Health
Social Development

A FLIPCHART

FOR CHILD AND ADOLESCENT DISCLOSURE COUNSELING (CADC)

SOP 3



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ACKNOWLEDGEMENTS

This tool was originally developed by Dr Leon Levin, Dr Marnie Vujovic and Dr Julia Turner from Right to Care and Saranne Meyersfeld based on a method developed by Dr Leon Levin.

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DISCLOSURE TOOL FOR ADOLESCENTS

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Acronyms and abbreviations

ARV - antiretroviral (medicine)
C/ALHIV - child or adolescent living with HIV
CADC - child and adolescent disclosure counselling
HCP - health care provider
NDOH - National Department of Health
PCG - parent or caregiver
PLHIV - people living with HIV
SOP - standard operating procedure
SSP - social service practitioner

Overview

- This disclosure tool is a desktop tool to be used while conducting partial, full and post-disclosure with children and adolescents living with HIV (C/ALHIV)
- It is intended to be used by either the health care provider (HCP) or social service practitioner (SSP) or the parent or caregiver (PCG). For the rest of the tool the abbreviation "HCP/SSP/PCG" will be used to refer to either of the three.
- The tool engages young people with illustrations (which should face the C/ALHIV), while the other side guides the HCP/SSP/PCG on what to say.
- The speech bubbles indicate the sections that should be said by the HCP/SSP/PCG
- The PCG should be given the option to choose whether they would like to either:
  1) do the whole process,
  2) do the whole "full disclosure" process,
  3) only do the actual disclosure section on page 27 and page 29 in which the PCG answers the C/ALHIV's question about whether or not they have HIV, or
  4) do none at all.
- If the PCG chooses to do the whole "full disclosure" process they should refer to the solid yellow blocks on page 25, 27,29 and 33, in which they refer to themselves in the first person.
- Where possible this tool was made to align with Annexure 7 of the NDOH ART Clinical Guideline, as well as the Child and Adolescent Disclosure Counselling (CADC) SOP3 in the Adherence Guideline.

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GUIDANCE FOR ALL SESSIONS

BEFORE EACH SESSION:

- Prepare the parent/caregiver
- Familiarise yourself with the content of the session
- Conduct readiness assessment and get consent before full disclosure

DURING EACH SESSION

- Prepare a warm friendly and conducive environment to conduct a disclosure session, establish language preference and assure caregiver and child of confidentiality.
- Build rapport with caregiver and child by introducing yourself and ensure the child is comfortable.
- Use age-appropriate simple, clear language.
- Do not use a tone of voice that makes the child think that living with HIV is a terrible thing
- Listen, respond and allow the child to express emotions.
- Discuss immediate concerns and help caregiver and child decide who in their social network may be available to provide immediate support.
- Provide information on care and support, adherence, treatment and prevention services. (do not mention the word HIV until after full disclosure)
- Encourage and provide time for the caregiver and child to ask questions
- Accept and normalise feelings, contain reactions with empathy and allow space for personal expression

AT THE END OF EACH SESSION:

- Ask the caregiver and the child if they have any questions or concerns.
- Ensure ongoing assessment of the child's wellbeing.
- Refer for psychosocial support such as social worker, psychologist, support group for both child and caregiver.
- Schedule and confirm the follow up visit after determining a suitable date and time with the caregiver (ideally align with treatment supply appointment dates).
- Document sessions in the disclosure records.
- Leave IEC materials with the patient after making sure that the patient understands information on IEC material in their language. (do not share anything with the word HIV with a child who has not finished full disclosure)
- Provide hope and encouragement to caregiver and child.
- Encourage the PCG to create an environment in which the young person feels comfortable asking questions and expressing emotions.

CAREGIVER PREPARATION

PREPARATION FOR PARTIAL OR FULL DISCLOSURE: CONTENT TO BE COVERED WITH THE CAREGIVER ONLY (WITHOUT THE CHILD).

If the child has already had partial disclosure you can leave out the discussions about partial disclosure, but if not, then you should talk about both in order to start preparing the PCG for both partial and full disclosure in the future.

1 Ask what the caregiver has told the child so far about the reason for coming to the clinic and taking treatment.
Explain the disclosure process as follows:

Adolescent disclosure refers to telling a teenager they have HIV. We recommend that the disclosure process is like a journey with many stops. At each stop, we will explain a little more to the child.

From 5 years old, we do not tell the child they have HIV but tell them that they need to take medicine to make their soldier cells strong to fight other germs. We call this “partial disclosure”.

At the end of the journey, when it is the right time for the child (around age 10-12 years old), the child will learn that they have HIV. We call this “full disclosure.

2 Explain the advantages of partial disclosure (age 5-9 years):

It is important to tell the child the truth but without telling them they have HIV. It gives them a reason to take their medicine and builds honesty in the relationship.

3 Explain the advantages of full disclosure (usually 10-12 years old if the child is of normal maturity):

Usually, adolescents who know their status take their medicine better and take responsibility for their own health. Children often know that something is wrong. They may have fears that are worse than the real thing. Hearing about HIV from you rather than anyone else will help the child to accept the situation. They need to know their HIV status before they are sexually active, and before they figure it out through other mechanisms. Adolescents have the right to know about their own health and don’t like to be lied to.

4

Explain that:

Children and adolescents living with HIV (C/ALWH) often learn negative myths about HIV from their community, their friends and school, such as “HIV kills”, “people with HIV are promiscuous or bad” and “people with HIV can’t live a normal life.”

