only suggestions, however, as different studies have made varying recommendations. In a study among caregivers of children living with HIV, caregivers thought that general discussions about HIV should begin around age 11, and specific information about HIV shared when the child is approximately 12 years old.<sup>3</sup> Studies in other African countries have recommended initiating health discussions at around age 10 with specific discussion of HIV at 14–15 years. Each child is unique, and each case of disclosure should always take into account the developmental level of the child and the readiness of the caregiver and family to discuss these issues.

The differing abilities of children at developmentally different stages have been described by Jean Piaget who proposed that at approximately five or six years of age, children develop the ability for concrete-logical thinking. However it is not until approximately eight or nine that they develop the ability to understand the complex factors that may cause the disease. Though Piaget’s theories have been challenged, research among South African children has somewhat validated the different levels of understanding of health and disease among five year olds and nine year olds.<sup>4</sup>

## **DISCLOSURE AND THE CHILDREN’S ACT**

The Children’s Act<sup>5</sup> supports and acknowledges that children over the age of 12 years may be accorded more rights to knowledge about their health or to consent to treatment. The HIV Counselling and Testing Policy Guidelines state that a child may consent independently to HIV testing if he or she is:

- 12 years old or older; or
- Under the age of 12 years and of “sufficient maturity” (as outlined below) to understand the benefits, risks and social implications of such a test.

A child is considered to be “sufficiently mature” if the child can demonstrate that he or she understands information on HIV testing and can act in accordance with that appreciation. In deciding whether a child is sufficiently mature, the factors that should be taken into account include:

- Age: the older the child the more likely it is that he or she will have sufficient maturity
- Knowledge: children with knowledge of HIV and its implications are more likely to understand its consequences
- Views: children who are able to articulate their views on HIV testing and whether it is in their best interests are likely to meet the maturity requirements
- Personal circumstances: an assessment of the child’s personal situation and his or her motivations for HIV testing may help in assessing their maturity.

If the child is not of sufficient maturity to consent to testing, this does not mean that he or she cannot be tested. Rather, the child can only be tested with the informed content of his or her parent or guardian.

### **DEVELOPMENTAL STAGE VERSUS AGE**

Many times children appear to understand more than they actually do. In one true story, a nine-year-old child seemed to be well-versed and comfortable discussing his HIV, but when his mother and nurse began discussing his “disease”, he became very uncomfortable all of a sudden. What did they mean he had a disease? He knew he had “HIV”, but he did not know he had a “disease”.

It is also possible that children may appear to understand less than one might think. For example, if adults have conversations about HIV in front of a child, the child may be getting an incomplete idea of what HIV really is. This is more likely to occur among younger children who have not yet developed more formal-logical thinking. It is therefore vitally important that information be passed on to children when they are mature enough to understand the meaning of what they are told *and* in a context where they are allowed to ask questions. When children are not allowed to ask, or if secrecy about the illness heightens their sense of shame, fantasies and fallacies about HIV may increase.

It is important to note that developmental stages are associated with approximate ages; however, just because a child is a certain age does not necessarily mean that his or her development is the same as those of others in that age group. For a number of reasons, you may find an eight-year-old at the developmental level of a five-year-old...or a 12-year-old. Thus, it is critical to assess the child’s developmental stage to help the caregiver plan a developmentally appropriate approach to disclosure. It is also important to follow up with questions to assess the child’s understanding.

Table 6.1 includes suggestions of what to say to children by age group, given their approximate developmental stage. See Appendix 1: Childhood Development for a full overview of movement, cognitive, language, emotional, social/relationships and self-care characteristics of each age group and associated developmental stage.

**Table 6.1: Guidance for sharing developmentally appropriate HIV information**

Age group characteristics	Disclosure guidance	Possible questions	Possible responses
<b>Pre-School Children (approx 3–5 years old): Partial disclosure</b>			
<ul style="list-style-type: none"> <li>Understanding is closely tied to their own experiences (me, here, now); language is mainly used to communicate</li> <li>Most will not understand HIV and will not be able to keep it private</li> </ul>	<ul style="list-style-type: none"> <li>Be truthful</li> <li>Emphasize the child’s health and illness, and delay disclosure specifically of HIV status.</li> <li>Give information in response to the child’s questions or reactions (e.g. refusing to take medication).</li> <li>Use play activities (e.g. playing or “healthcare worker”, drawing or painting) to help the child express feelings and concerns.</li> <li>Explain that it is not their fault that they (or their parents) are sick.</li> </ul>	<ul style="list-style-type: none"> <li>Why do I have to see the nurse?</li> <li>Why does the healthcare worker take my blood?</li> <li>Why do I need to take this medicine?</li> </ul>	<ul style="list-style-type: none"> <li>You have to see the nurse so she can check your blood.</li> <li>The nurse takes your blood to make sure you stay well.</li> <li>You need to take medicine because there is a germ in your blood that can make you sick.</li> </ul>
<b>Early Primary School Children (approx 6–9 years old): Partial disclosure</b>			
<ul style="list-style-type: none"> <li>Beginning to understand cause and effect, but still struggles with abstract concepts</li> </ul>	<ul style="list-style-type: none"> <li>Be truthful</li> <li>It is important to start the disclosure process at this stage</li> <li>Give information that describes the effects of the illness, without necessarily discussing specifics about HIV.</li> </ul>	<ul style="list-style-type: none"> <li>Why do I have to go to the clinic?</li> <li>Why am I sick?</li> <li>Why do I</li> </ul>	<ul style="list-style-type: none"> <li>Going to the clinic will help you stay well.</li> <li>You have to take medicine so the germ fighters can work and you won’t get sick so much.</li> <li>You take medicine to keep you strong.</li> <li>The medicines that we have to treat this virus are very good. If you take your medicine, you can stay healthy for a very long time.</li> </ul>

<ul style="list-style-type: none"> <li>• Growing vocabulary, but struggles to express ideas and feelings in words</li> <li>• May regress and want help from adults if feeling insecure or unsure</li> </ul>	<ul style="list-style-type: none"> <li>• If a child asks for more information (e.g. <i>What is the germ called?</i>) or <i>How did the germ get in my body?</i>), give short, clear answers.</li> </ul>	<p>have to take this medicine?</p>	
<b>Late Primary School Children (approx 9–11) years old: Full disclosure</b>			
<ul style="list-style-type: none"> <li>• Increasing vocabulary</li> <li>• Stronger sense of cause and effect</li> <li>• Enjoys activities that give a chance to control, organise and order things</li> </ul>	<ul style="list-style-type: none"> <li>• If safe to do so, begin discussions about HIV specifically.</li> <li>• Help the child deal with possible stigma.</li> <li>• Reassure the child that s/he can ask further questions or share any concerns now or later.</li> </ul>	<ul style="list-style-type: none"> <li>• How did I get this?</li> <li>• Am I going to die?</li> <li>• How did my mum get this?</li> </ul>	<ul style="list-style-type: none"> <li>• You have a virus in your blood called HIV (that you were born with). It attacks the germ fighters in your body. This is why you get sick sometimes.</li> <li>• Taking your medicines and eating healthy will help to keep you well so that you will not have to go to the hospital (as often).</li> <li>• HIV is nothing to be ashamed of, but it is something private.</li> <li>• You do not have to tell other people if you do not want to.</li> <li>• You can always talk to me about it at any time.</li> <li>• We are not sure how your mum got this; maybe this is something that you can ask her.</li> <li>• Maybe we should keep this in your family for now?</li> </ul>
<b>Adolescents (approx 12–18 years old): Full disclosure</b>			
<ul style="list-style-type: none"> <li>• Early adolescents beginning to be able to think in</li> </ul>	<ul style="list-style-type: none"> <li>• Give accurate and more detailed information in response to questions.</li> <li>• Give realistic information about</li> </ul>	<ul style="list-style-type: none"> <li>• What is HIV?</li> <li>• Why do I have it?</li> </ul>	<ul style="list-style-type: none"> <li>• You have the HIV virus. A virus is something that gets into your blood and can make you sick. Having HIV does not mean that you are sick all the time.</li> <li>• You most likely got HIV when you were inside your mother's</li> </ul>

<p>more abstract terms</p> <ul style="list-style-type: none"> <li>• Want solid, well-thought-out explanations</li> <li>• Body changes can create feelings of insecurity</li> <li>• Forming a sense of identity — peer approval and social acceptance very important</li> </ul>	<p>health status, answer all questions.</p> <ul style="list-style-type: none"> <li>• Be sure to ask about and discuss the adolescent's feelings and fears about HIV.</li> <li>• Ask questions about adolescent's understanding and address misperceptions, e.g. "<i>What have you heard about HIV?</i>"</li> <li>• Address adolescent's concerns about living meaningfully with HIV, including relationships.</li> <li>• It is very important to reassure adolescents that their HIV status and what they say is confidential.</li> <li>• Be aware that the transition to/struggle for independence may make the response to disclosure more difficult (e.g., less likely to adhere to medication).</li> <li>• Discuss issues of disclosure to others, but allow the adolescent to make his/her own decisions on this matter.</li> <li>• Give assurance of support and willingness to help without seeming intrusive.</li> </ul>	<ul style="list-style-type: none"> <li>• Can I give HIV to my (girl/boy) friends? How? What are the healthcare workers looking at in my blood? Why are people mean to people with HIV?</li> </ul>	<p>belly or when you were breastfeeding.</p> <ul style="list-style-type: none"> <li>• Healthcare workers look at your blood to see how much virus is in it, this is called your "viral load." They are also looking at how many healthy cells, called T-cells, are in your blood.</li> <li>• You can control the virus by taking your medications every day. But there is no way you can get rid of HIV completely.</li> <li>• If you stop taking your medicine the virus (HIV) will get stronger in your blood and damage all of your healthy T-cells. If that happens, you can get sick.</li> <li>• Knowing that you have HIV gives you a special responsibility to take extra good care of yourself and not pass HIV to other people.</li> <li>• People with HIV can and do live long lives, have relationships and get married.</li> <li>• If you have sex, it is important for you and your partner to use condoms.</li> <li>• You can have a baby in the future, but there are risks of passing HIV to your partner or to the baby. There are many things you could do to lower the chances that your baby gets HIV. We can talk more about this whenever you like.</li> <li>• Some people are mean to people with HIV because they do not understand how they can catch it and are therefore afraid.</li> </ul>
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**Exercise 2: Understanding a developmental approach**  
**Small group discussion: participants break into 4 groups**

<b>Purpose</b>	<ul style="list-style-type: none"> <li>To help participants understand the varying needs of children at different stages of development</li> </ul>
<b>Duration</b>	40 minutes
<b>Introduction</b>	<ul style="list-style-type: none"> <li>Participants will be divided into four groups and assigned a case study.</li> <li>Each group, based on their own experiences with patients and on their knowledge of children in general, will be asked to:             <ul style="list-style-type: none"> <li>Brainstorm and record the types of questions the children in the case studies are likely to ask about their illness.</li> <li>Develop responses to the questions.</li> </ul> </li> <li>If a small group needs further review of the content just discussed in this session refer to Table 6.1.</li> <li>After ten minutes of discussion in the small groups, participants will reconvene to share their questions and answers they developed.</li> </ul>

**Exercise 2: Case studies**

**Case Study 1: Lefu**

Lefu is a five-year-old female who lives with her grandmother, Mpho. Lefu has been enrolled in HIV care and treatment for the last year and has been doing well, with good growth for age, no major illness, and has reached all of the developmental milestones for a girl her age.

**Case Study 2: Naledi**

Naledi is an eight-year-old female who lives with her mother, Zoleka, a sex worker in poor health. Naledi knows that her mother is very sick and feels responsible for her mother's illness because her mother has to work long hours to pay for Naledi's food, clothing and school fees. Naledi herself takes medication "to keep her strong" but she has never been specifically told why she must take it.

**Case Study 3: Sipho**

Sipho is a 10-year-old male who lives with his father who is a truck driver. His mother died of AIDS when he was an infant. Over the years he has been sick a lot, but it was not till very recently that he was first hospitalised with an infection and diagnosed. His father has not yet told him that he has HIV.

**Case Study 4: Thabo**

Thabo is a 13-year-old male who has lived with his maternal aunt and uncle since his mother died a year ago. He does not know his HIV status, but has been taking medications for several years and is doing well on treatment.

\* Three of these cases (1, 2, 4) will be used throughout this module.

## **POINTS TO KEEP IN MIND WHEN DISCUSSING HIV**

As mentioned earlier, discussions about illness or HIV with an infected child should be individualised based on the child's cognitive ability, developmental stage, clinical status, and social circumstances. The process for disclosure should be discussed and planned with the caregivers and may require a number of visits to assess the child's knowledge and coping capacity.

- In general, younger children, if symptomatic with illness, are most interested in learning what will happen to them in the more immediate future. They do not need to be informed of their diagnosis, but the illness should be discussed with them. If children are informed of their diagnosis, considerable effort should be directed toward eliciting and addressing their fears and misperceptions.
- Older children have a better capacity to understand the nature and consequences of their illness. Considerable effort will need to be directed to facilitate coping with the illness.
- Adolescents should know their HIV status. They should be fully informed, so that they can make health-related decisions and take responsibility for these decisions, including decisions around relationships and sexual behaviour. Knowledge of HIV status also allows adolescents to make appropriate decisions about treatment. Healthcare workers should encourage adolescents to involve their caregivers in their care.

While much of the research into the stages of development has been conducted outside of South Africa, the concepts are widely assumed to be universally applicable. Because HIV often affects the rate at which children develop and mature however, healthcare workers, in advising caregivers, should be aware that these stages should be used only as a guide. As previously mentioned, a child of eight years old with some developmental delays may be functioning at the level of a child who is five years old, for example. Consideration of the actual developmental stage of a child should be an important factor when disclosure discussions occur.

### **HELPING CAREGIVERS WITH DISCLOSURE**

Caregivers often need information, guidance and ongoing support to help them talk with children about their health and treatment in ways that are developmentally appropriate for the child. This module is designed to help healthcare workers assist caregivers throughout the process of disclosure of HIV status to children ages 3–18 years of age. The focus is on disclosure to children with perinatally acquired HIV infection, but also includes content relevant to children infected through sexual abuse.

The importance of the child's developmental stage, the fact that disclosure is a process, and not a one-time event, and ensuring that the caregiver is at a stage of readiness for the disclosure discussion was emphasized in this session and continues as a theme in the next sessions.



## SESSION 6.2: BENEFITS AND CHALLENGES IN THE DISCLOSURE PROCESS



### SESSION DURATION

1 hour (60 minutes)



### SESSION LEARNING OBJECTIVE

- Discuss the benefits and challenges, including parental disclosure and stigma, of the disclosure process.

## BENEFITS OF DISCLOSURE

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Studies have demonstrated that children with chronic diseases, including cancer, have demonstrated better coping skills and fewer psychosocial problems when appropriately aware of the nature and consequences of their illness.

The studies on disclosure to children with HIV do not agree on the effect of disclosure. For example, although healthcare workers generally think that disclosure is important to help children understand the need to take antiretroviral therapy, some studies have shown better adherence after disclosure and others worse adherence.<sup>vi,vii</sup> A study about the impact of disclosure on quality of life (general health perception, symptom distress, psychological status, health care utilisation, physical functioning, and social/role functioning in children with HIV infection) found that disclosure did not significantly affect well-being (either positively or negatively).<sup>viii</sup>

In the context of paediatric care, it is important to consider disclosure from a family-centred perspective. A Ugandan study found that when the primary caregiver was the only person who knew the child's HIV status, the child was three times more likely to be non-adherent than when multiple caregivers were aware of the child's status.<sup>ix</sup> Another study found that disclosure to friends did not affect the child's behaviour or self-concept.<sup>x</sup> These studies, while not conclusive, suggest the importance of family and friend network support for the well-being of the child and provide additional evidence for the benefits of disclosure.

### PREPARING CAREGIVERS TO DISCLOSE

Session 6.1 focused on ensuring the child was ready for disclosure, but readiness for disclosure on the part of the caregiver is important as well. To improve the chances that the disclosure process proceeds as smoothly as possible, the healthcare worker should:

- Ensure the caregiver is able to cope with disclosure to the child
- Assist the caregiver to prepare for the process of disclosure
- Help the caregiver to convey a sense of hope and optimism to the child

Healthcare workers should share the following information with caregivers of children with HIV:

- Children who know their HIV status can take an active role in their care and treatment plan and when old enough, can take steps to live positively and prevent new infections.
- When children learn about their status directly from their caregivers, it can provide comfort and reassurance. Keeping secrets is hard. Too often, children overhear healthcare workers and caregivers talking about their health as if they are not in the room. Efforts should be made, when developmentally appropriate, to include children in discussions about their health.
  - Children often ask to know what is wrong. Children are observant, smart and curious. They often know much more than adults realise.
  - Children may already suspect their HIV status but are keeping it a secret or waiting for an adult to tell them.
  - Children may have fears about their HIV status, especially if one or both of their parents have died.
- Children who have not been disclosed to may:
  - Develop their own views about their illness
  - Feel isolated from support
  - Learn their HIV status by mistake
  - Present with behavioural problems
- Children have a right to know:
  - When children are able to understand, they have a right to know about their body and their health.
  - When children know about their diagnosis, they can also learn to protect others.

## CHALLENGES

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The following sections outline the range of challenges that may provide barriers to child disclosure.

### CAREGIVER BARRIERS

Disclosure of HIV status can be a very difficult topic. Caregivers may not want to disclose diagnosis to a child living with HIV for a number of reasons. These reasons often reflect valid concerns that must be addressed before caregivers are ready and able to initiate the process of disclosure. By understanding the common challenges and barriers to disclosure, listed below, healthcare workers can support caregivers and facilitate the process of disclosure. Each of these barriers will be further discussed later in this module.

**Table 6.2: Caregiver barriers to disclosure and possible healthcare worker responses**

<p><b>1. Caregiver thinks the topic is too complicated for the child to understand or that the child is too young.</b></p>
<ul style="list-style-type: none"> <li>• A child’s age and developmental stage must be taken into consideration throughout the disclosure process.</li> <li>• Healthcare workers can help caregivers identify what information is appropriate according to the age and development of the child so the child is “appropriately aware of their illness”. These developmental milestones and approaches will be</li> </ul>

discussed later in this module.

**2. For reasons based on tradition and culture, the caregiver is unused to discussing important issues with the child and may think that it is inappropriate to do so.**

- Healthcare workers should address the importance of disclosure, and the caregiver's vital role in this process.
- Healthcare workers may assist caregivers by first helping them open up discussion with the child about their health, in general. Healthcare workers, based on their knowledge of the environment in which the caregiver functions, may suggest opportunities where these conversations could most naturally occur.
- Healthcare workers may help the caregiver with specific words, ways of explaining, or answering questions to support them to initiate discussions with the child about HIV.

**3. Caregiver does not know where to start, or how to anticipate or respond to children's questions. Caregiver may lack support in the home and in the community and have no access to a trained healthcare worker to help prepare for disclosure.**

- Healthcare workers can begin talking to the caregiver about the disclosure process long before anything is said to the child. This will help them plan where and when to begin disclosure (see also barrier 2, above).
- Healthcare workers — even those with limited training in disclosure — can educate caregivers on the questions and responses that should be anticipated from the child.

**4. Caregiver lacks support at home or in the community for disclosing to the child.**

- Healthcare workers may talk with caregiver about supports and barriers to disclosure within the family and in the community to determine ways of increasing support.
- Healthcare workers can encourage the caregiver to bring other family members or a close friend to the disclosure counselling sessions.
- Healthcare workers can discuss with the caregiver how to increase support in the family.

**5. Caregiver lacks knowledge/comfort with topic.**

- Healthcare workers should assess the caregiver's knowledge about HIV and provide basic education starting from what the caregiver understands. Knowledge about HIV and its treatment empowers caregivers.
- Healthcare worker should assess caregiver's comfort level with the topic, and provide support to openly discuss HIV, HIV prevention and HIV care.
- Healthcare workers can assist caregivers to decide what information is appropriate and necessary to tell the child. The initial conversation does not have to include uncomfortable or taboo topics, such as sex/sexual transmission or how the child got HIV, particularly for young children.
- Healthcare workers should assure caregivers that they will support and help them answer children's questions as needed throughout the disclosure process.
- A special note about adolescents: Caregivers will benefit from additional support and resources to address the needs of adolescents during the disclosure process. These include psychosocial support, disclosure of their status to others, sexuality

education, peer support and others.

#### **6. Caregiver fears causing psychological harm to the child.**

- Healthcare workers need to be aware of the caregiver's specific fears about disclosure. It is common for caregivers to feel that knowledge of HIV status could:
  - Reduce the child's will to live
  - Make the child think he or she is not normal, or
  - Upset the belief that children are supposed to be happy, and knowing they have HIV may strip them of his or her happiness
- Healthcare workers can provide information to address caregivers' fears. Contrary to common assumptions, some studies have shown that there are positive psychological benefits for children when they are appropriately aware of their illness.
- Peer support from other caregivers going through the process of disclosure or who have already disclosed to their child can provide powerful support and reassurance to address specific fears about psychological harm.

#### **7. Caregiver wants to protect child/family from stigma, discrimination and rejection. HIV is a stigmatising illness in most communities and within many families.**

- Healthcare workers should make caregivers aware that disclosure of HIV status may be more difficult than disclosure of other chronic illnesses. HIV infection raises issues about stigma and discrimination that are rarely associated with other diseases. Caregivers may be concerned that these will lead to rejection of the child within the community and even within the family. Additionally, if there are other children in the home who are not HIV-infected, there may be concern about how the other children will react or how the child will feel if he or she is the only child in the house with HIV.
- Healthcare workers can provide specific support to address needs related to stigma and discrimination, as described later in this module.