5

These are not true! It is therefore extremely important to educate C/ALWH and dispel all of these myths **before you tell them they have HIV.** Do you think you would be able to start teaching your child about HIV at home from a young age **(without telling the child that they have HIV)?**

6

Try to bring it up in normal conversation, and to ask the child what they know about HIV.
Five important things for them to understand include:

1. These days we have very good treatment for HIV, so people living with HIV (PLHIV) can remain perfectly healthy and never get AIDS.
2. PLHIV can live as long as people without HIV if they take their treatment every day.
3. Anyone can have HIV and it does not make them different or bad. Many people around you have HIV and you do not know because they are just as healthy as those without HIV.
4. PLHIV can have relationships and have children, and if they are taking their treatment and have a suppressed viral load, they will not transmit HIV to their sexual partner or children.
5. Living with HIV does not prevent people from living a completely normal life and following any career they want.

ASSESS BARRIERS TO PARTIAL AND FULL DISCLOSURE:

If preparing for partial disclosure ask:

7

How do you feel about giving information to the child today without calling it HIV?
What are your fears about telling the child they have HIV when they are 10-12 years old?

8 If preparing for full disclosure ask:

What are your fears about telling the child they have HIV?

9
- Try to address these fears with empathy.
- Talk the PCG through the relevant session to be held in the future (partial or full disclosure) so that they get an understanding of what will be told to their child.
- Explain to the PCG that they can choose what role they play – if they would like to do all the talking, or only do the end part where they tell their child they have HIV (on page 31), or if they don't want to do any of the talking.
- Allow them to ask questions and reassure them about the benefits of partial/ full disclosure.
- Allow them to talk to other PCG who have been through the disclosure process to get reassurance.
- Repeat this session with caregiver until caregiver is ready to bring the child for partial/full disclosure.

CONDUCT READINESS ASSESSMENT AND CONSENT AS BELOW:

10

	PARTIAL DISCLOSURE	FULL DISCLOSURE	POST-DISCLOSURE
Readiness assessment	Age over 5 years, and ask the PCG if the child is of normal maturity for age (if they are in the correct grade for	Within DSD: SSP to use Disclosure Readiness Assessment Checklist Within DOH: HCW to check the following: • Age > 10 years old • Normal maturity for their age (for example they are in the correct grade for their age. If not, and they are not sexually active, suggest delaying for a year or two.) • Child agrees that they want to know the name of their illness. • Ensure adequate family/peer/social support or refer to SSP if necessary • Caregiver has been through preparation session, chosen their role and given consent.	Not applicable
Consent	Verbal consent (and write in the individual file of the client)	Written or verbal consent (and write in the individual file of the client for example "I _____, parent/caregiver of _____ give consent for full disclosure. Signed _____ Date_____", and ask the PCG to sign. If PCG cannot sign, 2x HCW/SSP can sign as witness).	Not applicable


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PARTIAL DISCLOSURE (Age 5-9)

Healthcare provider / parent or caregiver / Social Service Practitioner



- *Prepare for this session by ensuring that you are familiar with the content and following the sections on "Guidance for all sessions" and "Caregiver preparation."*
- *Assess child's readiness for partial disclosure by checking if they have normal cognitive maturity for a 5-9 year old. If they are in the correct grade for their age they can be assumed to be of normal maturity.*

1 **How are you feeling today?**

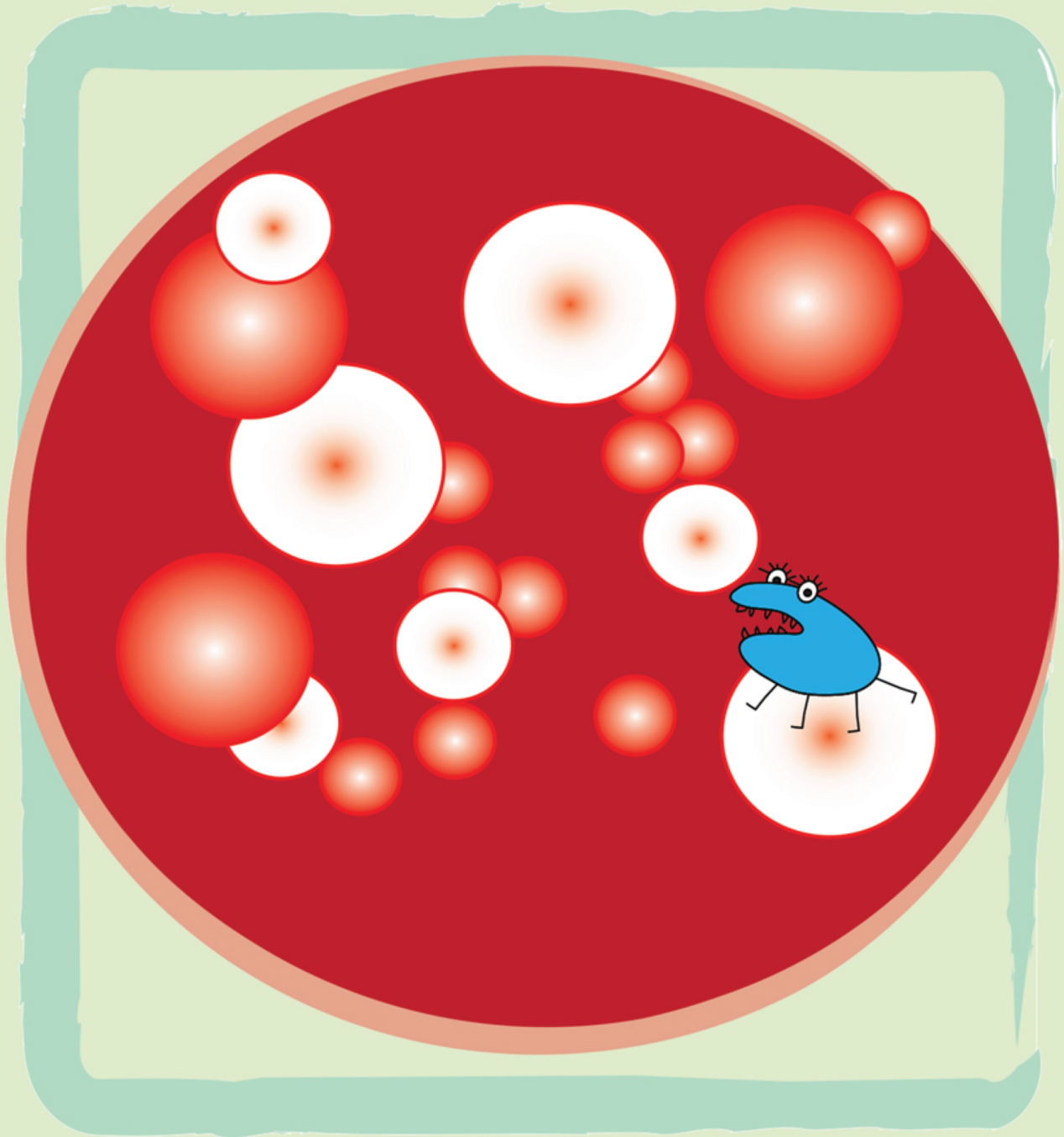
*Put the young person at ease and assess current state of health **(the session is postponed if the young person is ill or psychologically not well).***
Conduct a feelings check.