#### **8. Caregiver is experiencing parental guilt regarding transmission, or fears the child will accidentally disclose his or her HIV status or the parent's HIV status.**

- Recognise that disclosure of HIV status to children is often a family issue, as it is related to one or both of the parents' infection status. Disclosure in such a family setting can pose unique challenges regarding parental guilt and shame or fear that the child may accidentally disclose the parent's status to others.
- Healthcare workers should assess and address specific concerns, such as guilt or accidental disclosure by the child. These issues will be discussed throughout this module.

#### **9. Caregiver has difficulty coping with his or her own illness, or that of loved ones.**

- Recognise that some family coping strategies around illness/death (such as silence, limited open communication within the family, denial), may make it more difficult to disclose to the child.
- Through ongoing counselling and discussion with the caregiver about the disclosure process, the healthcare worker may be able to help the caregiver open up and communicate better about HIV within the family.

**10. Caregiver is unrelated to the child and/or the child is an orphan.**

- The healthcare worker may assist the caregiver by helping him or her understand the need for and importance of disclosing to the child in a sensitive manner.
- Orphaned children often need greater levels of support, emotional, financial and logistic, than children with parents. As such, healthcare workers should assess the child's need for additional support and assistance and provide referrals to needed services.

**HEALTHCARE WORKER BARRIERS**

Healthcare workers may also find it difficult to discuss HIV infection and disclosure with caregivers and children. This topic area will be further addressed in Session 6.3 and the following exercises.

**Table 6.3: Healthcare worker barriers to disclosure**

<b>1. Healthcare workers experience some of the same barriers experienced by caregivers, such as not knowing where to start or being concerned about harming the child.</b>
<ul style="list-style-type: none"><li>• Training and clinician support tool resources are essential to equip healthcare workers to support caregivers and children throughout the disclosure process.</li><li>• Asking the advice of other healthcare workers who have been through this process with caregivers, observation of more experienced healthcare workers, and knowing the backgrounds, limitations and resources of caregivers will help to improve healthcare workers' sense of mastery over facilitating the process.</li></ul>
<b>2. Healthcare workers may be unsure about their role in the disclosure process or think that the process of disclosure is not their responsibility.</b>
<ul style="list-style-type: none"><li>• Physicians, nurses, counsellors and others can all support the process of disclosure. This support may involve addressing caregiver barriers to disclosure (such as demonstrating good communication with children or by helping caregivers learn about HIV) or may involve leading the disclosure discussion with a child's caregiver.</li><li>• Healthcare workers in a clinic or department should convene a multi-disciplinary meeting to discuss the role of each team member in the disclosure process. Such discussion will help define the role of every team member and promote effective coordination.</li></ul>
<b>3. There may be differences of opinion about disclosure between a healthcare worker and caregiver — or among healthcare workers. It can be challenging when the healthcare worker thinks that the child needs to understand his or her HIV diagnosis but the caregiver is not ready to move ahead with disclosure.</b>
<ul style="list-style-type: none"><li>• When conflicts about disclosure arise, it is helpful to remember that disclosure is a process that can take time. Careful assessment of barriers to disclosure and working with the caregiver is often required to agree on what, when and how to disclose to the child. It is always important to remember that the decision of the caregiver should be respected.</li></ul>

## CHILD BARRIERS

Beginning disclosure discussions with children is a necessary element of their care. While caregivers may be reluctant to initiate discussions, the fact is that many children already know there is something wrong. Approaching children with elements of the truth that they are developmentally and emotionally able to manage is a necessary first step to getting children involved in their own care.

The barriers to disclosure among children include lack of developmental maturity and perceived inability to emotionally handle information about HIV and to keep the information confidential (as defined by the family). If disclosure is approached as a series of conversations that incorporate increasing levels of information and complexity about HIV and the child's role in managing his or her own health, the caregiver, with guidance from healthcare worker, will be able to assess when the child is ready for the next steps in the disclosure process.

Some caregivers make a decision not to talk about HIV in front of their child, thinking that they are protecting the child. While the role of the healthcare worker is to support the caregiver's decision regarding disclosure, it is important too, that the healthcare worker share with the caregiver signs or "red flags" that information about HIV needs to be shared with the child. These behaviours generally fall into the categories of internalising (e.g., becoming more withdrawn and non-communicative) or externalising (e.g., crying/tantrums, engaging in risky sex or drug use behaviours).

### **Red flags indicating the possible need to disclose include\*:**

- Becoming more withdrawn, not playing, interacting with others as before
- Not wanting to go to school
- Experiencing reduced appetite or sleeping more than usual
- Exhibiting hyperactive behaviour that is not normal for the child
- Not wanting to be among people outside the family
- Behaviour becoming more immature, not being able to do things they previously could, for example, self-care
- Bedwetting in a child who previously had stopped this behaviour
- Soiling one's clothes in a child who has already been toilet trained
- Becoming more clingy to the caregiver
- Crying or having tantrums more frequently than usual
- Exhibiting oppositional defiant behaviour, e.g., not listening to caregivers, aggression, committing petty crimes
- Expressing more fears of the future or of death
- Expressing more fears than usual about going to the clinic
- Becoming more sexually promiscuous
- Becoming involved with peers engaging in risky behaviours
- Experimenting with alcohol/drugs

\*Note that these are symptoms that may also be exhibited among children who have experienced trauma or who have been sexually abused.

This is not a comprehensive list, but provides some guidance to healthcare workers and caregivers about the types of behaviours that may indicate the need to begin talking with the child about HIV (discussed more fully in the following sessions of this module). These signs may also indicate other problems that the child may be facing. The

healthcare worker should guide the caregiver to be open to conversations about general matters with the child first, and then focus questions on what is bothering the child. Asking questions, probing and encouraging open discussions with the caregiver are the best tools the healthcare worker has to learn about the child and encourage disclosure, when appropriate.

It should also be noted that even if the disclosure discussions go well with the child, there may be a period after the child begins to understand his or her health issues when the child exhibits some of the “red flag” behaviours noted above. The healthcare worker should explain to the caregiver that this is normal, and if the caregiver continues to encourage questions and openness from the child, these behaviours should pass.

### **Special case of orphans**

Children who are orphaned may be faced with task of transitioning to a new home and new caregivers while also coping with the death of a parent. These children may face challenges in providing food and shelter for themselves and younger siblings, may have problems in school, and often drop out of school due to lack of resources. Healthcare workers may be in a position to assist by linking them with support groups and connecting them with persons who may be able to help them with the grieving process.

Orphaned children are a particularly vulnerable group — whether living on their own, in an orphanage or with extended family members or caregivers. Because there may not be an adult whose specific role it is to ensure the well-being of an orphaned child, the needs of an orphan may be forgotten. Healthcare workers may find themselves in the difficult situation of recognising unmet needs for this vulnerable group, possibly without having the resources to assist in meeting those needs. For this reason, it is particularly important that healthcare workers are knowledgeable of the resources and possible referral locations that are available for these children, and to constantly ask questions to ensure that needs are being met.

With regard to disclosure, healthcare workers may bear primary responsibility for initiating discussions about disclosure with the caregiver of an orphan. An orphaned child may have already heard stories or misinformation about the death of his or her parents, particularly if the death was HIV-related. Therefore it is especially important that disclosure discussions not be delayed, but proceed according to the maturity of the child and his or her ability to deal with the information. Special care also needs to be taken to ensure that the orphan has someone to whom he or she can talk and ask questions.

### **Disclosure in the context of sexual abuse**

The disclosure of HIV is particularly difficult among children, however disclosure in the case where the child has also been traumatised by sexual abuse or rape brings with it an added burden. The evidence in South Africa suggests that forced sexual contact is not uncommon. A study in KwaZulu-Natal, for example, revealed that almost 46% of young women in a community sample had been forced the first time they had sex.<sup>xi</sup> These girls were more likely to report a sexually transmitted disease and unintended pregnancy, compared to girls who had not been forced the first time they had sex.

Adolescents who have been sexually forced face many of the same issues as those who acquire HIV perinatally. They worry about the impact of the disease on their future romantic relationships, on their ability to have healthy children, and on the chances that they will live into adulthood. In addition to coping with HIV, these adolescents are also dealing with the psychological impact of having been raped or sexually abused. In a study in the Caribbean, adolescent girls who became HIV-positive as a result of forced sex were more likely to have very high levels of thoughts/intentions of committing suicide.<sup>xiii</sup> It is extremely important, therefore, that these adolescents receive social support to help them cope with their feelings.

When disclosing HIV status to a child who has been raped or sexually abused, it is absolutely necessary that a support system is in place for the child. Support, in the form of professional counsellors — or in their absence, lay/peer counsellors — as well as family support, is needed. The child must know that she or he has someone to talk to and with whom he or she can share difficult feelings. As the child becomes older, and this is particularly relevant for adolescents who contracted HIV as the result of forced sex, a single event disclosure discussion, meaning a one-time discussion during which HIV status is revealed, may be needed. This discussion requires a high level of sensitivity and should be led by the caregiver with the assistance of a healthcare worker who has experience disclosing to adolescents.

Particularly for adolescents, but for younger children as well, it is important that the child be connected with others who may have had shared experiences. This will help them to feel that they are not alone and that their feelings, fears and anxieties are normal, given the difficult experiences they have had.

## **DISCLOSURE OF PARENTS' SEROSTATUS**

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Parental disclosure is often a barrier to disclosure to the child. Perinatally-infected children have a mother (and often a father as well) who is also living with HIV. Disclosure to the child will usually therefore also involve maternal disclosure. A study in South Africa<sup>xiii</sup> found that mothers have a number of concerns about their children's well-being when it comes to disclosing their own HIV status. Of 103 mothers in the study, 50% had disclosed their own HIV status to their children within one year of learning their diagnosis and 70% within two years. Mothers were mostly concerned with depression, anxiety and other effects on their children. Another study in South Africa found that mothers who had disclosed their status to their HIV-infected children were seven times more likely to disclose the child's own status.<sup>xiv</sup> Therefore, while maternal disclosure is often seen as a potential barrier in the disclosure process, it may actually facilitate disclosure.

An important finding from this study was that a mother's strong relationship with her child and co-caregivers helped children regardless of whether disclosure had occurred. Issues with communication within families (for example, when information is withheld from children or when there is a lack of communication between spouses) create challenges to the uptake of health-related advice. Healthcare workers should therefore encourage a focus on strengthening family relationships as an early part of the disclosure process.

Caregivers should be counselled that disclosure of parental HIV status is also a process that should be planned.

- If a mother/father is not prepared to disclose his or her status to the child, the healthcare worker should use the guidance presented in the following section to help move the parent through the process of pre-disclosure.
- Typically, adults disclose to their partner and then to other adults in the home. The reaction to this information will provide some guidance on how and when to approach disclosure with the children. Disclosure to children is important as accidental disclosure, for example a child overhearing adult conversations, may be harmful to the child. Often, children already suspect something before learning the truth. A planned approach helps to ensure that disclosure poses the least harm to the child.
- The disclosure discussion with children can begin with explanations about physical symptoms and general information about HIV and eventually proceed to a discussion on the meaning of HIV. Children's information needs will vary as they grow and develop but an honest, open relationship paves the way for a positive experience.
- Healthcare workers can help parents to base the level of the discussion on their child's age and development. The parent should also take the time to prepare answers to the expected questions. He or she should encourage children to come back with questions or to discuss their feelings, particularly as their information needs will change. This process is similar to the process of disclosure to an HIV-infected child.
- An important consideration for women who disclose is risk of violence in the home as a result of disclosure. Before encouraging a mother to disclose her status, a healthcare worker should assess the woman's level of risk for violence (see box to the right) and identify her support network. These points are important when the mother is disclosing to her partner as well as when she is disclosing to the child, as the child may accidentally disclose, with possibly negative repercussions. Fear of violent repercussions is a serious barrier for many women living with HIV.

#### **QUESTIONS TO ASSESS HISTORY OF DOMESTIC VIOLENCE**

- *Do you ever feel unsafe at home?*
- *Are you in a relationship in which you have been physically hurt or felt threatened?*

Because of the anxiety that can arise when a parent wants to keep his or her diagnosis secret, it is advisable that she or he provides the child with one or more "safe" people with whom the child can freely share his or her concerns (discussed in "HIV-Related Stigma").

#### **REACTIONS TO PARENTAL DISCLOSURE**

Should the parent decide to disclose his or her status to the child, the child's reaction will depend on age and level of development. In general, pre-adolescent and adolescent children experience more anxiety and fear than do younger children because they have a better understanding of health, illness and death.

Potential reactions from children who find out that their parent is HIV-positive include:

- Worry
- Sadness

- Anger
- Fear
- Sympathy
- Denial
- Concern (for parent and self)

They may also:

- Stop blaming themselves if the parent is sick or tired
- Better understand when something unexpected happens (such as a sudden hospitalisation)
- Feel more involved in planning their future
- Feel pleased their parent has shared something with them

### **HIV-RELATED STIGMA**

The stigma attached to HIV leads many families to avoid disclosure with children or to require secrecy. Research shows that many children can and do keep the information to themselves (to protect themselves and their families from stigma and discrimination) — particularly children who are older. However, children tend to become more distressed when they are *required* to keep the secret, which can lead to behavioural problems.

As part of disclosure planning, caregivers should be encouraged to identify one or more trustworthy people with whom the child is regularly in contact (other than the healthcare worker) to be a “safe” person — one with whom the child can discuss his or her HIV status, concerns and treatment. This person may be a relative, close family friend, a teacher, etc., and should be consulted by the caregiver on a regular, if informal, basis to identify any potential problems or misperceptions the child may have that could be addressed with ongoing counselling and follow-up. Note that, despite having a safe person, some children do disclose their HIV status to others; caregivers should be prepared for this scenario.

#### **Maintaining Confidentiality**

Once a child knows his or her status, caregivers have limited control over who else a child may tell. Some children will be able to keep a secret, others will not. During the disclosure process, caregivers should provide guidance to children and tell them with whom they may safely speak about their illness. Sample statements include:

- *HIV is nothing to be ashamed of, but it is something private. You do not have to tell other people if you do not want to.*
- *You can always talk to me about it at any time.*
- *Maybe we should keep this in the family for now?*
- *It is very important that you only talk to your family and your healthcare worker about being sick; children can be mean to other children and make fun of them and we do not want anyone being mean to you.*
- *It is important to keep information about your body and your illness to yourself. This is private information and should only be talked about with your healthcare workers and your family.*
- *Children can make fun of you or treat you badly if they find out private things about you. It is important to keep information about your body, your illness and your medicine private.*

Stigma and discrimination of children living with HIV occurs on many levels. As healthcare workers, it is important to be aware of these potential areas and to help caregivers assist children in overcoming these obstacles:

- **Discrimination in the household:** Withholding of food, requiring use of separate utensils, requiring extra work (possibly prostitution) to “earn their keep” can be detrimental to children’s psychological health. Discrimination within the household is the most easily hidden and the most difficult to address. Healthcare workers should review the basics of HIV transmission with caregivers and review children’s daily habits to ensure they are not facing such discrimination. Healthcare workers can also observe the interaction between the child and caregiver within the clinic for clues about behaviours at home
- **Discrimination in schools:** In South Africa, the national policy to prohibit discrimination among learners and educators is poorly enforced. Many children fear bullying. Even if they do not disclose their status, being seen taking medication can lead to disclosure. This may have a particularly difficult effect on adolescents who are especially sensitive to social stigma. Healthcare workers should regularly ask the family about any discrimination experienced in school and make referrals to support groups, if possible.
- **Discrimination in the community:** Being a member of a church or participating in community youth groups are an integral part of life for many children. However, in some cases church or community leaders may not allow participation by persons who are living with HIV. Stigma experienced in the community is difficult to combat. However, if key leaders in the community are educated and informed, changes in community-wide attitudes are more likely to occur. While it may not be the role of the healthcare workers to become change agents, they can model acceptance and tolerance in the communities in which they live, improving the chances that changes in attitudes may occur.

## OVERVIEW OF THE DISCLOSURE PROCESS FOR CHILDREN LIVING WITH HIV

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The disclosure process can be seen as having three parts or phases that include pre-disclosure, initial disclosure discussions and ongoing disclosure and support.

1. The **pre-disclosure phase** spans from the time when a caregiver learns of his or her child’s HIV infection until the first discussion about disclosure with the child. During this phase caregivers learn to accept their child’s HIV status and, eventually, prepare and plan for disclosure of HIV status to the child.
2. The **disclosure discussion phase** begins with the first conscious discussion with the child about his or her illness, treatment and care (partial disclosure discussions). In some references, this phase may refer to the initial disclosure “event”, when the child is told he or she has HIV infection (full disclosure). This phase may require many discussions over time so the child understands what he or she is being told and is able to receive support.
3. The **ongoing disclosure and support phase** is a permanent part of the chronically ill child’s care. As the child ages and develops or his or her family or clinical status changes, disclosure needs will change and the child will need continued education and further support with psychosocial issues related to his or her illness.

While the process of disclosure in general covers three main phases, each case is individual and unique because of the many factors that influence a child’s and caregiver’s

life. In addition, the phases of the disclosure process should be tailored to the child’s age and developmental stage.

For those who use the Stages of Change model for medication adherence work, it may be helpful to consider the analogies between that model and the phases of the disclosure process (see Table 6.4).<sup>xv</sup>

**Table 6.4: Similarities between Stages of Change of Phases of Disclosure**

Stages of Change	Phases of the Disclosure Process
Pre-contemplation stage	Pre-disclosure phase: Period of secrecy, not thinking or talking about disclosure
Contemplation	Pre-disclosure phase: Exploratory period when caregivers engage in discussion about disclosure with healthcare workers or family/friends and are guided in activities to empower them for disclosure.
Readiness	Pre-disclosure phase: Developing an action plan for disclosure
Action	Disclosure discussion phase
Maintenance	Ongoing disclosure and support phase



## SESSION 6.3: PRE-DISCLOSURE PHASE



### SESSION DURATION

2 hours 30 minutes (150 minutes)



### SESSION LEARNING OBJECTIVES

- Discuss the role of the healthcare worker in facilitating the three stages of the pre-disclosure phase.
- Discuss how to support caregivers to move to the next stage/phase of readiness to disclose.

## HEALTHCARE TEAM'S ROLE IN SUPPORTING DISCLOSURE

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The role of the healthcare team, as opposed to an individual healthcare worker, has already been noted. Before exploring the phases of disclosure, this session will first consider the role of the team in the overall disclosure process.

To ensure all healthcare workers in a facility actively and effectively participate as a team in the disclosure process, it is important for each one of them to define and discuss their roles. The following exercise is a first step in facilitating the process of assigning team roles, and may serve as a guide for participants to begin discussions once they return to their own sites.

<b>Exercise 3: Role of the healthcare team in disclosure</b> <b>Large group discussion: participants stay in large group</b>	
<b>Purpose</b>	<ul style="list-style-type: none"><li>• To encourage participants to think through how disclosure works in their clinics and the role of each member of the multidisciplinary healthcare team in the disclosure process.</li></ul>
<b>Duration</b>	20 minutes
<b>Introduction</b>	<ul style="list-style-type: none"><li>• As a large group, participants will be asked multiple questions to guide discussion about how disclosure works in their own clinical setting and how to make it more supportive. Key points from the discussion will be posted on the flipchart.</li></ul>

## **PRE-DISCLOSURE**

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When roles have been assigned and healthcare workers understand their responsibilities in the disclosure process, they are then ready to engage caregivers and their families in the pre-disclosure phase. The pre-disclosure phase is divided into the pre-contemplation, contemplation and readiness stages. Each of these stages is discussed below.

### **I. PRE-DISCLOSURE: PRE-CONTEMPLATION**

When children are diagnosed with HIV infection as infants or toddlers, the issue of disclosing diagnosis to the child is usually not an immediate concern. As time passes and the child reaches pre-school age (3–5 years), healthcare workers will need to initiate discussions with caregivers about talking with their child about health and illness.

Healthcare workers can help caregivers during the pre-contemplation stage by:

- Not insisting that they tell the child right away, but rather showing compassionate understanding
- Assuring caregiver of confidentiality as he or she adjusts to and accept their child's HIV diagnosis
- Creating an accepting and supportive environment that provides a safe space for the caregiver to talk about HIV and allowing them to share their fears and anxieties about the diagnosis
- Supporting caregivers to address their fears and concerns
- Answering questions

The content of this session is also discussed later, in the section entitled “Guidelines for preparing, educating and planning disclosure”.

### **PRE-CONTEMPLATION AND PARENTAL BARRIERS**

Some caregivers may decide not to talk about HIV with their children when they first learn of their child's diagnosis. The reasons to maintain silence around the child's diagnosis are numerous: fear of stigma, cultural traditions that discourage discussing important issues with children, or norms that indicate it is the role of the father to determine whether important issues will be discussed with the child.

Some caregivers may experience feelings of guilt or shame about their child's HIV diagnosis. This guilt can also present as a barrier to initiating the disclosure process. In the context of perinatal HIV transmission, some parents may blame themselves for their child's illness and may harbour negative thoughts about their worth as a person or a parent. Acceptance and support by healthcare workers can open up communication and help parents and caregivers deal with negative feelings.

### **Helping parents deal with guilt**

Healthcare workers can help parents deal with the shame or guilt of passing on HIV to their children by encouraging them to:

1. Understand that they should not blame themselves for getting HIV.
2. Take care of themselves. Now that they know they have HIV, they are able to take action — for example, go to the clinic regularly, take medication when they are supposed to — that will help them to lead a healthier life. Taking specific actions to improve their health will reduce the sense of powerlessness that may accompany feelings of guilt.
3. Model positive living for their children. Parents who live a healthy lifestyle also model healthy behaviours for their children. Healthy behaviours reflect a positive attitude towards life, thereby encouraging children to also see life with optimism.

By assessing barriers to disclosure and beginning to address them, healthcare workers can assist caregivers to move from a period of silence to a stage where they begin to explore the issue of disclosing to their child. During this time, it is important to identify cultural norms that may influence caregivers' perspectives about talking with their child or that may influence decision-making within the family.