2 Hmm you say you are not sick/feeling unwell. Maybe you are wondering why you are taking medicine every day**?**
Do you know why that is?

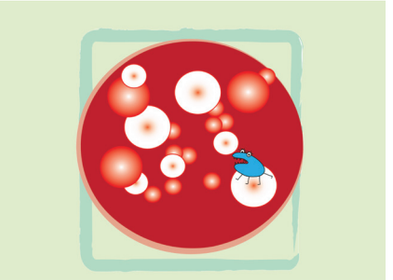
If the young person indicates that s/he does not know ask:

3 **Do you want to know?**

4 **Ok I will tell you**.



PARTIAL DISCLOSURE



5 Let's start by talking about blood.
What colour do you think blood is?

Provide the answer "Red" if the young person cannot.

6 In your blood there are red blood cells which make it red. There are also some other little cells in your blood, what colour do you think they might be?

If the young person is unsure say "I am going to give you a clue" and point to the white cell in the picture, that will assist him or her in providing the answer "white".

7 Right!
Now we are going to talk about those white cells.

8 White cells are the soldiers in our bodies.
They fight germs and keep us well.
This little blue creature in the picture is a germ!
Do you know what a germ is?

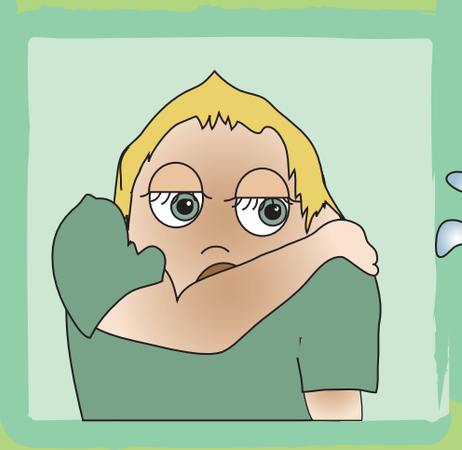
Allow the young person to answer.

9 **Let's try this little quiz about germs.**
You can guess if what I say about germs is true or false.

Caregiver can be included e.g. by asking young person and caregiver a question each.



Coughing and sneezing spreads germs



When sneezing or coughing, covering mouth keeps germs from spreading



Washing hands keeps germs from spreading



Taking medicine helps kill germs

PARTIAL DISCLOSURE

GERM QUIZ
True or False

Q 1 **Germs can make us sick.**

True



Q 2 **Coughing and sneezing spreads germs?**

True



Q 3 **When sneezing or coughing, covering your mouth keeps germs from spreading.**

True



Q 4 **Washing hands prevents germs from spreading**

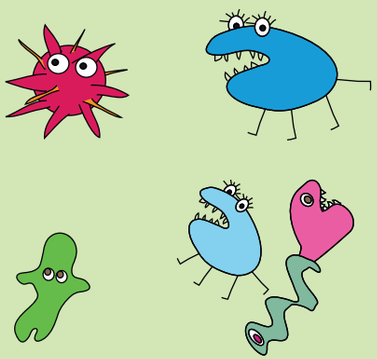
True

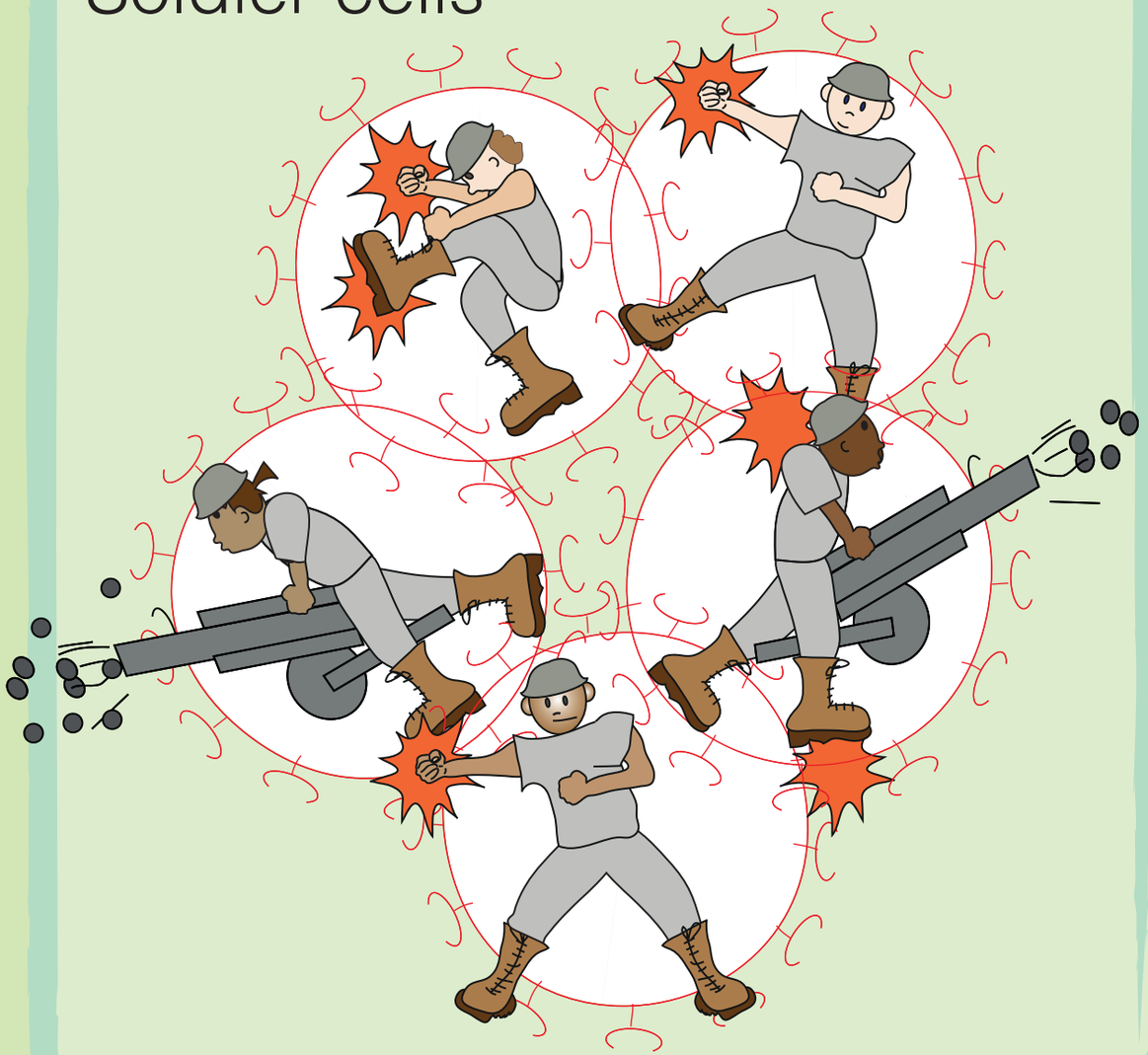


Q 5 **Taking medicine helps kill germs?**

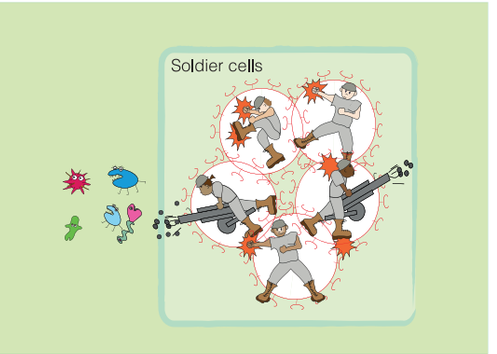
True

Soldier cells





PARTIAL DISCLOSURE



10 Great! You know some things about germs already. **So we can say that a germ is something that makes us sick.**

11 Remember we said white cells are the soldiers that fight germs. **What do you think a soldier cell would do if it found a germ?**

Encourage the young person to answer.

12 The **white cells** travel around our bodies in our blood looking for germs. **When they find them they kill them so that we don't get sick.**

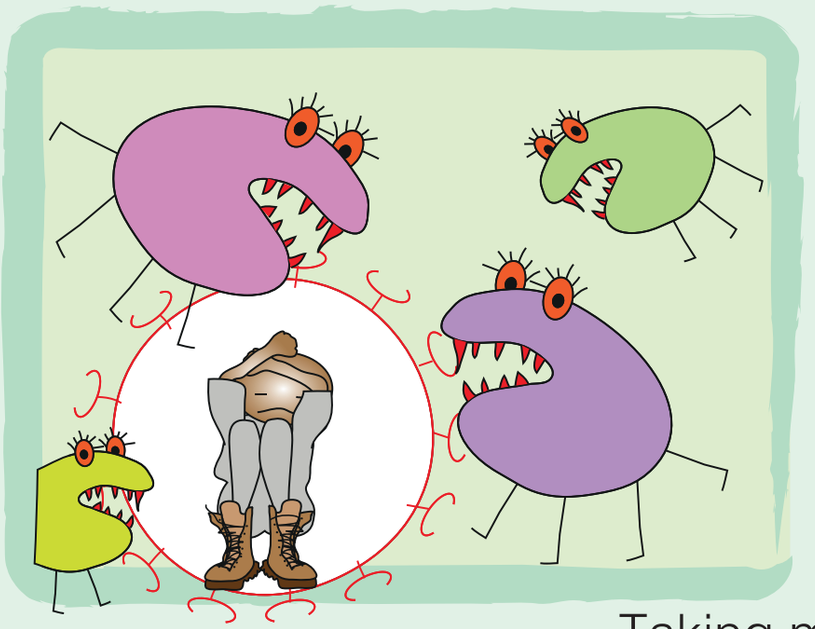
13 But what would happen if a person did not have many soldier cells in his/her blood but only very few?

Encourage the young person to answer and assist if necessary.