## **2. PRE-DISCLOSURE: CONTEMPLATION**

In the contemplation stage, the caregiver may become more willing to talk about the issue of disclosure and less guarded about secrecy. Caregivers may begin to ask the healthcare worker about how to open up discussions about disclosure with the child. They may begin to feel comfortable telling the child about their need for clinic visits and tests, but perhaps may not be ready to disclose specifics about HIV.

During this time, healthcare workers help caregivers understand the benefits of disclosure and continue to assess and address barriers to the disclosure process. When possible, it can be helpful to encourage caregivers to talk to others who are in a similar situation, perhaps through peer support groups.

## **3. PRE-DISCLOSURE: READY FOR ACTION**

In this stage, the caregiver begins to actively plan discussions about disclosure and may seek direct advice from the healthcare worker on how to do so. The healthcare worker should provide the caregiver with tools and strategies to assist with disclosure, based on the child's age and developmental level, and guide the caregiver on whether partial or full disclosure discussions would be most appropriate.

## **ASSESSING READINESS FOR DISCLOSURE**

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The healthcare worker, in conjunction with the caregiver, should evaluate readiness for disclosure. Table 6.5 lists characteristics at each of the pre-disclosure stages in terms of readiness to disclose. Suggestions are also offered on how the healthcare worker can assist with the process of preparing the caregiver for disclosure.

The healthcare worker may open up the discussion of disclosure by asking, “How are you feeling about disclosing to your child?” or “What have you thought about telling your child about HIV?” Asking open-ended questions such as these will encourage the caregiver to respond honestly.

**Table 6.5: Assessing the caregiver’s readiness**

✓	Characteristics	Suggestions to encourage movement to the next stage
<b>Pre-contemplation</b>		
	Caregiver has never brought up the issue of disclosure.	<ul style="list-style-type: none"> <li>• Listen to the caregiver’s concerns.</li> <li>• Explore barriers to discussion of disclosure.</li> <li>• Do not try to force change.</li> <li>• Bring up issues without judgement so that caregiver feels comfortable in bringing up difficult issues.</li> <li>• If caregiver tries to put all of the responsibility onto the healthcare worker, the healthcare worker should gently remind the caregiver that he/she will be there to help throughout the process.</li> </ul>
	Caregiver may have thought of the issue, but is unsure how to approach it.	
	Caregiver feels the process may be too overwhelming for self or child.	
	Caregiver expresses reluctance to bring up the issue with child or says that there is no need to do so.	
	Efforts to bring up the issue with the caregiver are met with resistance.	
	Caregiver may try to place responsibility for the process onto someone else or the healthcare worker.	
<b>Contemplation</b>		
	Caregiver accepts that disclosure should occur but brings up issues that will make disclosure difficult.	<ul style="list-style-type: none"> <li>• Offer a supportive environment where the caregiver feels comfortable exploring options</li> <li>• Do not attempt to use blame or guilt</li> <li>• If the caregiver has indefinite plans, assist the caregiver with some specifics (e.g., opening statements for initiating the discussion, specific time/place when discussion might begin)</li> <li>• Give the caregiver time to think and slowly move to the next step</li> </ul>
	Caregiver may understand how to begin disclosure discussion, but is unwilling to do so.	
	Caregiver may have indefinite plans about “someday” starting the disclosure discussion.	
	At the end of this stage, there may be a greater sense of anxiety about the process, compared to the earlier stage.	
<b>Ready for action</b>		
	Caregiver may want to discuss the various options and methods for how to begin the disclosure discussion.	<ul style="list-style-type: none"> <li>• Although the caregiver may have made the decision to begin disclosure process, he/she may still be unsure, and may need encouragement and support from the healthcare worker.</li> </ul>
	Caregiver may want/need more specific	

	information about HIV.	<ul style="list-style-type: none"> <li>• Encourage and praise early efforts.</li> <li>• Educate caregivers about medical aspects of HIV.</li> <li>• Assist in problem-solving and in coming up with alternative approaches if first attempts do not go well.</li> <li>• Caregiver should be made to feel that he/she is the one who will determine when and how the disclosure process will proceed.</li> </ul>
	Caregiver may have a plan for how to begin the discussion with child.	
	Caregiver may have started setting up the groundwork for discussion with child (e.g. remembering past questions the child may have asked, and thinking about how to respond).	
	Caregiver may initiate some action, as a test, to try to better understand how the process will proceed.	

This checklist provides a guide to help healthcare workers assess the caregiver’s stage of readiness. By ticking the characteristic(s) that describe the caregiver, the healthcare worker will have an idea of which stage the caregiver’s thoughts and actions most represent. The caregiver may show evidence or signs of being in more than one stage. The most important point is that the healthcare worker should address each of the caregiver’s concerns and help move the caregiver along the process.

Once the stage has been determined — pre-contemplation, contemplation, ready for action — the healthcare worker should find out how the caregiver’s environment will affect the process of disclosure.

Table 6.6 lists questions to help the healthcare worker understand child, family and community factors that may help or hinder the disclosure process.

**Table 6.6: Questions to evaluate caregiver readiness to disclose**

<b>Is the child ready for disclosure?</b>
<ul style="list-style-type: none"> <li>• Is the child symptomatic, is the child taking medication?</li> <li>• Is the child developmentally able to understand what will be explained, or developmentally delayed?</li> <li>• Is the child asking about HIV?</li> <li>• Does the child seem distressed, anxious or worried?</li> <li>• Has HIV been discussed with the child in school? By peers or other adults?</li> <li>• Is the child sexually active? Or thinking about engaging in sex?</li> </ul>
<b>Is the family ready for disclosure?</b>
<ul style="list-style-type: none"> <li>• Are there other family members in the household who have HIV? Who knows this?</li> <li>• Are there other children in the family? Do they have HIV? Who knows?</li> <li>• Are other family members taking HIV medications?</li> <li>• Does the family function well together? Are there family problems, divorce, separation, conflicts, extended family, in-laws to deal with?</li> <li>• Is there a possibility of violence or abandonment if HIV status is disclosed?</li> <li>• Are there substance abuse issues? Or mental health problems?</li> </ul>

### Community considerations regarding disclosure:

- Are there people in the community who are open about their own HIV status?
- Does the child know anyone in the community with HIV? How is this person regarded in the community?
- How strong is stigma in the community? Are there risks to the family e.g., isolation or discrimination, if disclosure should occur by accident?
- Are there support groups for persons living with HIV (PLHIV)?
- Are there resources within the community for children — a youth group and/or trusted adults that they can talk to?

Answers to the questions in Table 6.5 and

Table 6.6 can help the healthcare worker and the caregiver identify level of readiness for disclosure. If the answers to these questions indicate disclosure is not yet appropriate, review Table 6.5 and give thought to the next steps. The healthcare worker, together with the caregiver, should put together a plan for moving toward greater readiness for disclosure.

### WHAT TO DO IF CAREGIVER, CHILD OR FAMILY IS NOT READY FOR DISCLOSURE

Sometimes one family member is ready to begin the disclosure process, but another is not. If the caregiver is the family member ready for disclosure, then he or she and the healthcare worker can work out a plan to increase readiness among others.

If the child is not ready, the caregiver and healthcare worker may be able to determine the reasons:

- **Is the child not yet mature enough to understand the information?** If the child is not yet mature enough to understand or cope with knowledge of having HIV, partial disclosure discussions may be initiated. The healthcare worker may suggest giving information to the child a bit at a time, using words that the child can accept, to allow the child time to understand the information.
- **Is the child emotionally unprepared to hear the news?** If the child appears to be emotionally unprepared, the healthcare worker may suggest that the caregiver create an open environment for the child, letting the child know that both caregiver and healthcare worker are available to answer questions and encouraging questions if the child seems somewhat hesitant.
- **Does the child appear fearful of hearing such information?** If the child appears fearful, it may be that he or she has overheard conversations and understands only a part of what has been heard. In this case, the healthcare worker should discuss with the caregiver how to encourage the child to ask questions. With children, it is also useful to encourage them to speak or ask questions of other trusted adults, with whom they may feel more comfortable.

If the family or community situation is such that disclosure is not currently an option, the healthcare worker may assist the caregiver in determining which factors are within their control to change and which are not. The safety of the caregiver, infected child and other children in the household, as well as their need for continuing source of livelihood, are vitally important. If any of these are at stake, careful consideration should be given before full disclosure discussions are initiated.

**Exercise 4: Determining the caregiver's stage of readiness**  
**Small group work: participants break into at least three groups**

<b>Purpose</b>	<ul style="list-style-type: none"> <li>To give participants practice in determining caregiver's stage of readiness to disclose to his or her child</li> </ul>
<b>Duration</b>	45 minutes
<b>Introduction</b>	<ul style="list-style-type: none"> <li>Participants will be divided into at least three groups. Each group should select one person who will act as the healthcare worker, and one who will act as the caregiver.</li> <li>The role of the healthcare worker will be to determine in which stage of pre-disclosure the caregiver is (Table 6.5 is available as a guide). The remaining members of the group will be observing and also trying to determine which stage the caregiver is in.</li> <li>When asked questions by the healthcare worker, each caregiver will role play at least three characteristics of the stage he or she has been assigned. In addition, the caregiver should pick one of characteristics in the each of the other two stages, to try to confuse the healthcare worker a bit. So, for example, if the caregiver has been assigned to the ready for action stage, he or she will choose three characteristics of that stage, as well as one from pre-contemplation and one from contemplation.</li> <li>Participants will have ten minutes for the role plays and an additional ten minutes for each group to try to determine which stage the caregiver was in.</li> <li>Participants will reconvene in the large group and discuss how they felt the process went, with a focus on challenges.</li> </ul>

## **GUIDELINES FOR PREPARING, EDUCATING AND PLANNING DISCLOSURE**

Supporting the caregiver with disclosure process begins at the first clinic visit. At that visit the healthcare worker establishes a relationship with the child and caregiver and assesses their needs. The first visit or visits will provide opportunity for the healthcare worker to:

- Build trust by getting to know the caregiver; find out what HIV means to him or her.
- Assess the caregiver's psychosocial situation and ability to cope; answer questions and establish their sources of support.
- Use age-appropriate communication with the child and model effective communication for the caregiver.
- Discuss the implications of full disclosure with the caregiver and the family to help them consider in advance the reactions of the child, family members, friends, and teachers. Assist the caregiver to decide whether partial or full disclosure is appropriate at this time.
- Help the caregiver develop a plan of disclosure for the child. This will cover any preparations he or she needs to make before disclosure, what will be said, how and where the discussions on disclosure will be initiated, the level of disclosure (partial or

full) and plans for ongoing support. Knowing this information will help the healthcare worker more effectively assist the caregiver through the process.

- Arrange to see the caregiver (and the child) again — at a date and time agreed to by both of you — to review this process.
- Remember, if the caregiver is not ready to disclose, the process cannot be forced. Continue to work with the caregiver to help him or her become ready to disclose.

The questions and healthcare worker actions outlined in Table 6.7 can be used to address caregiver support needs as they prepare for disclosure. By educating caregivers, helping them plan for disclosure and ongoing follow-up, healthcare workers empower caregivers to move from the pre-disclosure ready for action stage to the disclosure discussion phase. Note that this process requires give and take among healthcare worker, caregiver and child. Each situation is unique and the healthcare worker should be prepared to tailor recommendations and support for each family situation.

**Table 6.7: Caregiver support in preparation for disclosure**

<b>1. Educating and preparing caregivers</b>
<ul style="list-style-type: none"> <li>• What do you think is important to communicate to the child?</li> <li>• What do you think will be the hardest part of the disclosure process?</li> <li>• What do you think will be the hardest questions to answer? <ul style="list-style-type: none"> <li>• Acknowledge that disclosure is difficult.</li> </ul> </li> <li>• What are your feelings about their child’s health (address any guilt or shame)? <ul style="list-style-type: none"> <li>• Affirm the caregiver’s commitment to disclosing to the child.</li> <li>• Answer the caregiver’s questions about paediatric HIV.</li> <li>• Help caregivers anticipate the child’s questions and responses.</li> <li>• Plan how the child will receive support after disclosure.</li> </ul> </li> </ul>
<b>2. Helping caregivers plan for disclosure</b>
<ul style="list-style-type: none"> <li>• When and where will disclosure discussions start?</li> <li>• Will the disclosure discussions involve full or partial disclosure?</li> <li>• Who will lead the discussion? (If not the caregiver, What is this person’s relationship to the child?)</li> <li>• Will there be other people involved, for example if the child becomes angry and withdrawn or has questions that the caregiver may have trouble answering?</li> <li>• How will you/they start the conversation?</li> <li>• How will you/they provide support to the child after disclosure?</li> <li>• What anxieties do you have and what can help reduce this anxiety?</li> <li>• How might disclosure impact family members, friends, school, and community members?</li> <li>• What support do you/your family need?</li> </ul>
<b>3. Planning ongoing follow-up and support</b>
<ul style="list-style-type: none"> <li>• What support do you need to make sure that you have the opportunity to talk about the process and feelings?</li> <li>• Who does the child have to talk with if he or she has questions?</li> <li>• When shall we meet again?</li> <li>• What are your next steps to support your child to live positively with HIV (i.e. live a healthy life — eat well, take medicine, take exercise, drink safe water, etc.)?</li> <li>• To whom are you planning to disclose to next?</li> </ul>
(Steps 2 and 3 will be brought up again in Sessions 6.4 and 6.5)

**Exercise 5: Role of the healthcare worker in disclosure**  
**Small group discussion: participants break into groups of three**

<b>Purpose</b>	<ul style="list-style-type: none"> <li>To encourage participants to think through difficult situations they may face in paediatric disclosure</li> </ul>
<b>Duration</b>	25 minutes
<b>Introduction</b>	<ul style="list-style-type: none"> <li>Participants will break into groups of three and will be assigned one of four questions.</li> <li>Each group will have ten minutes to record their answers on flipchart paper.</li> <li>One member of each group will report responses, starting with the first question. If second group was assigned the same question, they will share how their discussion agreed or differed from the first group.</li> <li>After the groups have discussed the first question, follow the same procedure for the remaining three questions.</li> </ul>

## **GETTING READY FOR DISCLOSURE: CHECKLIST, TIPS AND TOOLS TO ASSIST CAREGIVERS**

In addition to the child, family and community readiness assessment questions (see

Table 6.6: Questions to evaluate caregiver readiness to disclose), the checklist below can help to assess if the caregiver is prepared to move forward with actual disclosure.

**Table 6.8: Checklist to evaluate caregiver preparedness to disclose**

✓	Question
<b>1. Is the caregiver trusted by the child?</b>	
	<ul style="list-style-type: none"> <li>If <b>yes</b>, proceed to the next step.</li> <li>If <b>no</b>, identify a trusted person who could disclose to the child. You, the healthcare worker, may be a trusted source, however, try to identify a family member or friend who might more appropriately disclose.</li> </ul>
<b>2. Does the caregiver fully agree that disclosure to the child is necessary?</b>	
	<ul style="list-style-type: none"> <li>If <b>yes</b>, proceed to the next step.</li> <li>If <b>no</b>, review the reasons disclosure to children is important and ask probing questions to identify what, in particular, is keeping the caregiver from moving forward (this might be guilt, fear, etc.). Remind caregiver that disclosure is not a one-time event, but rather that the conversation can begin with general discussions about the child's health. Discussions specifically about HIV may not occur for months or years after the initial discussions about health.</li> </ul>
<b>3. Has the caregiver decided on either partial or full disclosure to the child? If partial, is there a plan for full disclosure?</b>	
	<ul style="list-style-type: none"> <li>If <b>yes</b>, proceed to the next step.</li> <li>If <b>no</b>, encourage the caregiver to identify when disclosure about the child's</li> </ul>

	status will occur.
<b>4. Is the caregiver (and others involved in the disclosure process) prepared with developmentally appropriate information about HIV in response to the child's questions?</b>	
	<ul style="list-style-type: none"> <li>• If <b>yes</b>, proceed to the next step.</li> <li>• If <b>no</b>, review key elements of child development, discuss possible questions and model answers (see Table 6.1: Guidance for sharing developmentally appropriate HIV information).</li> </ul>
<b>5. Has the caregiver identified a comfortable and familiar place to disclose to the child and prepared what he or she will say?</b>	
	<ul style="list-style-type: none"> <li>• If <b>yes</b>, proceed to the next step.</li> <li>• If <b>no</b>, ask the caregiver to identify his or her plans and assist, if necessary, with what could be said.</li> </ul>
<b>6. Has the caregiver identified who else will know of the child's HIV status (teacher, other family members, etc.)?</b>	
	<ul style="list-style-type: none"> <li>• If <b>yes</b>, proceed to the next step.</li> <li>• If <b>no</b>, ask caregiver to consider who else will know this information and how that might impact the child. Have them create a plan for additional disclosure and prepare for questions.</li> </ul>
<b>7. Is the caregiver prepared to help the child address possible stigma that the child might experience?</b>	
	<ul style="list-style-type: none"> <li>• If <b>yes</b>, proceed to the next step.</li> <li>• If <b>no</b>, review ways to deal with stigma, such as finding a support group for the child, or identifying someone with whom the child can discuss his or her feelings.</li> </ul>
<b>8. Has the caregiver identified particular tools (drawing, storytelling, drama, etc.) to use with the child to identify his or her feelings and questions?</b>	
	<ul style="list-style-type: none"> <li>• If <b>yes</b>, proceed to the next step.</li> <li>• If <b>no</b>, review tools from the tool box in Table 6.9.</li> </ul>
<b>9. Does the caregiver acknowledge that disclosure is a process and not a one-time event? Is there a plan to follow up with the caregiver and the child?</b>	
	<ul style="list-style-type: none"> <li>• If <b>yes</b>, proceed to the next step.</li> <li>• If <b>no</b>, review the need to continuously monitor the child's feelings and answer questions as needed. Make a plan to follow up with the caregiver at a mutually convenient time.</li> </ul>
<b>10. Do the caregiver and the child have access to support services post-disclosure?</b>	
	<ul style="list-style-type: none"> <li>• If <b>yes</b>, proceed with disclosure.</li> <li>• If <b>no</b>, assist the caregiver in identifying a support network for comfort, advice and questions. This may involve you, the healthcare worker, but should not be only you.</li> </ul>

### **Tips for Healthcare Workers and Caregivers on Talking to Children**

- When talking with children, adults should be at the same eye level (such as sitting on the floor together).
- Make sure there is privacy.
- Listen to the child, and show that you are listening.
- See what concerns the child has before giving information. Focus on answering the child’s question and avoid giving “extra” information the child may not be ready for.
- Reassure the child that he or she has not done anything wrong.
- Allow children time to talk without being interrupted.
- Use stories, play and drawing to help learn how the child is feeling (see the tool box in Table 6.9).
- Always give children correct information — never lie.
- Help children understand their choices and empower them to make decisions.
- Remind children that they can come to you any time to talk or ask questions.

When talking with caregivers about increasing communication with the child, healthcare workers should provide a range of options that fit into the natural environment of the caregiver. For example, if the caregiver does not normally play with the child or draw with the child, recommending these methods might alert the child that something is different about the situation, and may make them suspicious of what is to follow. If it is more natural for the caregiver to talk to the child while doing household chores, or telling stories after the evening meal, these opportunities should be used to initiate discussion with the child, as they are a natural extension of what is normal for the child.

Encourage caregivers to experiment with new ways to spend time with their children and create opportunities for communication. If a caregiver, for example, wants to draw with his or her child or work with her children to create a drama presentation for other family members, give the caregiver tips to get going. An initial foray into a new activity should not be centred on HIV or disclosure of HIV status; instead its purpose should be to spend time together. Because disclosure is an ongoing process, integrating a discussion about health and later about HIV, while drawing for example, will occur over a period of weeks or months. The discussion will then seem to be a natural part of what the caregiver has already shared prior to the disclosure discussions. Table 6.9 offers ideas to facilitate communication within families.

**Table 6.9: Ideas to encourage communication between caregiver and child**

<b>Joining</b>
Form a good relationship with children by talking about things that are easy for them to discuss with you. For example, for children under age five — sit at the child’s level and find a game they like to play. For children 6–12 years of age — find a fun activity to do together, such as reading, jumping rope, playing ball, cooking/preparing a favourite food, discussing a magazine or an interesting object. For children 13 and over — find out about their interests (sports, music, etc.) and their likes and dislikes, go to the market or a local football match together, ask specific questions about school, friends, hobbies (avoid general questions such as “How was school today” because the response is likely to be a single word); try asking about a particular class, or how a friend reacted to a certain situation, or their favourite song.
<b>Storytelling</b>

Listening to a story about someone in a similar position can be comforting to children; it gives them a sense of feeling understood and that they are not alone. When using storytelling, it is helpful to use a familiar story or folktale to convey a message to a child; for young children you may want to use animals to represent humans. Avoid using real names or events. At the end of a story, encourage the child to talk about what happened. Alternatively, you could ask a child to make up a story about a topic you give them, for example, “Tell me a story about a child who was very sad”. For an older child or adolescent, describe a situation a peer may have faced, or find another peer who may be willing to share his or her story.

### **Drawing**

Allows children to identify their thoughts without saying them. Provide pencils, crayons, paper, etc. and ask the child to draw something related to what you would like to explore, for example, “Draw a picture of something that makes you angry”. Ask the child to explain what is happening in his or her drawing and use open-ended questions about what he or she has drawn, for example, “How do the people in the drawing feel about what is happening?” For older children or adolescents, ask them to draw a picture of themselves within their family or community. Ask questions about how and why they see themselves that way.

### **Drama**

This is a good way for children (and friends or other family members) to discuss issues indirectly. When using drama as a tool, give the children a topic to perform — such as “a day in my life”— related to the issue you want to explore. After the performance, encourage the child to discuss what happened and ask open-ended questions to explore specific areas, such as, “What was the saddest/happiest part of the day?”



## SESSION 6.4: BEGINNING THE DISCLOSURE DISCUSSION



### SESSION DURATION

2 hours (120 minutes)



### SESSION LEARNING OBJECTIVE

- Review and practise age and developmentally appropriate approaches to disclose HIV status to children.

## PLANNING TO BEGIN DISCUSSIONS ON DISCLOSURE

Review the following questions and guidance with the caregiver to help him or her begin discussions with the child (note that the questions are from Table 6.7):

**Table 6.10: Questions and guidance to support planning for disclosure**

Planning for disclosure
<ul style="list-style-type: none"><li>• When and where will disclosure discussions start?<ul style="list-style-type: none"><li>• Ideally when the child is in a comfortable place, such as the home.</li><li>• Start by doing something that caregiver normally does with the child, such as playing with the child, or talking about the child's day.</li></ul></li><li>• Will the disclosure discussions involve full or partial disclosure?<ul style="list-style-type: none"><li>• Making this decision will depend on the age of the child and developmental level as well as the readiness of the caregiver.</li></ul></li><li>• Who will lead the discussion? (If not the caregiver, What is this person's relationship to the child?)<ul style="list-style-type: none"><li>• The discussion should be with the caregiver, with or without the assistance of a healthcare worker, or with another trusted adult. In theory, the caregiver will <b>lead</b> the discussion, occasionally the caregiver will prefer to defer lead to another trusted adult.</li></ul></li><li>• Will there be other people involved, for example if the child becomes angry and withdrawn or has questions that the caregiver may have trouble answering?<ul style="list-style-type: none"><li>• Inform a trusted family member or friend about the disclosure discussion so that the child will have someone to whom he or she can confide after the meeting.</li></ul></li><li>• How will you/they start the conversation?<ul style="list-style-type: none"><li>• The first few conversations should be about general things related to health, clinic visits, medication, etc., NOT about HIV specifically.</li><li>• The caregiver may start out by asking the child if he or she has any questions about health, medications, etc.</li></ul></li><li>• How will you/they provide support to the child after disclosure?</li></ul>

- Let the child know of the “safe” people he or she can talk to if there are questions or need to talk about the illness.
- What anxieties do you have and what can help reduce this anxiety?
  - The healthcare worker may assist by linking the caregiver to support organisations or to other caregivers who are experiencing the same issues.
- How might disclosure impact family members, friends, school, and community members?
  - The healthcare worker should introduce this topic before the initiation of discussions with the child if the caregiver does not.
- What support do you/your family need?
  - Provide the family with referrals to organisations that can provide support, if available. Introduce the caregiver to other caregivers of HIV-infected children (assuming they have given permission) to foster peer support.

More specific guidance on partial, full and post-disclosure is provided in the disclosure flipchart. The flipchart includes objectives and a script for healthcare workers who are educating caregivers about disclosing to children.

<b>Exercise 6: Disclosure case study review</b> <b>Large group discussion: participants stay in large group</b>	
<b>Purpose</b>	<ul style="list-style-type: none"> <li>• To review a disclosure dialogue and discuss reactions. <b>This story is adapted from a book called “How Can I Tell You?” by Mary Tasker.</b> The story is not from this country, however, it has been adapted for South Africa.</li> </ul>
<b>Duration</b>	30 minutes
<b>Introduction</b>	<ul style="list-style-type: none"> <li>• In this exercise participants will be role playing paediatric disclosure based on the story about Thuli.</li> <li>• Volunteers will read the introduction and the roles of Thuli, Anne and the lay counsellor in the story.</li> <li>• Afterward, participants will discuss the story.</li> </ul>

**The Story of Thuli**

Anne, the mother of nine-year-old Thuli, made an appointment with the nurse to discuss Thuli’s questions regarding her illness and treatment. Anne said she believed Thuli had some suspicions about her diagnosis, but she was still unsure about whether she was ready to reveal it. By their next session, Anne reported that Thuli had begun to talk more openly about her illness and treatment, and that questions about why she came to the clinic and why she got sick so often were increasing. Anne, until then, had told Thuli that she had “a special illness that makes your body weak so it is not easy for you to fight germs”.

Thuli began to reveal the many concerns she had about her illness through her behaviour — she became more quiet than usual and would not play with her friends. After many sessions, Anne decided that she wanted help from a counsellor to disclose Thuli’s diagnosis to her. A meeting with the mother, the child, and a counsellor was arranged. On the appointed day, they met together in a small consultation room at the clinic.

**Anne:** “You know how Mummy always likes to tell you what is going to happen when you come to the clinic?”

**Thuli:** “Am I going to take a test? Will you help me to hold still?”

**Counsellor:** “No test today. We want to talk to you about why you have to come to the clinic, but we think you already have some ideas. Do you?”

**Thuli:** “It is because my body needs to get stronger. It is not good at fighting germs.”

**Anne:** “That is right. It is because you have a virus. It is called HIV. Do you know what it is?”

**Thuli:** “Is it about AIDS?”

(Anne appears to be very emotional and has difficulty responding. She looks to the counsellor to give assistance.)

**Counsellor:** “Yes, HIV is a virus and some people call it the AIDS virus. Did you already have some ideas about it?”

**Thuli:** “Yes. I heard Mummy talking on the phone about it. Mummy thought I was asleep.”

**Counsellor:** “You have been keeping this secret for some time then. Has it been worrying you?”

**Thuli:** “Well, sometimes. Does it mean I will have to go into the hospital and miss school?”

**Anne:** “Oh! I think we are going to help you to keep very healthy.”

**Counsellor:** “We hope you won’t ever need to be in hospital, but, if you do, your mother will try to arrange to get your school work and maybe you would be able to meet with some of the other children who are there.”

Thuli then asked if she could go and join some other children in the playroom. She left the room.

The following exercise is designed to provide practice using the developmental stage information in discussions with children and adolescents. While in reality, you as the healthcare worker may not be the one to disclose to the child, this practice will help you to better guide caregivers.

**Exercise 7: Applying a developmental approach to disclosure**  
**Small group work: participants break into three groups**

<b>Purpose</b>	<ul style="list-style-type: none"> <li>To think about disclosure in terms of a child's age and developmental stage and to focus on the need to have ongoing conversations with the child.</li> </ul>
<b>Duration</b>	60 minutes
<b>Introduction</b>	<ul style="list-style-type: none"> <li>Participants will be divided into three small groups. Each group should select a healthcare worker and a caregiver. Each group will be assigned one of the following children who are at different stages of development (see the case studies below).</li> <li>There will be three different conversations with the child. The healthcare worker should advise the caregiver how to approach the child and speak to him or her about what information is appropriate to share with the child in the first conversation, when information about general health can be passed on, in the second conversation, when the caregiver can be a bit more specific about health issues, and the third conversation, when HIV is discussed.</li> <li>Each group will select a rapporteur and other members of the group should assist the participant role playing the healthcare worker in coming up with ideas for what to discuss at the various stages of disclosure.</li> <li>After 20 minutes, participants will re-convene as a large group and discuss their conversations and review key points.</li> </ul>

**Exercise 7: Disclosure case studies**

**Case Study 1: Lefu**

Lefu is a five-year-old female who lives with her grandmother, Mpho. Lefu has been enrolled in HIV care and treatment for the last year and has been doing well, with good growth for age, no major illness and has reached all of the developmental milestones for a girl her age. Mpho comes to the clinic and tells you that she has had trouble giving Lefu her medication lately. She does not know what to do because she has always taken it quite easily in the past. Now, Lefu is running from Mpho when it is time to take the medication. She closes her mouth tight and shakes her head. Lefu wants to know why she always has to take the bad-tasting medicine. Mpho has to hold the child down and force open her mouth to take the medication. About half the time Lefu gags, chokes and vomits the medicine. Mpho is worried because she knows the medicines are important to keep Lefu alive. Mpho has never told Lefu why she must take the medicine because she thinks Lefu is too young to understand such things.

- Think about how and where you would first approach Lefu. How would you open up the conversation?
- How will you know when Lefu is ready to hear the specifics about HIV?
- How much time do you think should pass between first opening up discussion about her health and finding out about having HIV, given that she is five years old?
- How would talking about her health perhaps help Lefu understand the need to take her medication?

### Case Study 2: Naledi

Naledi is an eight-year-old female who lives with her mother, Zoleka, a sex worker in poor health. Naledi knows that her mother is very sick and feels responsible for her mother's illness because her mother has to work long hours to pay for Naledi's food, clothing and school fees. Naledi herself takes medication "to keep her strong" but she has never been specifically told why she must take it. She takes the medication because her mother asks her to and she wants to make her mother happy. Naledi is very worried about her mother's health and what will become of her if Zoleka dies. After overhearing several conversations that Zoleka has had with the healthcare worker, Naledi is beginning to suspect both she and her mother have HIV and she is worried that she might die as well. Naledi shares none of this with anyone.

- Think about how and where you would first approach Naledi. How would you open up the conversation?
- How will you know when Naledi is ready to hear the specifics about HIV?
- How much time do you think should pass between first opening up discussion about her health and finding out about having HIV, given that she already has an idea of what is going on?
- How would you help to reduce Naledi's concerns about her mother's health and her fears of what will happen to her if her mother dies?

### Case Study 3: Thabo

Thabo is a 13-year-old male who has lived with his maternal aunt (Sisonke, who happens to be a nurse) and uncle since his mother died of AIDS a year ago. He does not know his HIV status, but has been taking medications for many years and is doing well on treatment. He has always been a good student in school and occasionally earned extra money helping out at local construction sites. Recently, however, he has missed two clinic appointments. When the healthcare worker asks how Thabo is doing, Sisonke says she has been growing concerned about Thabo. He has been spending time with a new group of friends and seems uninterested in school all of a sudden. He is also not as cheerful and she has been having difficulty waking him in the morning. He has missed two days of school in the past month because he has been sick and she is not sure if he is taking his medication. When she tried to talk to him, he changed the subject and left the room. She wants to talk to him again, but she has been so busy with work and her own children that she has not had time.

- Think about how and where you would first approach Thabo. How would you open up the conversation?
- How will you know he is ready to hear the specifics about HIV?
- How much time do you think should pass between first opening up discussion about his health and finding out about having HIV, given that he is already a teenager?
- What signs are there now that Thabo suspects something and may be acting out?



## SESSION 6.5: ONGOING DISCLOSURE, CLARIFICATION AND SUPPORT



### SESSION DURATION

1 hour (2 hours with the optional panel presentation)



### SESSION LEARNING OBJECTIVE

- Discuss client support needs after disclosure and how to ensure these needs are met.

## ONGOING FOLLOW-UP

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Disclosure does not begin or end with a single conversation. As children grow and develop, their understanding expands and they have additional questions and new needs that have to be supported. Throughout, healthcare workers should serve as models for approaching disclosure with openness and honesty.

Ongoing follow-up about disclosure should be part of every subsequent clinic visit. The questions in Table 6.11 provide guidance for the ongoing follow-up and support sessions (note that the questions are from Table 6.7) with the caregiver.

**Table 6.11: Questions and guidance for ongoing support**

Planning ongoing follow-up and support
<ul style="list-style-type: none"><li>• What support do you need to make sure that you have the opportunity to talk about the process and feelings?</li><li>• Who does the child have to talk with if he or she has questions?<ul style="list-style-type: none"><li>• Offer support to the child to cope with his or her emotions and feelings after disclosure. Refer to a children's or family support group if possible.</li><li>• If these are not available, the healthcare worker may help to identify another person living with HIV, preferably a young person, or a trusted adult who the child may go to for support or to answer questions.*</li><li>• Make sure the child is given a chance to express his or her feelings — through talking, through role play, or through drawing, for example.</li></ul></li><li>• When shall we meet again?<ul style="list-style-type: none"><li>• Plan for a follow-up counselling session with the child and caregiver at the clinic.</li></ul></li><li>• What are your next steps to support your child to live positively with HIV (i.e. live a healthy life — eat well, take medicine, take exercise, drink safe water, etc.)?<ul style="list-style-type: none"><li>• Focus on steps the child can take to live a long, healthy life.</li><li>• Model good health behaviours and good coping for the child.</li><li>• Healthcare worker may provide ongoing support to strengthen the caregiver's relationship with the child and provide information on how to communicate with the child.</li></ul></li><li>• To whom are you planning to disclose to next?</li></ul>

- Plan for disclosure to others, (other family members, teacher, peers, etc.).

**\* Sites that do not have support groups**

Facilitators may ask the following questions of participants to help them determine what alternatives are possible in their settings.

- What age groups are most in need of support in your facility?
- How can you facilitate support meetings among those who most need it?
  - Caregivers may be supported on a one-to-one basis by other caregivers who have children living with HIV.
  - Younger children may simply need a play group, where they can be around others who are experiencing the same issues.
  - Adolescents may best be supported by a group with a facilitator who is an older adolescent or a young adult.
- What other possibilities would work in your setting? (Encourage the participants who may have experience supporting caregivers and children to share ideas that might be helpful for others in the group.)

## **PSYCHOLOGICAL IMPACT OF DISCLOSURE**

Depending on their age and development, children will react differently to the news of their HIV status, whether they were infected perinatally or acquired HIV another way (e.g., sexual abuse). Many may use denial as a temporary coping mechanism. Anxiety is often the predominant reaction, particularly among primary school aged and adolescent children. As previously discussed, blame, guilt, anger (at themselves or others), fear and shock are potential reactions as well. This can manifest in acting out behaviours and in low self-esteem. Healthcare workers who have children may think about how their own children react to challenging or difficult situations; these reactions may give healthcare workers some ideas about what to expect from children. The following are some of the ways children may react:

- Go quiet
- Be very matter of fact and accept what has been said
- Ask many questions
- Cry
- Be relieved that they can make sense of their experiences
- Want to get on with something else immediately
- Be angry or upset
- Be surprised

As mentioned earlier, healthcare workers should be alert to and share information with the caregiver about “red flag” behaviours that the child may be showing. These may include signs that the child is withdrawing (e.g., becoming more quiet and non-communicative) or is acting out with unacceptable behaviours (e.g., crying/tantrums, engaging in risky sex or drug use). These behaviours may occur before, during or after the child learns about their HIV status. They may occur even if the child has seemingly accepted and is coping well with information about their status.

Healthcare workers should encourage caregivers to notice behaviours that are not “normal” for the child and together come up with a plan to deal with those behaviours. Asking questions, probing and encouraging open discussions with the caregiver are the

best tools the healthcare worker has to learn about the child and encourage disclosure, when appropriate.

Table 6.12 provides guidance on age--appropriate support and counselling for children.

**Table 6.12: Age-appropriate support and counselling topics for children**

<b>Ages 3–5 years</b>
<ul style="list-style-type: none"> <li>• Provide comfort and reassurance</li> <li>• Encourage family involvement and provide family support</li> <li>• Be honest; but provide information in an age appropriate way</li> </ul>
<b>Ages 6–9 years</b>
<ul style="list-style-type: none"> <li>• Provide comfort and reassurance</li> <li>• Encourage family involvement and provide family support</li> <li>• Be honest; but provide information in an age appropriate way</li> <li>• Provide support to adjust to school</li> <li>• Encourage child to make and foster peer relationships</li> <li>• Reassure child that HIV is not his or her fault</li> </ul>
<b>Ages 9–11 years</b>
<ul style="list-style-type: none"> <li>• Provide comfort and reassurance</li> <li>• Encourage family involvement and provide family support</li> <li>• Be honest; but provide information in an age appropriate way</li> <li>• Provide support to adjust to school</li> <li>• Encourage child to make and foster peer relationships</li> <li>• Reassure child that HIV is not his or her fault</li> <li>• Focus on self-esteem and child’s ability to do all or most of what other children can do</li> <li>• Provide adherence support</li> <li>• Reassure the child that he or she is not alone living with HIV; may need a peer support group</li> <li>• Encourage child to identify an adult, older sibling, etc. with whom he or she can share feelings; provide guidance on who is safe to talk to</li> <li>• Inform the child that HIV is a long-term illness; but like other long-term diseases, he or she can learn to live normally with it</li> <li>• Let child know that it is normal to have negative emotions (e.g., anger, worry)</li> <li>• Provide education on coping skills</li> <li>• If possible, assess child six months post-disclosure (earlier if possible) to learn how child is adapting to disclosure</li> </ul>
<b>Ages 12–18 years</b>
<ul style="list-style-type: none"> <li>• Provide comfort and reassurance</li> <li>• Encourage family involvement and provide family support</li> <li>• Be honest; but provide information in an age appropriate way</li> <li>• Provide support to adjust to school</li> <li>• Encourage child to make and foster peer relationships</li> <li>• Reassure child that HIV is not his or her fault</li> <li>• Focus on self-esteem and child’s ability to do all or most of what other children can do</li> <li>• Provide adherence support</li> </ul>

- Reassure the child that he or she is not alone living with HIV; may need a peer support group
- Encourage child to identify an adult, older sibling, etc. with whom he or she can share his or her feelings; provide guidance on who is safe to talk to
- Inform the child that HIV is a long-term illness; but like other long-term diseases, he or she can learn to live normally with it
- Let child know that it is normal to have negative emotions (e.g., anger, worry)
- Provide education on coping skills
- If possible, assess child six months post-disclosure (earlier if possible) to learn how child is adapting to disclosure
- Encourage the child to begin to think more about the future, having a family and relationships
- Inform the caregiver that thinking about the future may increase feelings of depression, worry, wanting to commit suicide
- Provide education on safe sex, alcohol and drugs

Children are excellent observers, but not very good at interpreting. Many children will internalise and feel a sense of responsibility for what is going on around them. Healthcare workers should encourage caregivers to use some of the techniques in Table 6.9 to provide opportunities for children to discuss their feelings and reassure them that they are not to blame.

An important part of helping children to cope with learning their status is to encourage caregivers to strengthen their relationship with the child. This may involve talking more with the child, allowing him or her to ask questions, encouraging him or her to talk about feelings while doing routine things together. Often the caregiver may have other responsibilities, such as work, or taking care of other children, that may make it difficult to spend time with the child living with HIV. In such cases, the healthcare worker should consider suggesting that other trusted adults, for example an aunt, grandmother or older sibling, play the role of listener and advisor to the child. At the same time, however, the healthcare worker should encourage that the caregiver be aware of, and participate as much as possible, in the discussions these other adults have with the child.

Much of the research available suggests that children adapt well, and with time and follow-up counselling, levels of anxiety decrease and family cohesion can be stronger after disclosure. Adolescents require particular attention, however, as their anxiety tends to be higher and last longer. Stories about children living with HIV appear in Appendix 2: The story of Thandi and Musa, and Appendix 3: Brenda has a dragon in her blood. These can be read to children as a means of showing them how disclosure and living with HIV can be managed.

It is important to note that non-disclosure does not protect the child. Levels of anxiety, depression and low self-esteem have been shown to be higher in children who have NOT been disclosed to.

## SPECIFIC ISSUES AMONG CHILDREN WHO HAVE BEEN SEXUALLY ABUSED

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As mentioned in Session 6.2 of this module, children who have been sexually abused have particular needs for support that may differ from children who were perinatally infected. There may be a high level of shame associated with the abuse that may be unknowingly perpetuated by families because of the silence that often surrounds the abuse. This silence may be internalised by children and interpreted to mean that they themselves are to blame for the abuse. Having HIV potentially adds another layer of shame to the experiences of these children. These feelings must be dealt with and discussed in a manner that allows the child to understand that he or she is not to blame.

Children who have been abused are more likely, compared to children who have not been abused, to engage in sexually risky behaviours, to become further victims of abuse or rape and to become abusive towards other children. It is therefore particularly important for these children to receive counselling, for their families to be educated about what to expect and how to manage the behaviours, and for the children to be told repeatedly that the abuse was not their fault. Survivors of abuse also must be made to understand that many of the negative emotions they feel as a result of the abuse are normal. Efforts must be made to help these children to cope with the impact of the abuse.

Among younger children who have been abused and who seem to have learned to cope with the impact, it is important that at developmental transitions, for example at puberty, and when they have their first romantic relationship, that their adjustment is monitored. At these stages of life, children are particularly vulnerable, and memories of the abuse, particularly elements of shame and blame, may resurface.

## FOLLOW-UP AND SUPPORT

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Children need ongoing support to help with issues around anxiety, newly emerging questions about their bodies or their illness, and to help them deal with possible stigma and discrimination. For children who have been sexually abused, follow up counselling is vital for help in dealing with emotions regarding the abuse as well as the HIV infection.

Caregivers also need support to continue to be a resource for children. It is important to schedule a follow-up conversation after the initial disclosure discussion and then make time at every healthcare visit to ask about any physical or psychological problems that either the caregiver or child is facing due to disclosure.

Children's understanding of their illness should also be periodically discussed to be sure they have accurate information and to evaluate how they are handling their illness.

### **At each visit, healthcare workers should discuss:**

For the child:

- **The child's level of understanding of their illness** (by asking questions, e.g.)
  - *Why do you think you take these medications?*

- *What do you know about HIV?*
- **Feelings of guilt/blame/shame**
  - *Why do many people try to keep their HIV status a secret?"* For children who have been abused, it is extremely important that they are told the abuse and subsequent HIV infection was not their fault in any way.
- **Peer support/counselling**
  - *Who else knows about your illness?*
  - *Who else do you talk to about HIV?*
  - *Do you find that helpful?*
- **Daily routines**
- **How much the child participates in his or her own care**
- **Medication adherence**

For the caregiver:

- *What support needs do you have around disclosure or providing information to your child?*
- *Do you need further assistance in disclosing to others in your family?*
- *What other support needs do you have (e.g., group support)?*

The healthcare worker should also make a point of asking if the child or caregiver has any questions and answer them.