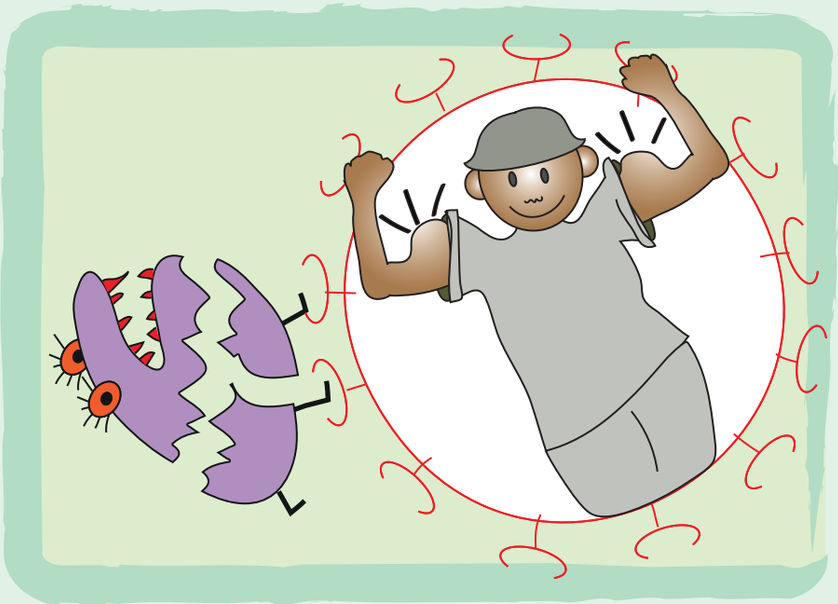
14 A person with very few soldier cells in his/her blood may become sick. You had very few soldier cells when you first started coming to the clinic / hospital.

Helping soldiers fight strong germs

Germs fighting soldier



Soldier strong again

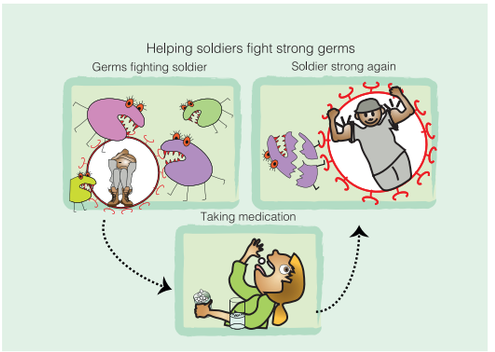


Taking medication



PARTIAL DISCLOSURE

15 That is why you started taking medicine to keep your body strong and help to make more soldiers cells. You can see in the picture, when the girl takes her tablets, her soldier cells become strong and the germs die.



16 Remember when I asked you if you were sick or not? You said you were not sick. **Is that right?**

Allow the young person to answer

17 You are not sick because your medicine is keeping you well. It is preventing you from getting sick.

18 What do you think will happen if you stop taking the medicine?

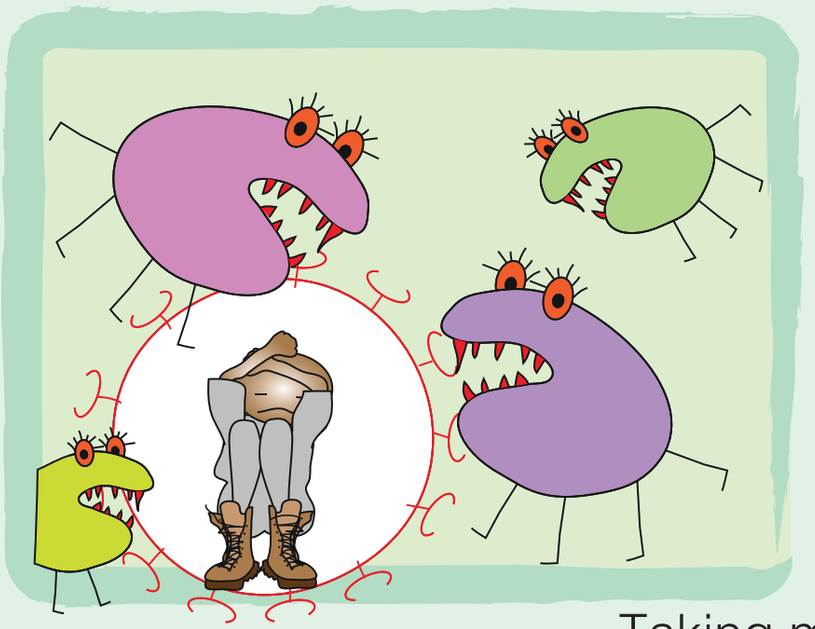
*Allow the young person to work it out. If they can't, assist by saying **"you may get sick."** Explain that this doesn't always happen quickly. Sometimes a person may only become sick after some time.*

19 This is why it is very important to take your medicine. **You need to take your medicine every day so that you don't get sick**.

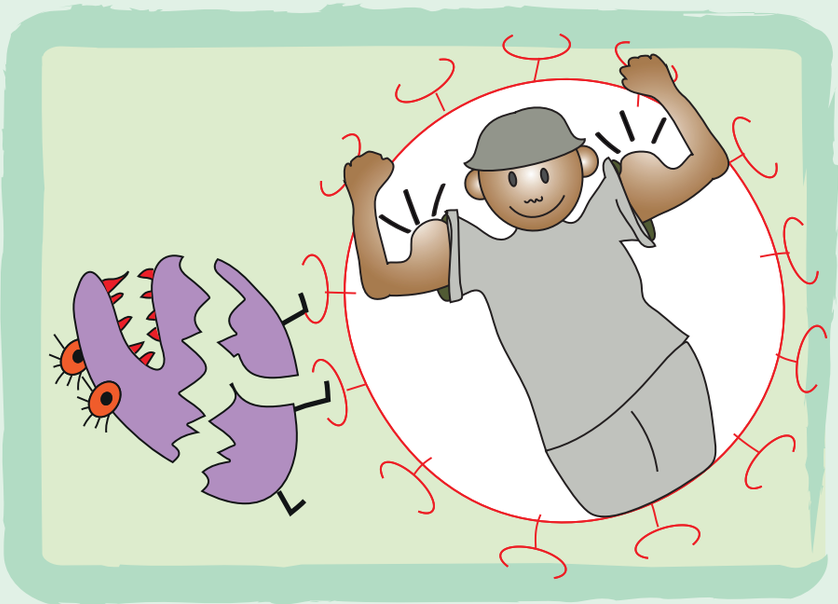
Summarise the session:
*Ask the young person/caregiver if there are any questions. **Make an appointment for the next session (**this can be a further partial disclosure visit or a full disclosure session depending on the age, readiness and maturity of the young person.*

Helping soldiers fight strong germs

Germs fighting soldier



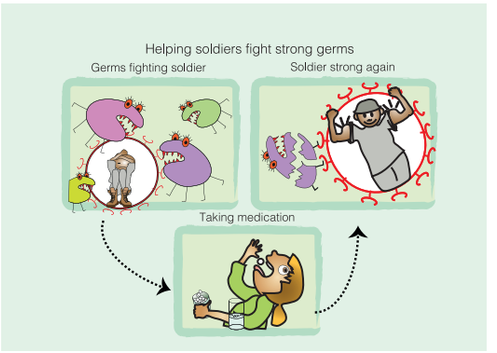
Soldier strong again



Taking medication



FULL DISCLOSURE Age 10-15 (ideally 10-12 if of normal maturity)

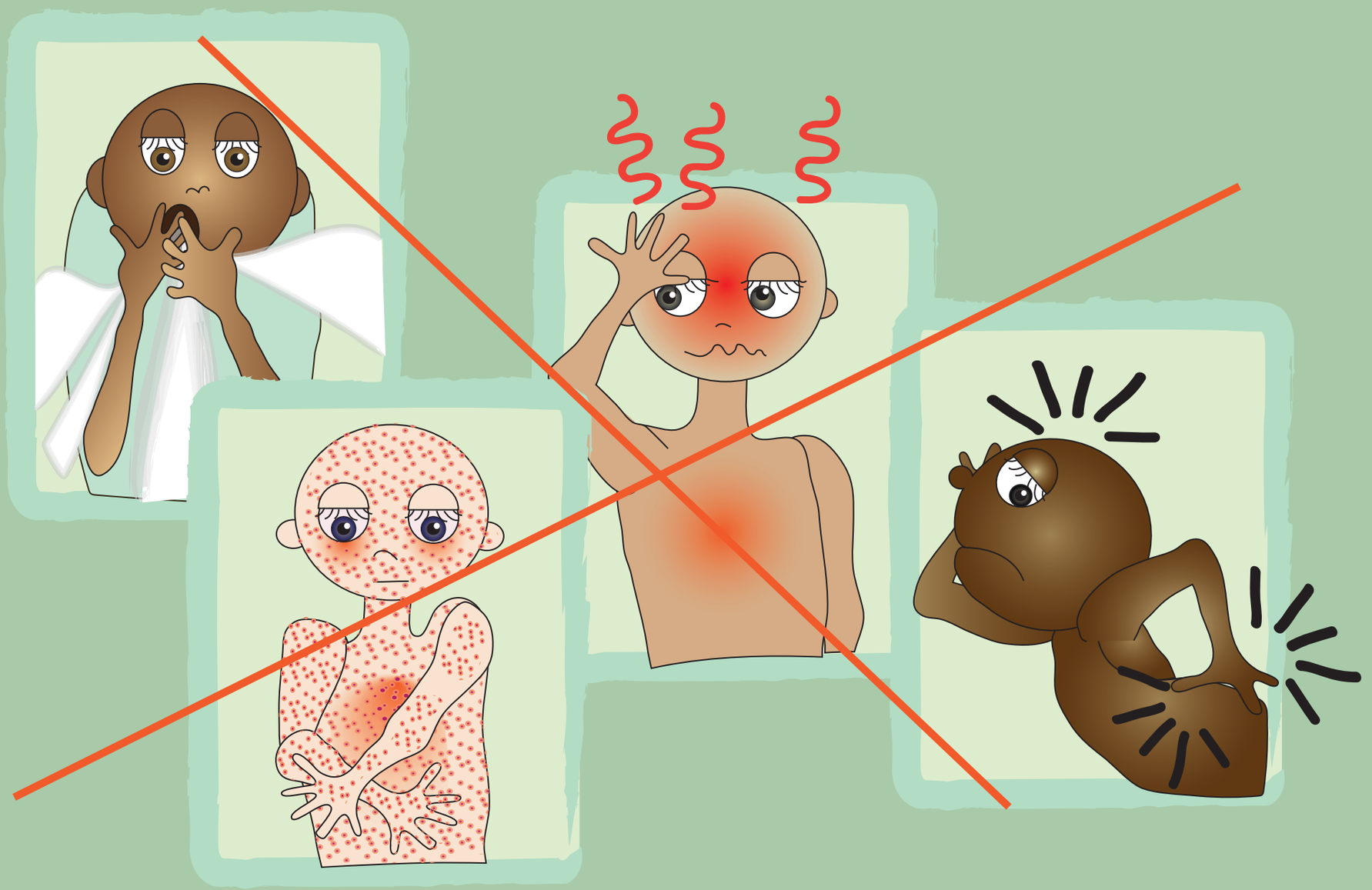


- *Ensure you have consent from the parent/ caregiver to tell the child they have HIV and ideally to also disclose that the parent or caregiver has HIV.*
- *Prepare for this session by ensuring that you are familiar with the content, and following the sections on "Guidance for all sessions" and "Caregiver Preparation."*
- *Greet the young person warmly.*
- *Explore what has happened since the partial disclosure session and do a feelings check.*
- *Disclosure readiness should be assessed for the C/ALHIV and the caregiver. C/ALHIV should be assessed for sufficient maturity. If the readiness assessment outcome indicates that child is not ready; establish the reasons and challenges thereof; and work on them first.*