## ONGOING SUPPORT

At least three levels of ongoing support are needed for children and families coping with HIV:

- **Support by the healthcare worker/team:** The role of the healthcare team and workers was discussed in Exercise 3 and Exercise 5 as well as throughout this module. It may be helpful, however, to individually review the roles of the healthcare team in disclosure support and assess how successfully caregivers and children are supported in your institution.
- **Support in the household:** As part of ongoing disclosure support, healthcare workers should specifically review the level of support within the household and who within the household or the immediate community knows about the child's illness. It can be extremely burdensome to keep secrets — particularly at home — and helping the caregiver to identify who can provide support will help reduce some of that stress. It is also crucial that discussions be held about when siblings will be told about the HIV status of an infected member. Disclosure to siblings may provide an ongoing and positive source of support for children living with HIV.
- **Support through groups:** Support groups can be a very useful tool for families. In most cases, all that is needed is a group of people with a similar issue and a room for discussion. If possible, healthcare workers should get information about the local sources of support and provide that list to families in need. Where there are no support groups or groups that do not meet the specific needs of families, healthcare workers should consider starting one, if there are enough people interested. See Appendix 4: Guidelines for Starting a Support Group. Support groups for children should be split into groups based on the age of the child, as older children need a different form of support and interaction than younger children. Additionally, healthcare workers could approach caregivers who have successfully been through the disclosure process and encourage them to start a peer group for other caregivers. Healthcare workers may feel more comfortable in doing this once they gain confidence in empowering caregivers during the disclosure process.

Within South Africa, there are a range of resources available for caregivers and children who are living with HIV. One group, Mothers2Mothers (<http://www.m2m.org/>) links mothers who are living with HIV with other mothers who are pregnant and living with HIV to provide guidance, support and mentorship. Lovelife (<http://www.lovelife.org.za>) is another social networking resource, specifically targeted to adolescents, which helps them deal with issues related to HIV and sexual health.

<b>Exercise 8: Impact and follow-up case studies</b> <b>Large group work: participants will work in the large group</b>	
<b>Purpose</b>	<ul style="list-style-type: none"> <li>To gain an understanding of the impact of disclosure as well as the need for follow-up with children</li> </ul>
<b>Duration</b>	40 minutes
<b>Introduction</b>	<ul style="list-style-type: none"> <li>The same case studies from Exercise 7 will be used in this exercise to explore the possible impact of disclosure and the ongoing support needs of children.</li> <li>Participants will review each case study and discuss the questions as a large group.</li> </ul>

<b>Exercise 8: Disclosure case studies</b>	
<p><b>Case Study 1: Lefu</b> Lefu is a five-year-old female who lives with her grandmother, Mpho. Before the discussion of her health, Lefu had been refusing to take her medicine. Mpho had not told Lefu why she must take the medicine because she thought Lefu was too young to understand such things. After being told about needing medicine to be healthy, Lefu still continued to refuse medicines, but she has now begun asking her grandmother more questions about her “sickness”.</p> <ul style="list-style-type: none"> <li>What was the impact of disclosure?</li> <li>What continuing needs, including support, does Lefu and the family have?</li> </ul>	
<p><b>Case Study 2: Naledi</b> Naledi is an eight-year-old female who lives with her mother, Zoleka, a sex worker in poor health. Before finding out about having HIV, Naledi had begun to suspect both she and her mother had HIV and she was worried about death. After being told about HIV, Naledi appears to be somewhat less anxious, but she has become quieter than usual and spends much of her time stacking and re-stacking bowls in the kitchen.</p> <ul style="list-style-type: none"> <li>What was the impact of disclosure?</li> <li>What continuing needs, including support, does Naledi and the family have?</li> </ul>	
<p><b>Case Study 3: Thabo</b> Thabo is a 13-year-old male who has lived with his maternal aunt and uncle since his mother died a year ago. Before finding out about his status, he had missed a few clinic appointments, and became uninterested in school. Immediately after finding out his status, he seemed to become interested in school again and started taking his medicines more regularly (without being reminded by his aunt). However, two weeks after disclosure, he became friends with a dangerous crowd and his aunt has heard that he now has a “serious” girlfriend. She loves and cares for him, but cannot find time to talk to him about his behaviours.</p> <ul style="list-style-type: none"> <li>What was the impact of disclosure?</li> </ul>	

- What continuing needs, including support, does Thabo and the family have?

<b>Exercise 9: Optional disclosure panel presentation</b> <b>Large group discussion: participants stay in large group</b>	
<b>Purpose</b>	<ul style="list-style-type: none"> <li>• To share the experiences of caregivers who have disclosed to their children</li> </ul>
<b>Duration</b>	60 minutes
<b>Introduction</b>	<ul style="list-style-type: none"> <li>• Caregivers of children with HIV will discuss the process of disclosure as they experienced it as well as how the healthcare system helped, or could have better assisted them, with this process.</li> <li>• Time will be allotted for a question and answer session.</li> </ul>

## SUMMARY OF KEY POINTS

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### KEY POINTS OF THE MODULE FOR PARTICIPANTS

- As healthcare workers, we should be aware of our own opinions about the need and timing of disclosure and communication and not impose these views on clients.
- Disclosure is an ongoing process between a child and caregiver; this process is supported by the healthcare worker. Healthcare workers can support the process by preparing, educating and empowering caregivers and by planning follow-up support for both caregivers and children.
- Disclosure of diagnosis to a child living with HIV child should be tailored to the child's cognitive ability, age, developmental stage, clinical status, understanding of their HIV status, and social circumstances.
- Children have a right to know their HIV status and often cope better when aware of their illness.
- Healthcare workers should encourage open dialogue about disclosure. It is important to offer practical preparation and strategies that are tailored to the individual family situation to support the caregiver to start the disclosure process with a child.
- The conversation with caregivers should be focused on when and how to begin discussions about disclosure, not whether or not to disclose. When caregivers do not want to disclose, it is important that healthcare workers try to understand their reasons for not wanting to disclose, help them to identify and overcome potential barriers and support them in their decision.
- Healthcare workers may assist with the disclosure process by helping caregivers understand the reasons why disclosure to the child is important. This supports development of better coping skills and allows the child to be a fuller participant in his or her own care.
- Healthcare workers also need support in working with paediatric HIV disclosure.
- Healthcare workers must recognise where caregivers are within the disclosure spectrum and help them address their information needs and concerns in the disclosure process.
- Healthcare workers should help the caregiver plan what to say, where to have the discussion and what support resources to draw on.
- Healthcare workers may or may not be involved in discussions about disclosure with the child. This decision will be made by the caregiver and depends on his or her need for ongoing guidance during disclosure discussions.
- Disclosure is an ongoing process; follow-up and additional support for the child, caregiver and family members is essential. After full disclosure, children need to be able to continue to ask questions and discuss their feelings.
- Children who contract HIV through sexual abuse may need a higher level of support, compared to those who were perinatally infected.



## APPENDIX I: CHILDHOOD DEVELOPMENT



Information on developmental stages of the child is presented to justify the recommendation that disclosure is structured as a process rather than as a one-time event. Just as a child's body and mind slowly develop and he or she is able to do and understand more complex things, the disclosure process first starts out with the sharing of simple material that increases in complexity as the child matures. This information supports guidance to caregivers about when it may be appropriate to start the disclosure process and what information to share with the child and at what age.

Because there are individual differences among children in rates and patterns of development, the description in the following tables represents what is typical for the average child. All children are unique and develop somewhat differently from each other therefore the healthcare worker should work with the caregiver to assess the developmental stage of the child as the first step in developing a disclosure plan.

HIV may slow the development of a child, so a child who is 10 years old may only have attained the developmental milestones of a six-year-old. The child's *actual* ability to understand, rather than the child's age, should be the main determinant of what information will be shared with him or her.

Note: information on children under three years is not included in this appendix as they have limited capacity to understand information about their illness. Module 1 provides additional information on developmental milestones.

Preschool (3–5 years)	
Domain	Characteristic
Movement	Motor development, e.g., walking and running, as well as fine and gross motor skills, are being refined.
Cognitive	Thinking is concrete, tied to what the child can see and manipulate; tends to focus on one aspect of situation, cannot easily keep many factors in mind. Tends to relate events to self (“this happened because of what I thought/did”). Can describe what they can remember. Difficulty separating make-believe and reality — afraid of monsters, witches, etc. Lots of “how”, “why” questions, however can generally understand difference between something real vs. not real. Beginning to understand/use basic concepts, e.g. size, weight, number, colour, time. Learns through doing and playing (a child’s “work”). Discussions about health should introduce only one or two concepts at a time; child should be encouraged to ask questions as they may pick up on one thing the caregiver said and add some element of distorted fantasy to the picture they have of their health.

Language	Talks in sentences, simple conversations. Asks and answers simple questions, can understand concrete explanations (especially with demonstrations/symbols/pictures). Uses words to share interest in something, e.g. “look, look — this is my car”. Discussions about health may therefore be aided by pictures, and by introducing concepts in simple words.
Emotional	Greater range of emotions, more control over how feelings are expressed, but still impulsive at times. Starting to be able to label feelings in simple ways, e.g. sad, cross, happy. More able to tolerate frustration. Sensitive about making mistakes — needs to be reassured that mistakes are an opportunity to learn, not something of which to be ashamed. Caregiver should allow child to express anxiety, fear, sadness about elements of care, for example clinic visits, needles, etc.
Social/Relationships	Wants to be independent, do things for self, but sensitive to adult reactions. Being able to say “No” gives a sense of control. Relates everything to the self (egocentric), but developing ability to see another’s point of view. Starting to learn what is socially acceptable. Gender identity (seeing self as girl/boy) established. Plays with other children, learning to share. May have imaginary friends (useful and normal). Caregiver figures still very important as source of support, recognition and praise. Able to separate from caregiver for short periods, if sure that caregiver will return (has not abandoned child). Child needs to know that the caregiver, or another caring adult, is always available for support and sharing.
Self-care	Feeds self, washes and dries hands on own, can undress completely and dress self with help, uses toilet with help and later independently. Not yet able to manage medicines on their own, but perhaps can help in the preparation for taking it, to give a sense of control over the process.

Primary school age (6–11 years)	
Domain	Characteristic
Movement	Motor skills are being refined, almost to the level of an adult towards the end of this phase. Able to use pens, pencils and scissors.
Cognitive	Concrete reasoning allows understanding of cause-and-effect relationships. Memory for past events begins to extend over longer periods of time, begins to develop expectations (looking ahead to the future). More able to organise self and do things on own. Enjoys activities that give a chance to control, organise and order things. Child will be able to understand more information about their health, viruses, immune system. It is very important that adults are careful about what they discuss in front of a child because children may understand more than what adults think they can or children may misunderstand and therefore have incorrect information about HIV. At the later ages of this stage,

	<p>child may be able to understand implications of having HIV and how they got it. They will be able to draw connections, perhaps between what they have heard about HIV from others, and their own health and future. In South Africa, at this age, children are capable of doing much of what may be considered to be adult tasks however children are protected from “adult” topics of conversation and may not be encouraged to talk and share their thoughts with adults. The challenge for healthcare workers is to encourage conversations with children, which may not culturally be the norm, but which will improve cognitive development and will ease the process of disclosure.</p>
Language	<p>6–9 years: Child’s vocabulary grows dramatically, but may struggle to express their ideas and feelings in words. May also struggle to understand abstract ideas and need to have them explained in a concrete way with clear examples. Caregivers should attempt to use simpler words and concepts when talking about their health.</p> <p>9–11 years: Improved command of language enables child to express ideas and engage in conversation. Language used as a tool to connect with and influence others. Can improve group relationships by exploring ideas and opinions of others through language. Child is now able to understand, speak about and ask questions that show their increasing ability to connect previously unconnected concepts, ideas.</p>
Emotional	<p>Gaining a sense of mastery and achievement, finding something that child is good at builds self-esteem. Failure at school or not being able to experience pleasure in schoolwork or other activities or not be able to persevere with a task can affect child’s confidence and feeling of personal value. The effects of stigma and teasing become very important at this stage. Caregivers should be aware of how the child is doing and how he or she is being accepted at school. Children may have strong feelings about the illness being their fault, therefore explanations and discussions should be continuous, to reduce any sense of blame on their part.</p>
Social/Relationships	<p>Becoming less egocentric (centred on themselves), more able to take others’ point of view. Growing interest in the outside world. Able to play and engage well. Starts to understand rules and why they are important. May stick rigidly to ideas of right and wrong. Develops labels for self and others, e.g. fat, clever, left-handed, always sick, etc. Can be mean and cruel at times. Peer relationships vital, mainly same-sex friends. Clear sense of gender differences and views these as important. As noted above, the effects of stigma and teasing very important at this stage. School work and peer relationships may be affected due to the child having HIV, therefore it is strongly advised that disclosure discussions begin by this stage. Strong efforts should be made to link the child and family with support networks, or to other caregivers with children who are living with HIV so that</p>

	they do not feel isolated.
Self-care	Increasingly able to organise self and function relatively independently. Able to competently take care of all cleanliness and dressing. May regress and want help from adults if feeling insecure or unsure due to external circumstances (including illness). Child may be more able to have some independence with taking medicine, but with adult supervision.

Early adolescence (12–14 years)	
Domain	Characteristic
Movement	Control of gross and fine motor coordination similar to adults, but may go through periods of lack of coordination due to rapid growth spurts.
Cognitive	Refining ability to think beyond the concrete, here and now, and think in abstract terms. Able to think in more complex ways about alternative ideas and challenges. May become interested in abstract concepts like religion and politics or concerned with what is ethical, “right”. Able to understand the implications of having a chronic illness and participate in future planning efforts.
Language	Language used as a tool to express identity — may become verbally challenging in defining own point of view. Less likely to accept statements or instructions at face value — logical, well thought out arguments become important. Able to understand more complex and specific information about HIV.
Emotional	Mood swings as hormonal and bodily changes create feelings of insecurity. May feel discomfort/anxiety about physical appearance, e.g., too tall/short/fat/thin. Any unresolved emotional issues from earlier phases may be re-aroused, giving an opportunity to rework and resolve issues during teenage years. It should be expected, particularly close to finding out about having HIV, that children at this age may seem to accept the diagnosis on some days and then on others, may seem angry, withdrawn or depressed about the information.
Social/Relationships	Forming sense of personal identity (“who am I?”) a central task — often defined by being part of a peer group with own norms. Identity may also be defined in opposition to caregivers, e.g. questioning their knowledge/authority in comparison with others/self. Peer group approval crucial — being understood, trusted and accepted by peers. Very anxious about what is considered socially acceptable by others. May become preoccupied with own image (“how do I look, how do I come across?”) compared with peers. Can be easily led and influenced by peers in attempts to “fit in”. Increasing interest in sexual, intimate relationships — may struggle to communicate/assert own needs regarding whether to engage in sex, practise safe sex. Culturally, boys may be encouraged to have sex and girls discouraged until they are married. Because there has been increasing numbers of teen pregnancies in the country,

	healthcare workers and caregivers should take the responsibility of talking to children and teaching them about safe sex. Despite reliance on peers and emphasis on independence, wants to feel trusted and relied upon by adults. Wanting to fit in with their peers may affect the adolescent's willingness to take medications, go to clinic, or disclose their status to their friends.
Self-care	Able to take care of self adequately and predominantly wants to do things for self. If feeling emotionally vulnerable, may seek or accept help from caregivers as source of comfort.

<b>Late adolescence (15–18 years)</b>	
<b>Domain</b>	<b>Characteristic</b>
Movement	Once growth has stabilised, gross motor coordination stabilises at adult level.
Cognitive	Has broad knowledge base. Capable of thinking about ideas and problems in the abstract. Able to look at both sides of an argument. May still tend to be somewhat impulsive and lack capacity to realistically plan into the future (only finally matures in late 20s). At this stage, adolescents will be aware of the implications of their illness and will be approaching a level of maturity to have independence with regard to their own medical care.
Language	Enjoys verbally debating issues that affect self (e.g. sex, friends, lifestyle) and challenging established positions. May take a position for sake of argument, sometimes the opposite of own personal beliefs and views. Able to understand more complex and specific information about HIV.
Emotional	Mood swings related to physical changes much reduced. Capable of greater depth of feeling, more able to handle emotions through applying logical skills. Builds sense of self-esteem through experiences that allow for feeling competent and capable. Wants total independence but, if feeling overwhelmed, may at times want to leave difficult decision-making to authority figures. May become lethargic and preoccupied when dealing with issues, particularly if feeling unable to cope with challenges of growing independence. Issues of how long they will live and their ability to have families may come up at this stage. Thinking of these issues may bring on feelings of hopelessness and anger that must be dealt with by means of support networks.
Social/Relationships	Still working out sense of identity — process will extend into early 20s, affected by opportunities available to be productive, independent member of society versus continued dependence on family/caregivers. Relationship with caregivers may remain strained or conflicting, but should start to improve near end of this phase. Peers remain vital, but capable of greater independence (e.g. ideas, lifestyle). Usually have boyfriends/girlfriends — with support, more able to handle relationships that may become sexual and negotiate sexual

	relationship and safe sex. Extremely important at this phase for teens to have a network of friends/peers who are living with HIV and with whom they can share feelings and anxieties about having HIV.
Self-care	Totally independent.



## APPENDIX 2: THE STORY OF THANDI AND MUSA



# The story of Thandi and Musa



## Child undisclosed

Now I'm going to tell a story about two children. One of them is Thandi, a 7-year old girl who lives with her parents. The other is Musa, a 6-year old boy who lives with his uncle and aunt.

### The two children are at school, playing and talking.

-Musa and Thandi are talking, and Thandi asks Musa why he missed school.

-Musa explains that he missed school because he had to go to hospital, as he was born with a disease and so he must go for a check-up every month and collect his medicines.

## Child fully disclosed

Now I'm going to tell a story about two children. One of them is Thandi, a 12-year old girl who lives with her parents. The other is Musa, an 11-year old boy who lives with his uncle and aunt.

### The two children are at school, playing and talking.

-Musa and Thandi are talking, and Thandi asks Musa why he missed school.

-Musa explains that he had to go hospital because he has a disease, and needs to see the doctor every month for a check-up and to collect his medicines.



## Child undisclosed

### Musa hand-in-hand with his uncle and aunt on the way to the hospital.

-Musa explains to Thandi that he goes to the hospital with his uncle and aunt, as his parents died because of a little bug they had in their bodies, and that he has the same bug.

-Thandi asks: what bug is that?

-Musa says he doesn't know. He says that the doctor only told him he has this bug inside. That is why he has to keep going to hospital to collect his medicines, so he will stay strong and stop the bug making him ill.

#### How to explain HIV to a child without mentioning it by name:

"Inside our bodies, we have soldiers that protect us from diseases. When this little bug gets into our bodies, it destroys our soldiers, and then we can easily catch any disease, as there is no-one to defend us. That's why we must take our medicines every day at the right time, to keep the bug asleep, and not give it any chance to destroy our soldiers."

## Child fully disclosed

### Musa hand-in-hand with his uncle and aunt on the way to the hospital.

-Musa explains to Thandi that he goes to the hospital with his uncle and aunt, as his parents died because of a little bug they had in their bodies, and that he has the same bug.

-Thandi asks: what bug is that?

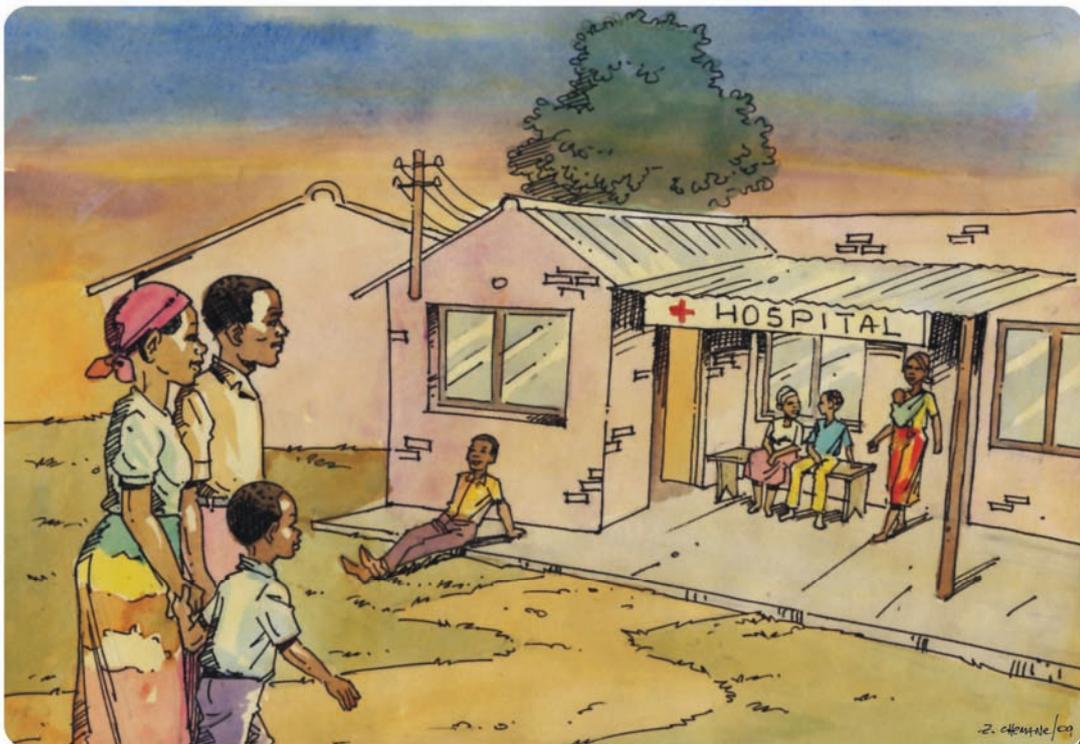
-Musa answers that it is called HIV, and asks her to keep it secret.

-Musa asks Thandi what she knows about this virus.

-Thandi says she doesn't know anything about it, so Musa explains to her what HIV is.

#### How to explain HIV to a child:

"Inside our bodies, we have soldiers that protect us from diseases. HIV is a virus, a little bug; when it gets into our bodies, it attacks our soldiers and then we can easily catch any disease, as there is no-one to defend us. That's why we must take our medicines every day at the right time, to keep the HIV bug asleep, and not give it any chance to destroy our soldiers."



## Child undisclosed

### Musa with other children at the hospital, listening to the counsellor explaining the importance of the “magic force” treatment, and how to stay strong.

-Musa explains to Thandi that there are other children in the hospital with the same bug as him, but that some of them don't know about their health status. He says he does not tell them about it.

-Musa and the other children learn a lot with the counsellor about how to grow strong, about the importance of eating well and taking their medicines every day as the doctor tells them, and what time they should take the medicine.

-Musa also tells Thandi that they play and draw, and it's fun to go to the hospital, meet the other children and play for a while. Musa says he sometimes is impatient to come to the hospital!

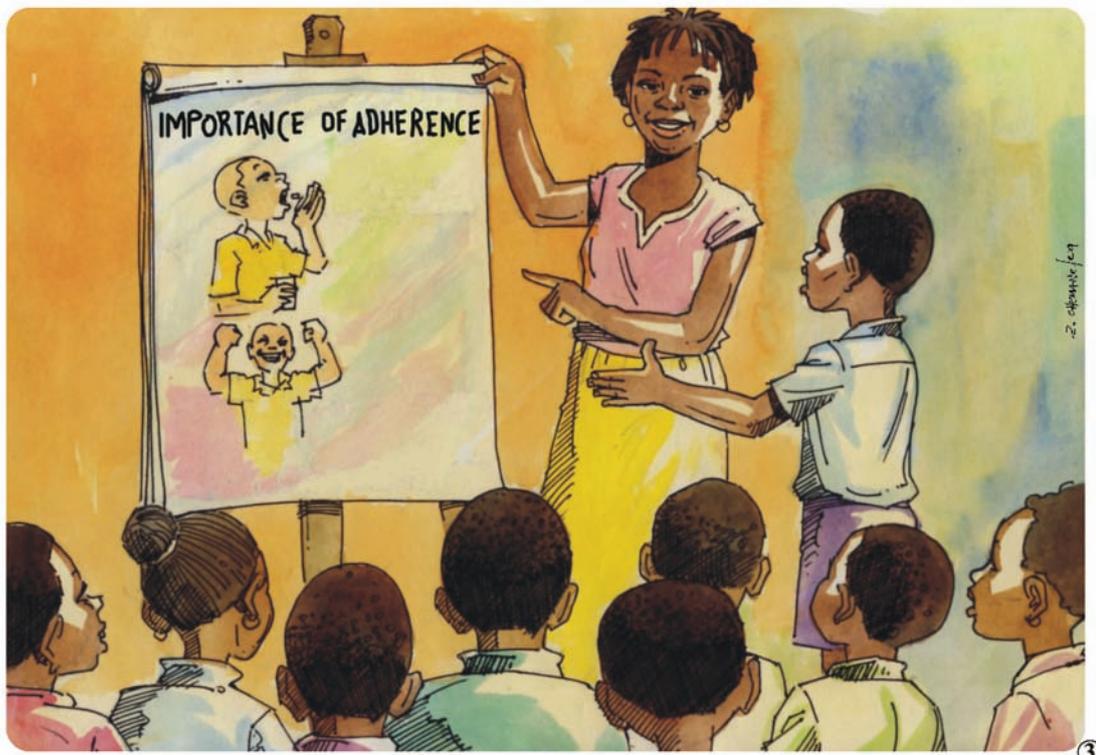
## Child fully disclosed

### Musa with other children at the hospital, listening to the counsellor explaining the importance of the “magic force” treatment, and how to stay strong.

-Musa explains to Thandi that there are other children in the hospital with the same bug as him, but that some of them don't know about their health status. He says he does not tell them about it.

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-Musa also tells Thandi that they play and draw, and it's fun to go to the hospital, meet the other children and play for a while. Musa says he sometimes is impatient to come to the hospital!



## Child undisclosed

Musa is with his uncle at the doctor's. The doctor examines him and gives the medicines directly to him.

-Musa explains to Thandi that he likes the doctor very much, because she looks after him very well, talks to him, is interested in his life (his school, his friends), and sometimes even gives him a balloon. Musa goes on to say that he told the doctor he has a friend called Thandi, and that she knows he goes to the hospital.

-Musa tells Thandi that the hospital walls are covered with puppets, it's a bright, cheerful place where you feel good; you feel like going back there and taking your medicine properly so you stay strong.

## Child fully disclosed

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-Musa explains to Thandi that he likes the doctor very much, because she looks after him very well, talks to him, is interested in his life (his school, his friends), and sometimes even gives him a balloon. Musa goes on to say that he told the doctor he has a friend called Thandi, and that she knows he goes to the hospital.

-Musa tells Thandi that the hospital walls are covered with puppets, it's a bright, cheerful place where you feel good; you feel like going back there and taking your medicine properly so you stay strong.



## Child undisclosed

### Musa is with his uncle and the laboratory nurse who is taking his blood sample.

-Musa explains to Thandi that there is something else he does when he goes to hospital: he gives a blood sample. He says that before, he used to cry a lot, but since the doctor explained why it is important to take a sample, he doesn't cry any more.

-Thandi asks Musa why it is important to take a blood sample.

-Musa replies: "The doctor told me that the bug I've got, that destroys my soldiers, is in my blood, so the nurse needs to take a little bit of my blood to see if the bug is awake or asleep, you know, if the medicine is working or not".

-Thandi to Musa: "Aaah... now I understand everything, I know why it's important to take a blood sample. Thank you for telling me, you're a real friend, but we ought to explain to the other children too, as they don't know and some of them still cry a lot".

-Musa tells Thandi that he likes the nurse very much. They talk about football, school, and so on. It's fun, and sometimes he gets a sweet.

-Musa tells Thandi that it doesn't hurt to give blood, and he really doesn't know why he used to cry so much before...

## Child fully disclosed

### Musa is with his uncle and the laboratory nurse who is taking his blood sample.

-Musa explains to Thandi that there is something else he does when he goes to hospital: he gives a blood sample. He says that before, he used to cry a lot, but since the doctor explained why it is important to take a sample, he doesn't cry any more.

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-Musa replies: "The doctor told me that the bug I've got, that destroys my soldiers, is in my blood, so the nurse needs to take a little bit of my blood to see if the bug is awake or asleep, you know, if the medicine is working or not".

-Thandi to Musa: "Aaah... now I understand everything, I know why it's important to take a blood sample. Thank you for telling me, you're a real friend, but we ought to explain to the other children too, as they don't know and some of them still cry a lot".

-Musa tells Thandi that he likes the nurse very much. They talk about football, school, and so on. It's fun, and sometimes he gets a sweet.

-Musa tells Thandi that it doesn't hurt to give blood, and he really doesn't know why he used to cry so much before...



## Child undisclosed

### Musa is at home with his uncle, who is giving him his medicines.

-Musa tells Thandi that although his uncle gives him the medicine, he already knows how to take it by himself when his uncle and aunt aren't there, after all, he's not a baby anymore!

-Musa says the medicines have no taste, he takes a pill in the morning and another in the evening. Other medicines are to boost his magic force, and he takes them when the doctor says he must.

-Musa says that before he used to take the medicines, he was always ill or in hospital, and now he prefers to take the medicines to feel strong, so he can join in sports like football and play more.

-Musa also says that he doesn't feel ill and he only has to go to hospital once a month because he has that bug, so the doctor can give him pills for him to stay strong.

## Child fully disclosed

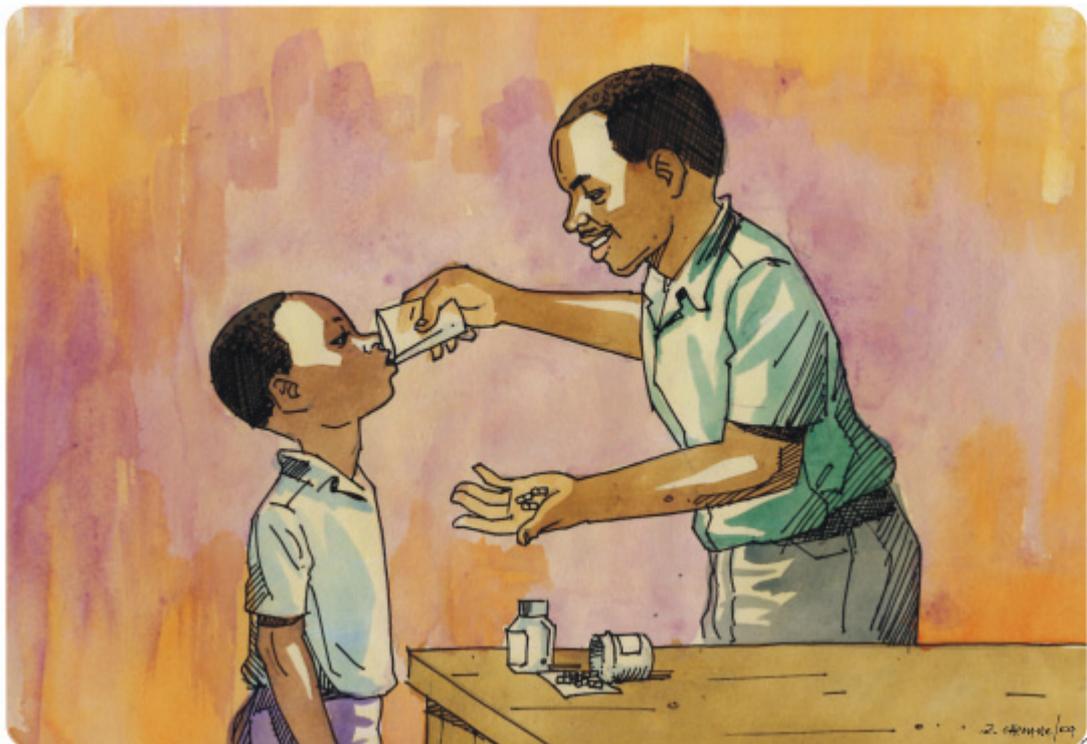
### Musa is at home with his uncle, who is giving him his medicines.

-Musa tells Thandi that although his uncle gives him the medicine, he already knows how to take it by himself when his uncle and aunt aren't there, after all, he's big now!

-Musa says the ARV medicines to treat his HIV have no taste, he takes a pill in the morning and another in the evening. Other medicines are to boost his magic force, and he takes them when the doctor says he must.

-Musa says that before he used to take the medicines, he was always ill or in hospital, and now he prefers to take the medicines to feel strong, so he can join in sports like football and play more.

-Musa also says that he doesn't feel ill and he only has to go to hospital once a month because he has HIV. He explains that HIV is a virus that can't yet be cured, and so he has to take medicines to stay strong and healthy.



## Child undisclosed

### Musa is colouring in the “pathway of life”.

-Musa tells Thandi he has a very good game he likes to play and to take to hospital. It's called “the pathway of life”.

-Thandi asks: “Pathway of life? How do you play it, Musa?”

-Musa shows Thandi and explains: “it's a game that shows how long it is until the day when I go back to the hospital. Each time I take a pill I colour in one square of the path. I have to do one in the morning and one in the evening.”

-Musa also says that the game has been a great help to him in remembering to take his medicine, as the game is fun. What's more, the doctor and the counsellor are very happy when they see everything coloured in, and say: “Musa, this way you'll grow up strong and healthy like all children”.

## Child fully disclosed

### Musa is colouring in the “pathway of life”.

-Musa shows to Thandi, the “pathway of life”, a game he got at the hospital.

He has to colour in one square of the path, every day, morning and evening, when he takes his ARVs. He says it has been a great help to him in remembering to take his medicine, as the game is fun. What's more, the doctor and the counsellor are very happy when they see everything coloured in, and say: “Musa, this way you'll grow up strong and healthy like all children”.



## Child undisclosed

### Musa hand-in-hand with Thandi.

-After Musa has finished telling Thandi his story, Thandi says to him, "Now I'm going to tell you my secret, after all, you're my friend and you've told me everything". Thandi tells Musa "I haven't got a father either. I don't know what he died of. I only have my mother, and she told me she has a bug inside too, and she will have to follow that treatment all her life to stay strong and look after me".

-Musa feels very reassured by Thandi, he feels her support and solidarity. He tells Thandi that he thought he was the only person at the school with this bug story.

-Musa reveals he doesn't know what the bug is, but he knows his parents died of the same thing.

-Thandi replies "It doesn't matter what bug it is, we're friends and we'll stay friends whether you've got some bug or not. I'm your friend: we must carry on playing together, so you have to be strong and healthy. So, you mustn't stop going for check-ups with your uncle and aunt, or taking your medicines".

-Thandi warns Musa, saying "You can't stop taking the medicines, my mother told me that the pills keep the bug asleep, and that stops her getting ill. You have to do the same".

-Thandi also tells Musa that although she doesn't have the bug, she thinks her father died because he didn't want to go to hospital. "I want you and my mother always to stay strong and beautiful!"

-Then Musa asks Thandi: "Does that mean that I'm not different to you, or you to me? I'm so happy you accept me as I am!"

-Thandi answers: "There's no difference between us, we're all people, and there's more to you than just that bug. And I don't care if you have it inside, because we are and we'll stay friends."

## Child fully disclosed

### Musa hand-in-hand with Thandi.

-After Musa has finished telling Thandi his story, Thandi says to him, "Now I'm going to tell you my secret, I can't hide it any more. After all, you're my friend and you've told me everything". Thandi tells Musa "I haven't got a father either, only my mother, and she told me she has a bug inside too, the same HIV bug that you've got, and she will have to take those ARV things all her life".

-Musa feels very reassured by Thandi, he feels her support and solidarity. He tells Thandi that he thought he was the only person at the school with this bug story.

-Thandi warns Musa, saying "You can't stop taking the ARVs, my mother told me that the pills keep the HIV bug asleep, and that stops her getting ill. You have to do the same!"

-Thandi also tells Musa that although she doesn't have HIV, her father had it and died because he didn't want to be treated. "I want you and my mother always to stay strong and beautiful!"

-Then Musa asks Thandi: "Does that mean that I'm not different to you, or you to me? I'm so happy you accept me as I am!"

-Thandi answers: "There's no difference between us, we're all people, and there's more to you than just HIV. And I don't care if you have it inside, because we are and we'll stay friends."



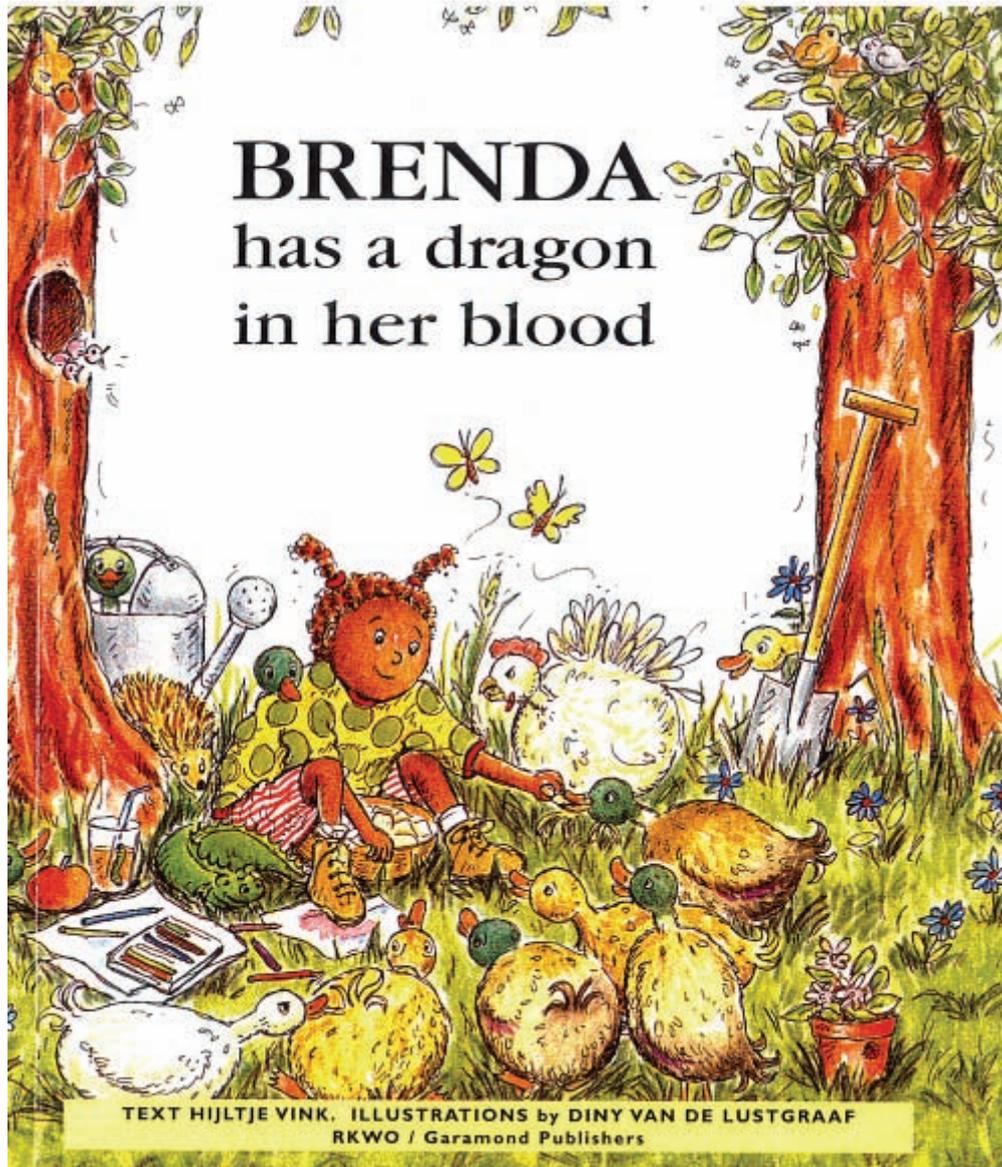
### How to use this booklet:

This booklet is intended for children between the ages of 5 and 14, whose status is either undisclosed or fully disclosed, and who are following ARV therapy. It touches on issues of infection, treatment and the importance of check-ups at a health centre. The booklet should not be given to the children and they should not read it by themselves. It should be read by a trained counsellor in group or one-to-one sessions, in the light of the child's level of disclosure. When reading, the counsellor should show the illustrations but not the text to the child. While reading, and afterwards, the counsellor can ask questions and talk with the child to make sure they have fully understood the story.





## APPENDIX 3: BRENDA HAS A DRAGON IN HER BLOOD



## BRENDA HAS A DRAGON IN HER BLOOD



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Illustrations: Dine van de Lustgraaf  
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### **What is the purpose of this book and how does one use it?**

All over the world, people have misconceptions about how someone contracts HIV or AIDS from someone who has been infected - like thinking that it is not safe to drink something from the same glass as someone else. Most healthy people would rather stay away from someone with HIV or AIDS and don't realize how very hurtful this attitude is for that person. It is definitely not necessary to avoid contact. You cannot get AIDS by swimming in the same pool as someone else or by drinking out of the same glass or by taking a pinch of sugar from the same sugar-bowl. This book is intended firstly to support those children (and adults) with HIV and AIDS, in the hope that the prejudices about this disease will disappear. Both the information in this little book and Brenda's story make this possible. Although Brenda lives in the Netherlands, there are many children in many countries, also in our country, who suffer from the same sickness.

### **A story from "real life"**

What is it like for a child to have AIDS? What problems does he or she face? And what can people in the child's circle do to help him or her? This book tries to explain at a level that children understand what it means to be HIV positive. In the story we are told that Brenda has the HIV dragon in her blood (that is, the HI

# BRENDA has a dragon in her blood

Hiltje Vink

Illustrations: Diny van de Lustgraaf



Garamond Publishers / RKWO

virus). The HIV dragon is present in each illustration, mainly asleep, just as the HI virus is always present in Brenda's life but doesn't affect her day-to-day activities. Only when she is sick or when her mother's death is mentioned is the dragon drawn larger. These are the times when the HI virus is also more strongly present in Brenda's life.

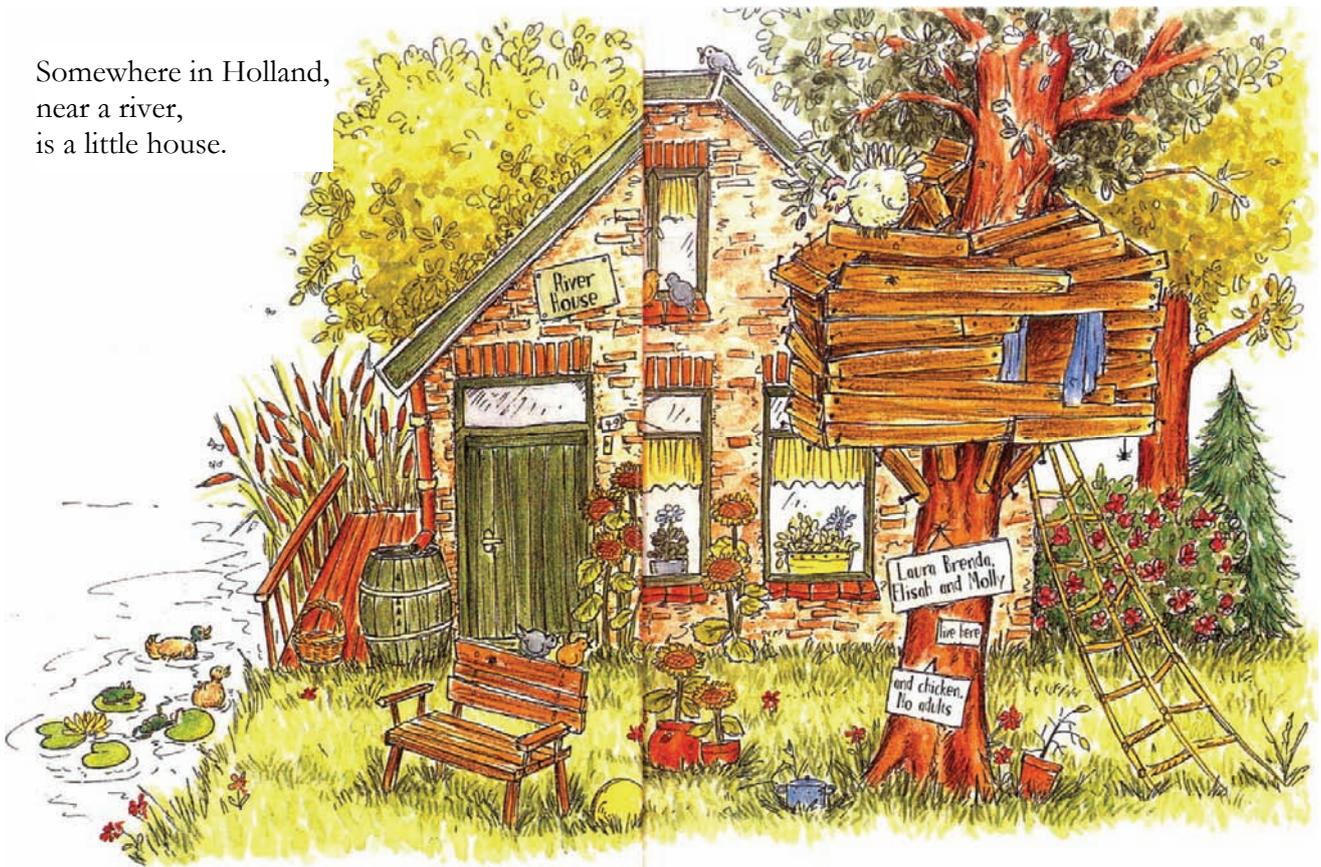
The book ends with an informative chapter (for somewhat older children).