1 Do you remember what we talked about last time?

2 Would you like to know the name of the germ which was killing your soldier cells?

Allow the young person to answer. If necessary, remind the young person by saying: ***"When you first came to this clinic / hospital you had very few soldier cells in your body to fight infection. Your body is able to fight infection now because the medicine you take every day is keeping your soldier cells strong so they can fight germs and keep you strong."***

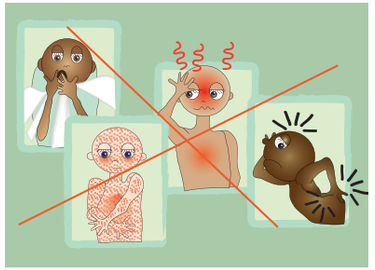


FULL DISCLOSURE

3

(Child's name), "I can see that you are very clever. You and I will work out together what the name of your sickness is. We are going to do that by playing a **game. This is how the game works.** We are going to discuss many sicknesses, one at a time. With each sickness, we will discuss that sickness and decide together if that is what you have. If not, we will throw that sickness away and discuss a new sickness. We will continue until we finally decide which one is your sickness. **Are you ready to start?"** (Once the child says yes, then say…) "Ok, what sicknesses do you know ..."

Let the child name any sickness. If child can't name a sickness, then you can name one of the sicknesses in column A and continue from there. ***Note: If the young person mentions HIV straight away say:*** *"That is a good answer but a little complicated, let's come back to that. Lets talk about some other sicknesses together."*



4

What do you know about that germ/sickness? What kind of sickness does it cause? Is there treatment for this sickness? How long does the sickness last?

If they don't know, tell them using the Information in column C.
Tell them the answers if they don't know

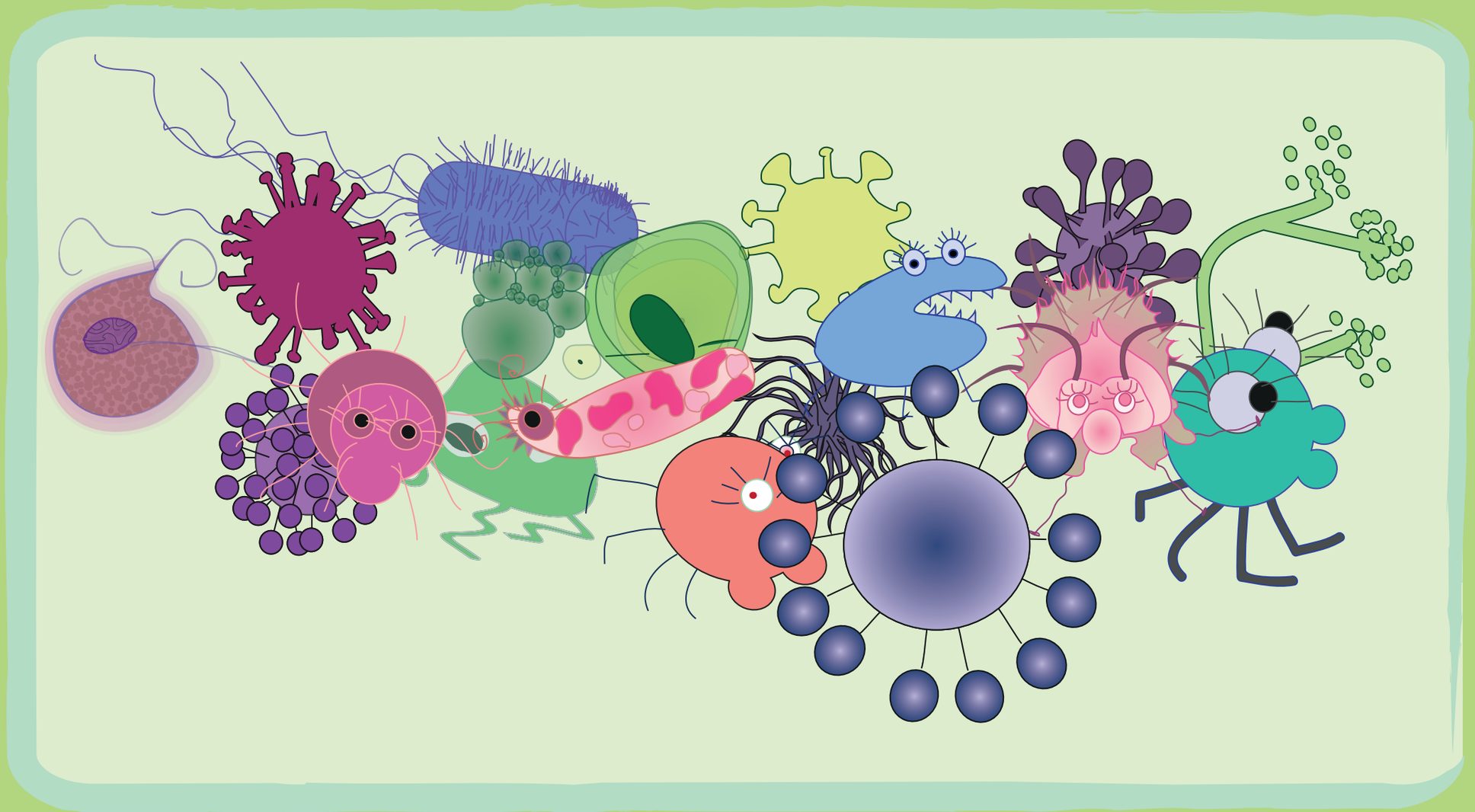
5

"Do you think you have that germ/illness? If not, why not?"