Perhaps it is only a dream, but I dream of a world where people are no longer discriminated against because they are brown, yellow or red. Or because they have AIDS, are poor or disabled. I hope that this book will contribute to raising children to be understanding and compassionate adults who accept each other: Each a unique individual.

*hiltje vink*

This book has been made possible by the generous advice of the PIETER Clement-Stichting, the HIV Association of the Netherlands, the Stichting AIDS Fonds and Henriette Scherphier, a paediatrician associated with the AMC.

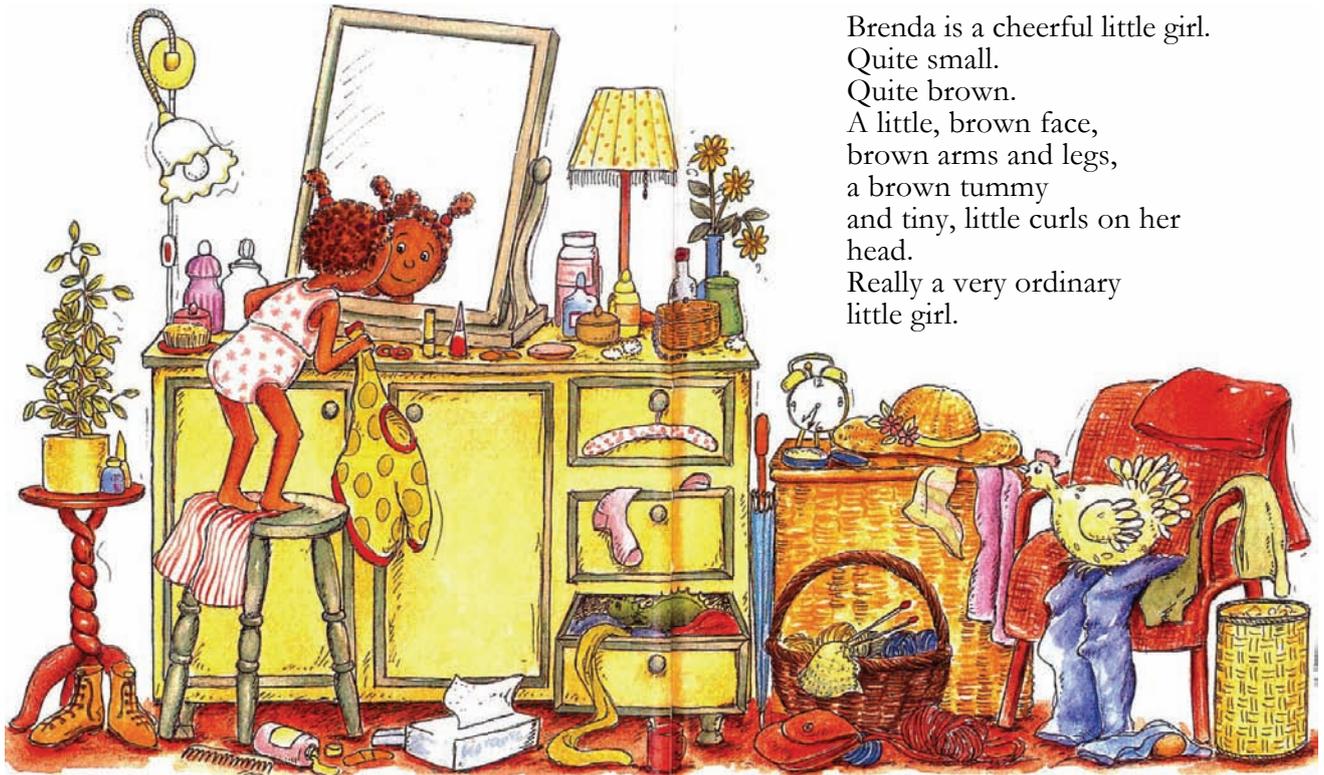
Somewhere in Holland,  
near a river,  
is a little house.



In this friendly house, Brenda,  
Uncle Pete, Auntie  
Hannah and her three  
sisters, live.

Her sisters' names are  
Elizah, Laura and Molly.  
Elizah is seven, Molly  
is two, and Laura is  
three years old, the  
same as Brenda.





Brenda is a cheerful little girl.  
 Quite small.  
 Quite brown.  
 A little, brown face,  
 brown arms and legs,  
 a brown tummy  
 and tiny, little curls on her  
 head.  
 Really a very ordinary  
 little girl.

Brenda likes to draw, to sing,  
 to dance and  
 to jump.  
 But most of all she likes to  
 cuddle and to snuggle.  
 "You're my little snuggle-  
 bunny, Auntie Hannah,"  
 teases her.  
 "My own little hug-bug."

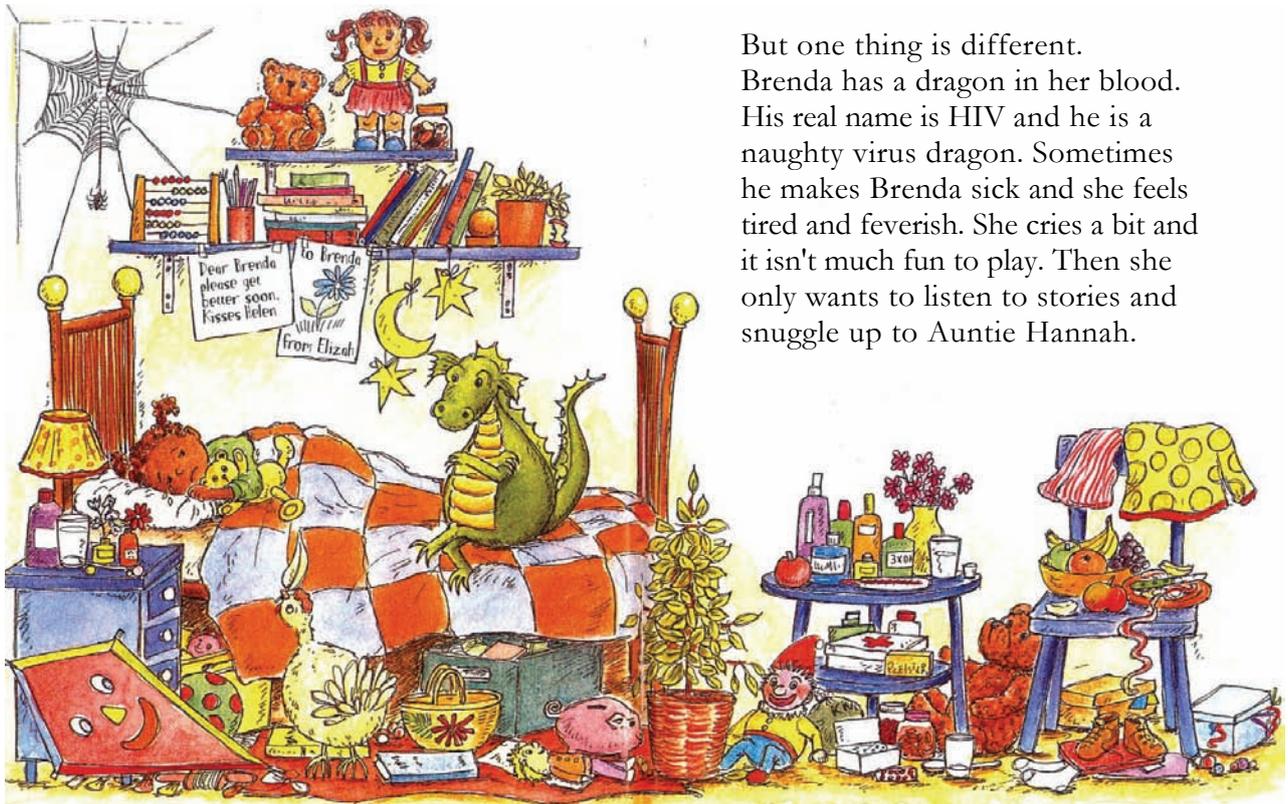




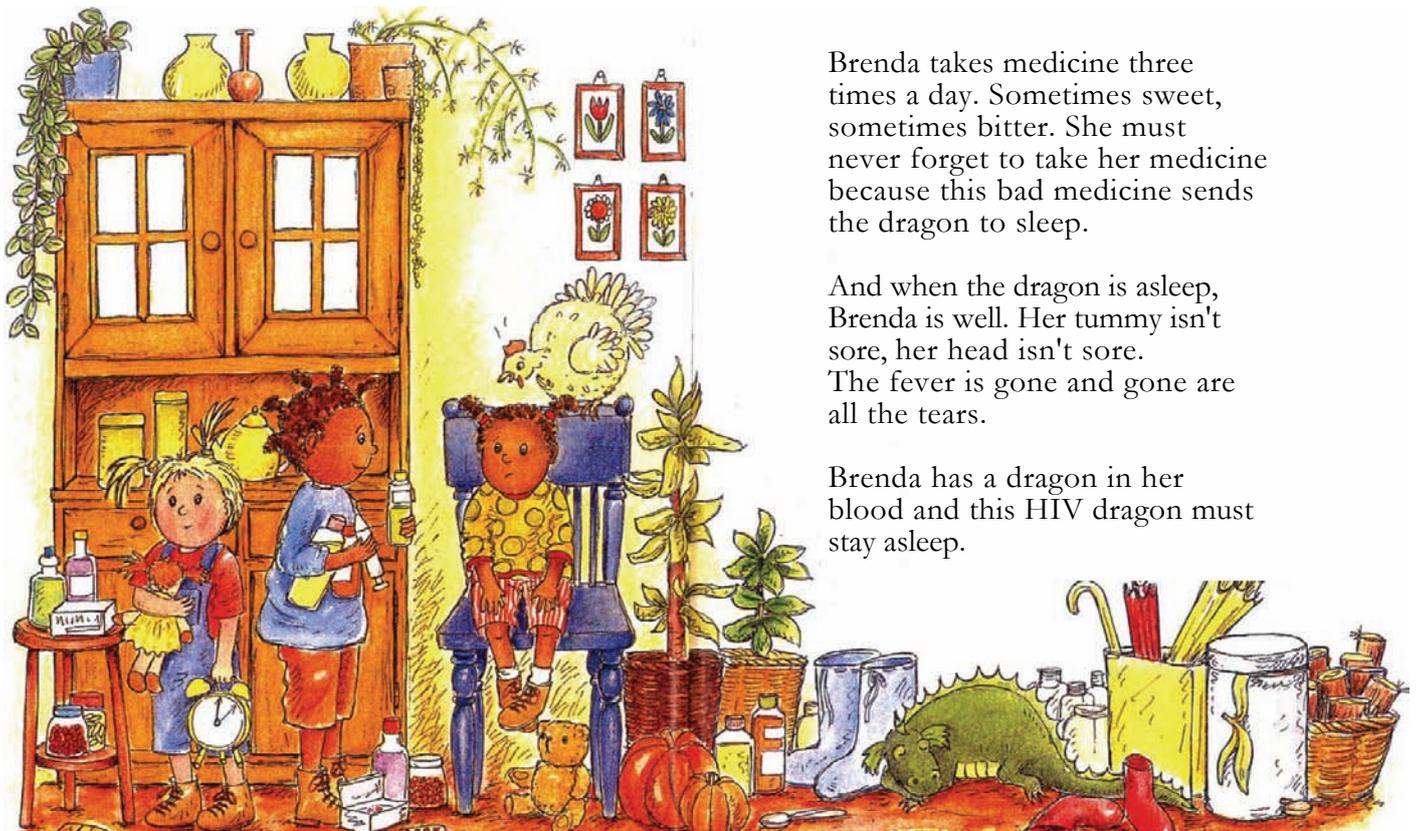
Every morning when Brenda wakes up she is excited about the new day. Then she climbs into bed with Laura. They cuddle up together. They wrestle and tickle each other, and the day starts full of fun. Then they go to playschool together. There they play together and with the other children. "I love playing!" says Brenda.

Brenda is just like all children. She likes to feed the ducks. She loves to ride on her kart. She likes to fly a kite and to look at the clouds. She loves to help Auntie Hannah bake pancakes. She likes to walk in the rain and she loves to stick her finger in the sugar-bowl, just like you.





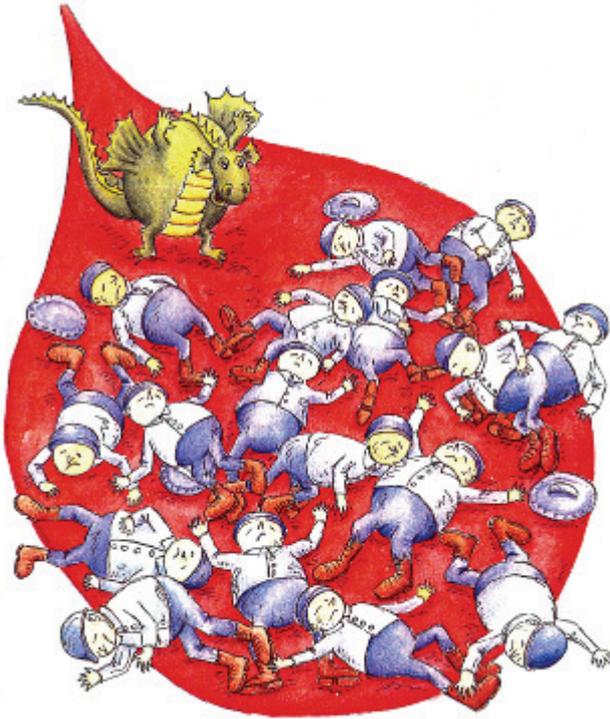
But one thing is different. Brenda has a dragon in her blood. His real name is HIV and he is a naughty virus dragon. Sometimes he makes Brenda sick and she feels tired and feverish. She cries a bit and it isn't much fun to play. Then she only wants to listen to stories and snuggle up to Auntie Hannah.



Brenda takes medicine three times a day. Sometimes sweet, sometimes bitter. She must never forget to take her medicine because this bad medicine sends the dragon to sleep.

And when the dragon is asleep, Brenda is well. Her tummy isn't sore, her head isn't sore. The fever is gone and gone are all the tears.

Brenda has a dragon in her blood and this HIV dragon must stay asleep.



HIV dragons which wake up are dangerous. They start to fight the little soldiers that live in everybody's blood and protect us. In the beginning the soldiers are strong and they win easily. But the longer they fight, the more tired the good, little soldiers become. Then they can't fight so well and slowly, slowly the dragon starts to beat the soldiers. That was what it was like with Mommy Mary, Brenda's own mother. She died. The HIV dragon won the battle and Brenda was very, very sad.



Once in a while they go to the cemetery to visit Mommy Mary's grave. Brenda often talks to Laura about Mommy Mary. Sometimes they are sad together. They comfort each other and get angry in their own way: "Silly, stupid dragon!"

Brenda was already living with Uncle Pete and Auntie Hannah and Elizah and Molly and Laura when Mommy Mary died. They all went to bury Mommy Mary together. And together they placed a stone and planted flowers on her grave. Pretty, white flowers.

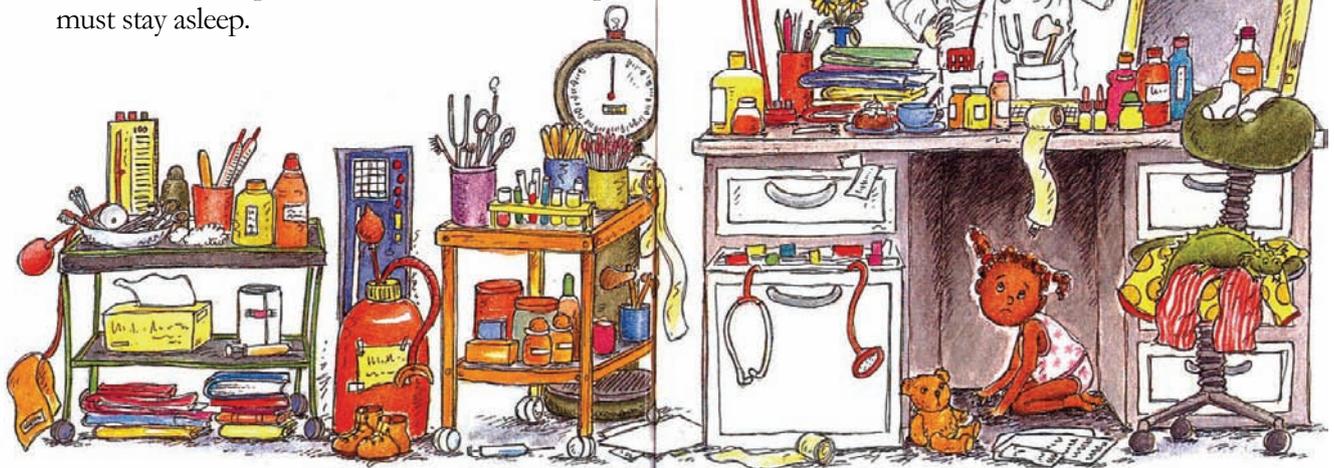


Brenda has to visit the hospital regularly. Usually just for a short while. The doctor wants to know if the soldiers in Brenda's blood are still strong and if the ugly HIV dragon is still asleep. Then Brenda gets an injection. Brenda doesn't like injections.

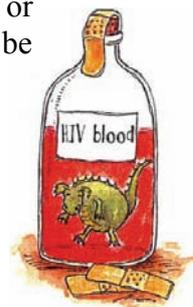
Brrrr...

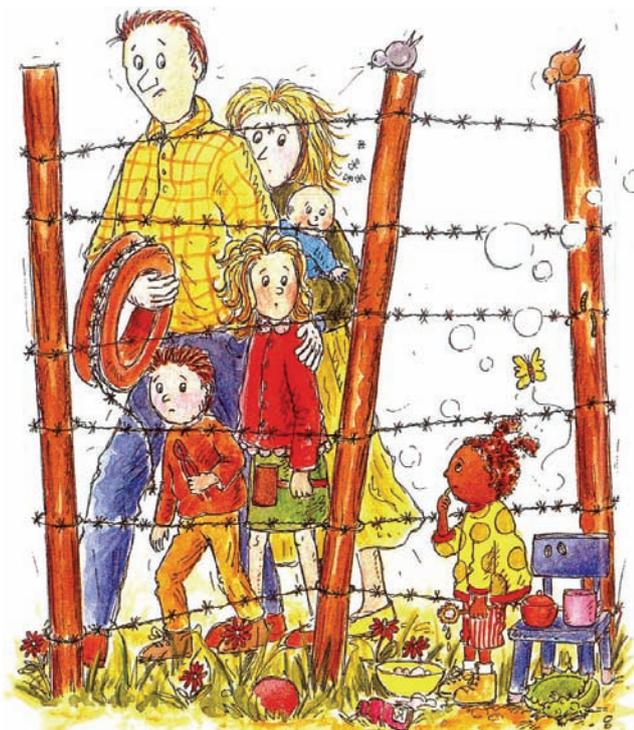
Brenda thinks injections are awful. She cries and cries, but, oh well, it has to happen because...

Brenda has a dragon in her blood and this dragon must stay asleep.



People are sometimes a little afraid of Brenda's dragon. They think that the HIV dragon can get out and crawl into their own blood. But that cannot happen. Only if Brenda gets a cut on her finger, or her knee is bleeding, must they be careful. Just like you. Because we must always be careful with blood. One shouldn't take chances with blood. Not you, not Brenda, not anybody. So... when Brenda has a cut on her finger, or her knee is bleeding, she just sticks a plaster on it. Just like you and all other children. Just the same.





Yet there are people who are afraid of Brenda's little dragon.

They say "It's better not to play with Brenda."

Or "You shouldn't sit next to Brenda." Or,

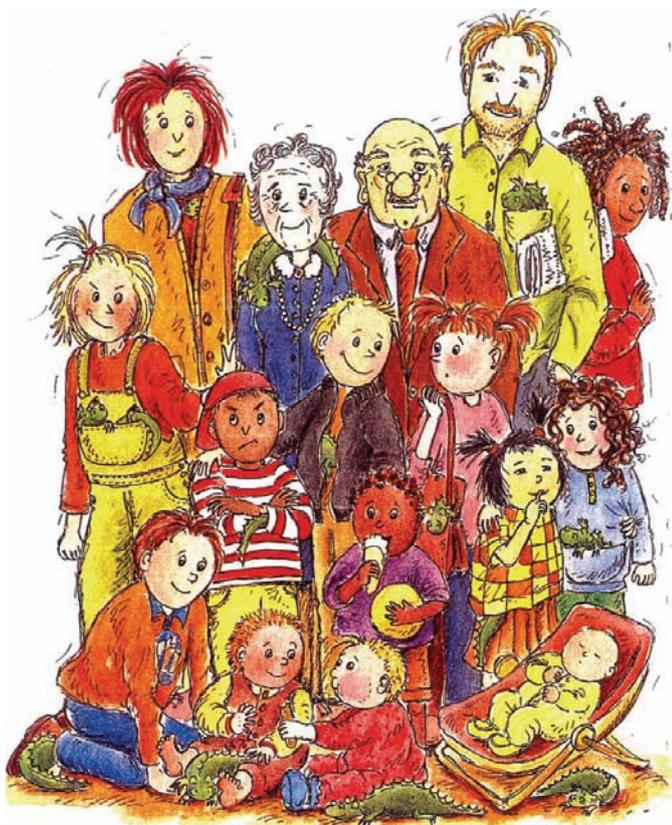
"You'd better not drink out of the same glass as Brenda or take a lick of sugar from the same bowl as her." In fact, they would rather stay as far away from Brenda as possible.

Not because of Brenda ...

but because of the HIV dragon.

And, did you know that this makes Brenda very, very sad. Almost sadder than when Mommy Mary died. If no-one wants to play with you, if no-one wants to sit next to you at school, if no-one wants to take a pinch of sugar from the bowl with you...

it makes you sad,  
very sad!



Brenda has a dragon in her blood. But not only

Brenda. There are children in our own country

who have a dragon in their blood. Dark children, fair children, yellow children, big children, small children and tiny, little babies.

All these children are very ordinary children who need very ordinary friends to play with. To share a glass, to sleep in the same little bed and to take a pinch of sugar from the bowl together.



### **Question 1. HIV, AIDS, HIV positive... What's the difference?**

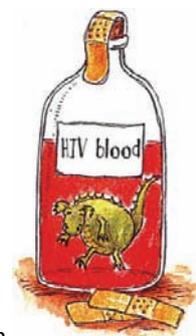
**Answer:** If you have the HI virus (the "HIV dragon" in the story) in your blood, you are HIV positive.

But this still does not mean that you are already sick. Perhaps you may be very tired now and then but otherwise you don't usually notice anything wrong.

If you are HIV positive and you catch a serious illness, such as pneumonia, with a fever and a bad cold, only then can one say that you have AIDS.

### **Question 2. What then is AIDS?**

**Answer:** If you get sick - for example, when you have flu - it means that an enemy (a virus) has entered your body. The soldiers in your blood will fight this enemy and you will probably get better within a few days. If you have AIDS, the soldiers in your blood can't fight the enemy in your body all that well anymore. This is because the HIV dragon has damaged the soldiers. Then one gets sick much more easily. A sickness like flu, for example, also lasts much longer and sometimes even develops into pneumonia.



### **Question 3. How do children get the dragon in their blood?**

**Answer:** Children can get the dragon in their blood while they are still growing in their mother's womb. Of course, this is when their mother already has the dragon in her blood.

The HIV dragon can also get into a child's blood while he or she is being born. Babies who are breast-fed can also get the dragon in their blood if it is passed on in their mother's milk.

In some countries children can get the dragon in their blood when they get a blood transfusion in hospital. Blood transfusions are sometimes necessary so that someone who has too little blood can get new blood. This means that he or she may, by accident, get blood from somebody who has the HIV dragon. But fortunately doctors and nurses in our hospitals are very careful and all blood is tested very carefully before transfusions are done.

### **Question 4. Must one always be very careful with blood?**

**Answer:** Yes, everyone, including children, must be careful if they are bleeding. If you have grazed your knee and it is bleeding, you must immediately stick a plaster over the wound. You should never play with blood because you may get sick. Doctors and dentists always wear rubber gloves because they know this very well.

You should be careful if you see an injection needle lying in the street or on a rubbish dump. Don't ever pick it up yourself. Ask the nearest adult to take it away.

### **Question 5. Can one get better if one has AIDS?**

**Answer:** One cannot recover from AIDS. This means that someone who has AIDS will die from it some day. Just like Brenda's mother. Then the HIV dragon has won the battle. Fortunately, there are now pills and medicines which make sure that the dragon hides away and that he cannot beat you unexpectedly. If one takes these pills and medicines on time and regularly, one may live much longer than anyone expects.

Many doctors and scientists are trying to make even better medicines so that people with HIV and AIDS can recover completely.

**Question 6. Is it alright for everyone to know about it if you have the HIV dragon in your blood or if you are already sick with AIDS?**

**Answer:** This is a very important question. Of course it is best if you can talk about it with all your friends, with Mommy and Daddy and with the people at school. If you can speak about it naturally, you no longer have to be afraid that people will discover your secret, because then it is not a secret anymore anyway. Other people, like your neighbors can help you if you suddenly have to go to hospital and your parents can't take you themselves.

It is a pity that people are sometimes still afraid of those who have the HIV dragon in their blood. They don't want to go near them. This of course is totally unnecessary. Some people who have HIV or AIDS don't like to talk about their illness because they know that other people will choose to stay away from them.

**Question 7. Can moms and dads also have HIV and AIDS?**

**Answer:** Yes, they can. If a child has HIV or AIDS from birth, it means that his (or her) mother has it too. Maybe even his mom *and* dad. This is a problem because sometimes the whole family is sick at the same time and then they can't help or nurse each other.

It is truly a blessing when others offer to help when this happens, for example by taking care of the children.



**Question 8. Can one play normally with someone who has AIDS?**

**Answer:** Children with AIDS will really appreciate it if you play with them just as you would with any other child and do things with them. You can happily drink something from the same cup, swim with them, laugh and play together and take a pinch of sugar from the same bowl. You don't have to worry at all that you will also get AIDS.



Important telephone numbers for children and adults who have to deal with HIV or AIDS (or for you, if you need information for a project):

**AIDS HELPLINE**

For all problems related to HIV/AIDS  
0800 012 322  
[www.aidshelpline.org.za](http://www.aidshelpline.org.za)

**LOVE LIFE CALL CENTRE: THETA JUNCTION**

For information about lifestyle matters  
0800 121 900  
[www.lovelife.org.za](http://www.lovelife.org.za)

**CHILDLINE**

For all children's issues  
0800 055 555  
[www.lifeline.org.za](http://www.lifeline.org.za)

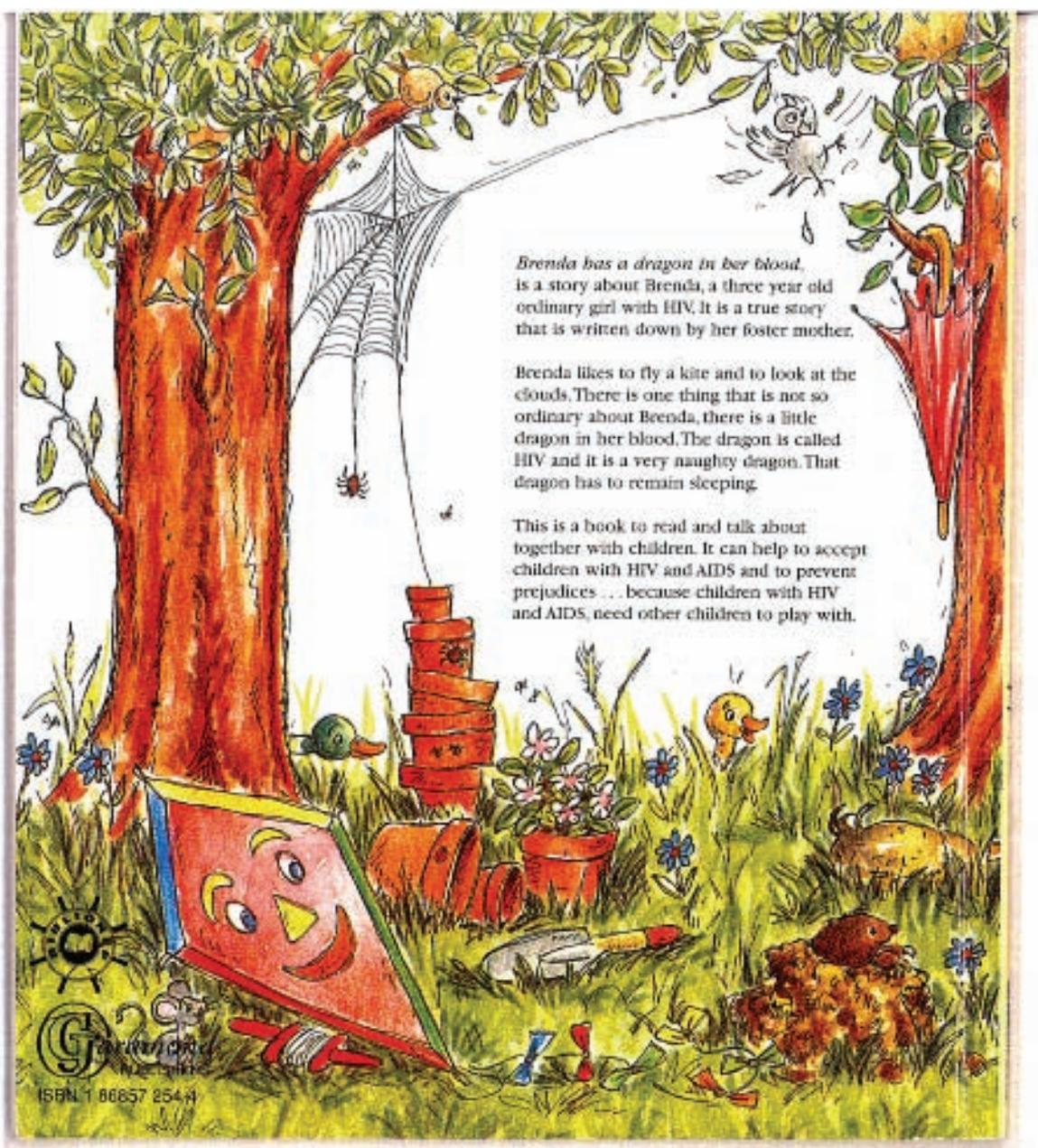
**HOPE WORLD WIDE**

Countrywide programmes to help children and young people to live with HIV or AIDS  
021 361 8158  
[www.africa.hopeww.org.za](http://www.africa.hopeww.org.za)

**PLANNED PARENTHOOD ASSOCIATION (PPASA)**

Countrywide counseling and life skills programmes for young people 011 523 1400  
[www.ppasa.org.za](http://www.ppasa.org.za)

*(Contact the national office for provincial numbers)*



*Brenda has a dragon in her blood,*  
is a story about Brenda, a three year old  
ordinary girl with HIV. It is a true story  
that is written down by her foster mother.

Brenda likes to fly a kite and to look at the  
clouds. There is one thing that is not so  
ordinary about Brenda, there is a little  
dragon in her blood. The dragon is called  
HIV and it is a very naughty dragon. That  
dragon has to remain sleeping.

This is a book to read and talk about  
together with children. It can help to accept  
children with HIV and AIDS and to prevent  
prejudices ... because children with HIV  
and AIDS, need other children to play with.



## APPENDIX 4: GUIDELINES FOR STARTING A SUPPORT GROUP



Providing ongoing support to children, caregivers and family members is a crucial component of the disclosure process. Disclosing to a child without having a plan for attending to the psychological and social needs of the child may lead to problems with the child adjusting to this new information about his or her health. This may have far-reaching consequences.

In many situations, such as out in the rural areas or areas with few resources, healthcare workers may not be able to set up and run support groups (also referred to as self-help groups) for a number of reasons: they may not feel they have the knowledge or training to do so, they may not have the time to facilitate the groups, etc. In these cases, healthcare workers can be encouraged to make connections among children living with HIV and their families, so that the families themselves may support each other.

As a first step, healthcare workers should attempt to find out about already existing support groups in the area. If there are no support groups locally, consult with key informants and with caregivers, to gain a better understanding of what types of support groups are needed, the goals and objectives of a support group, what topics might be discussed during a support group and the reservations they have (if any) about such groups.

Where there are no support groups, the first priority should be on setting up a group for caregivers. Once this group has been established and functioning, setting up a group for children may be the next step.

Some of the steps to consider in helping families start a support group are:

1. Define the group's shared concern.
  - HIV and disclosure or living with HIV, or any other life experience that will be shared.
2. Decide who can join the group.
  - At the beginning, most self-help groups include only those who have the shared concern or problem. Will an attempt be made to have a group for caregivers as well as one for children? If there will be a group for children, it will be important to ensure that there are different ones for the various age groups. For the younger children, it may be helpful to have structured activities. However, if staffing resources are limited, it might be just as helpful to have a play area where they can simply play and be with each other. For older adolescents, it may be important to establish a peer leadership model, again if staffing resources are limited.
3. Establish the group's initial focus.
  - Do not try to do everything at once. Consider focusing on only one or two activities at first. Here are some suggestions to choose from:

- Share feelings and experiences.
  - Exchange information and resources.
  - Discuss new ways to solve old problems.
  - Find ways to reduce stress and anxiety.
  - Allow the group to develop slowly.
4. Try to keep it small at first.
    - Since discussions are usually the main activity of a new group, it is wise to try to keep the size between 4–15 people. This is large enough to bring a variety of experiences to the group, yet small enough to allow everyone a chance to participate.
  5. Pick a name.
    - This can be fun. Although you may want the name to define your purpose or area of interest, a touch of humour can be appropriate. One group of people with leg amputations named their group Prosthetic Education and Group Support (PEGS). Be sure to make the name inviting. “Parents Supporting Parents” may be more appealing than “Parents Overwhelmed by their Kids”.
  6. Define your relationship with professionals.
    - Members of a self-help group are sometimes told that they cannot run their group without a professional “expert” at the helm. Not so! The real experts are the people who have the problem. They become more powerful and healthy by learning how to help each other as well as themselves. However, professionals can be very helpful as resources. For example, a physician or educator can serve as a guest speaker, spread the word about the group, or provide technical information.
  7. Establish levels of anonymity and confidentiality.
    - In an anonymous meeting, people are given the option of not revealing their full names. Confidentiality is the practice of keeping private what occurs and is discussed during a meeting. Since members often interpret this idea in different ways, it is important to define what your group wishes to keep confidential. Most groups ask members to say nothing about what was seen and heard in the meeting outside the group. Some groups practice a less strict degree of confidentiality. They allow members to talk about the meeting with people outside the group as long as no identifying information is used. Still other groups have no need for confidentiality.
  8. Consider whether or not the group really needs to collect money.
    - Many groups do not need to handle money. A friendly organisation, such as a church, synagogue or mosque is often willing to donate free meeting space and other resources. You can also ask members to buy and bring specific things (such as refreshments) or ask for a small donation to cover specific costs.
  9. Decide how often to meet.
    - Every support group is different. Some groups meet weekly. Others (such as those that deal with addictions) meet more frequently. Still others (such as those that deal with rare illnesses) may meet only a few times a year.
    - Meet often enough to provide steady group support, but space the meetings far enough apart to leave people looking forward to the next session.

10. Prepare a list of possible activities.

- Activities may include having a guest lecturer talk about medications or keeping healthy, a field trip to other groups as well as providing each other with support and exchange of ideas.

11. Think “Mutual-Help” from the start.

- Give every new member the opportunity to contribute to the group and feel appreciated from the beginning by:
  - Looking within the general membership for programs and ideas.
  - Rotating tasks among group members. Share in leading meetings, providing refreshments and other tasks.
- Sample discussion topics for caregiver support groups:
  - Responsibilities and rewards of caregiving
  - How to handle day-to-day problems
  - Information on community and support services
  - Self-advocacy
  - Effects of change and loss on marital and family relationships
  - Learning about health boundaries
  - Warning signs of caregiver stress
  - Ways to relieve caregiver stress
  - Taking care of yourself
  - What to say and do when you can no longer be a full-time or part-time caregiver
  - Coping with your feelings
  - Dealing with grief and moving on
- Sample discussion topics for older children and adolescent groups:
  - Dealing with stigma
  - Who to talk to if you have questions
  - Thinking about the future, having families and romantic relationships
  - How to talk to your friends about HIV
  - Dealing with anxiety, depression and other painful feelings
  - Understanding more about HIV so you can talk to others about not fearing getting HIV from you



## APPENDIX 5: GUIDELINES FOR PANEL PRESENTATIONS



Exercise 9: Disclosure panel presentation	
<b>Purpose</b>	Participants will gain insight into paediatric disclosure from a caregiver’s perspective. This panel could be used in a number of ways, depending on the setting. One possible panel might include both healthcare workers who have worked with families disclosing to children as well as caregivers who have gone through the process themselves. Each panellist will bring their own perspective and experience with real-world challenges and solutions.
<b>Room Setup</b>	Ensure panellists are comfortable and can be seen and heard by all audience members. Chairs at a table set up on a raised platform may be preferable; podiums may be intimidating for panellists. Ensure each panellist has access to a microphone, if necessary and available, and to a glass of water.
<b>Preparation</b>	<p>Start planning the panel a month in advance, if possible (but at least a week in advance).</p> <p><b>Choose a qualified moderator.</b></p> <ul style="list-style-type: none"> <li>The moderator must have experience working with and leading groups (e.g., a social worker, psychologist, or nurse experienced in caring for PLHIV). Meet with the moderator at least one week prior to the panel presentation to review the purpose of the exercise and their role. Provide practice questions for the panel and discuss strategies for avoiding problems.</li> </ul> <p><b>Recruit 1–4 panellists.</b></p> <ul style="list-style-type: none"> <li>Identify one or more healthcare workers who have gone through the disclosure process with families and can share the challenges and solutions from a healthcare perspective.</li> <li>Identify one or more people who have gone through the process of disclosure to their own children or a relative’s children to discuss their experience and real-world challenges and solutions. Client panellists should have publicly disclosed their HIV status and be comfortable talking about disclosure.</li> </ul> <p><b>Plan the presentation.</b></p> <ul style="list-style-type: none"> <li>Ask each panellist to take no more than four or five minutes to share their experience, challenges, solutions and lessons learned in the disclosure process.</li> </ul>

	<ul style="list-style-type: none"> <li>• Ask a few introductory questions to begin the discussion session (below).</li> <li>• Allow participants to ask their own questions and guide those questions to the appropriate panellist.</li> </ul> <p><b>Interview potential panellists in advance.</b> Interview panellists ahead of time to assess the individual's willingness to participate in the panel. Ensure potential panellists will be able to comfortably and clearly talk about the impact of HIV on their lives. PLHIV and family members who express a great deal of anger may make audience members and other panel members defensive or angry, preventing the group from achieving the purpose of the exercise.</p> <p><b>Confidentiality</b></p> <ul style="list-style-type: none"> <li>• Ensure that healthcare worker panellists maintain the confidentiality of their patients unless they have express permission from those patients.</li> <li>• Ensure that client/caregiver panellists feel comfortable sharing information with a large group. For all participants, stress that confidentiality of these stories is expected and nothing is to be repeated outside the room.</li> <li>• In accordance with confidentiality policies, do not identify by name any speaker who is HIV-infected in written agendas or printed materials without his or her explicit permission. Ask the referring agency or individual for suggestions on ways to contact panellists without compromising their anonymity.</li> </ul>
<b>Logistics</b>	<ul style="list-style-type: none"> <li>• <b>Prepare the panellists.</b> Once you decide on the final panellists, provide information about the date, time and objectives of the activity. Explain the training course to the panellists, the objectives and introduce the participants (e.g., who they are, their job positions, their attitudes toward people with HIV and disclosure). Advise the panellists that they may cancel their commitment at any time. Tell panellists that they should not feel obligated to answer questions that make them feel uncomfortable and that it is OK not to share information they think is too personal.</li> <li>• <b>About 3 to 4 days before the event,</b> contact the panellists to see whether they have questions about the panel and to confirm attendance. Also, discuss which issues they are planning to focus on and review concerns regarding anonymity (e.g., photographers, media presence).</li> <li>• <b>Budget for panel honoraria and expenses.</b> Whenever possible, pay panellists an honorarium and offer food, transportation and child care reimbursement, as needed. If policy allows, be prepared to make payments in cash on the day of the panel workshop. Make sure to obtain a signed receipt from panellists.</li> </ul>
<b>Moderator's role</b>	<b>The moderator's role is critical to the panel's success.</b> The moderator can:

	<ul style="list-style-type: none"><li>• Arrange to meet with all panellists before the panel to help make them more comfortable.</li><li>• Review the format for the panel: time allowed for each presentation, when and how the audience will ask questions.</li><li>• Ask panellists how they would prefer to be introduced to the audience. Panellists may prefer to introduce themselves so they control how much identifying information they disclose.</li><li>• Be supportive. Assure panellists that they may refuse to respond to any question — at any time and for any reason.</li><li>• When the panellists are speaking, monitor time closely to ensure that everyone gets a chance to speak. Gently remind panellists if they are exceeding the time limit.</li><li>• Facilitate a question and answer period.</li><li>• At the end of the panel discussion, the moderator should be available to provide panellists with support and to thank each panellist.</li></ul>
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Adapted from: Mountain-Plains Regional AIDS Education and Training Center. 1994. HIV/AIDS Curriculum, 5th Edition. Mountain-Plains Regional AETC: Denver, CO.



## RESOURCES FOR FURTHER INFORMATION



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Children's Rights Centre has a wealth of information on children and HIV. Accessed: <http://www.childrensrightscentre.co.za/site/awdep.asp?depnun=20723>

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<sup>2</sup> Myer, L., Moodley, K., Hendricks, F., & Cotton, M. (2006). Healthcare providers' perspectives on discussing HIV status with infected children. *Journal of Tropical Pediatrics*, 52(4), 293-295.

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