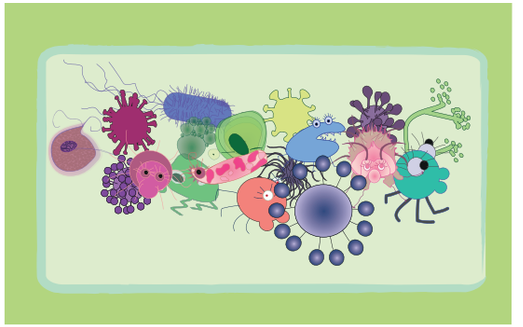
Refer to column B

Be prepared to respond appropriately if the illness named is not on the table or discuss one or two of the illnesses on the table if the young person can't think of any himself/herself.

A	B	C
ILLNESS	**RESPONSE - YOU DON'T HAVE THIS SICKNESS BECAUSE . . .**	**MOST COMMON SYMPTOMS**
Influenza - "Flu"	Flu only lasts about a week.	Temperature, runny nose, headache, body aches.
Chicken Pox	The rash of chicken pox only lasts about a week.	Itchy rash, temperature for about a week.
Measels	The rash of measels only lasts about a week.	Rash on the body, white spots in the mouth, temperature, runny nose, red eyes and a dry cough.
Ear Infection	Only lasts a couple of months at most and we don't treat for years.	Painful ear, discharge from the ear, headache, temperature.
Bronchitis	Children with bronchitis cough a lot and don't need treatment for years.	Wet, phlemy cough, painful chest when coughing.
Tonsilitis	You have a sore throat with tonsillitis and we don't treat it for years.	Sore throat, swollen glands, white spots on the tonsils, temperature.
Asthma	Asthma is common but it doesn't kill the soldier cells.	Cough, tight chest, wheeze and shortness of breath that comes and goes.
Cancer	Cancer and its treatment does kill the soldiers cells, but the treatment also lasts a year or two.	Many different symptoms depending on the type of cancer.
TB	TB can weaken your soldiers cells, and it could be that you have has TB, but you don't take medicine for TB for years and years.	Cough for a long time, night sweats and loss of weight.
COVID-19	You don't have any symptoms. Covid -19 only lasts about two weeks.	Fever, dry cough, tiredness.



FULL DISCLOSURE



After going through 3 or 4 sicknesses...

6 So we have decided that it is not……..
So then what else could it be?

If the young person mentions another illness refer to 5 on the previous page.

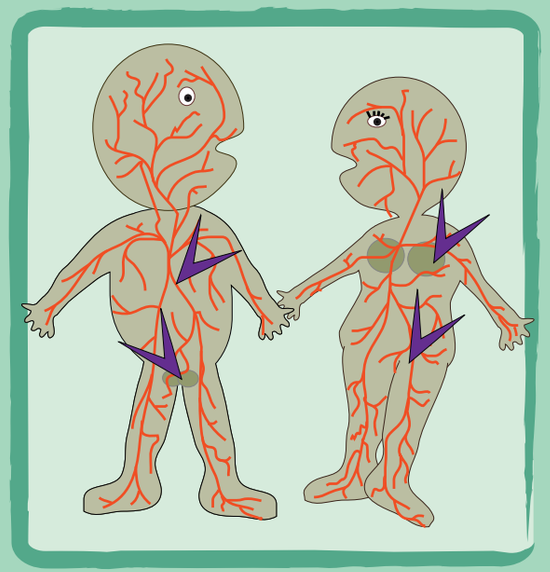
7 There is another illness we have not spoken about. **It is called HIV.**

***Note:** If a young person has mentioned HIV earlier say "you mentioned HIV earlier, let's come back to that one now"*

8 Let's talk about HIV.
Maybe you know a lot about HIV from school?

Find out what the young person knows.

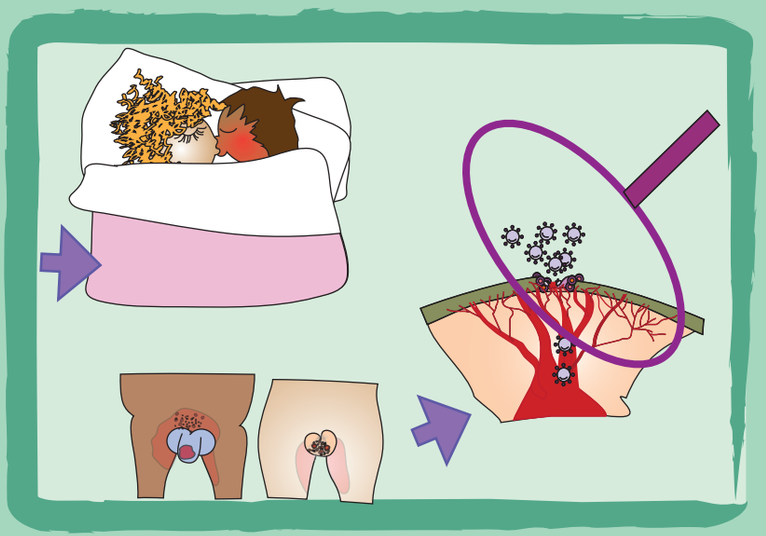
Where HIV lives in the body

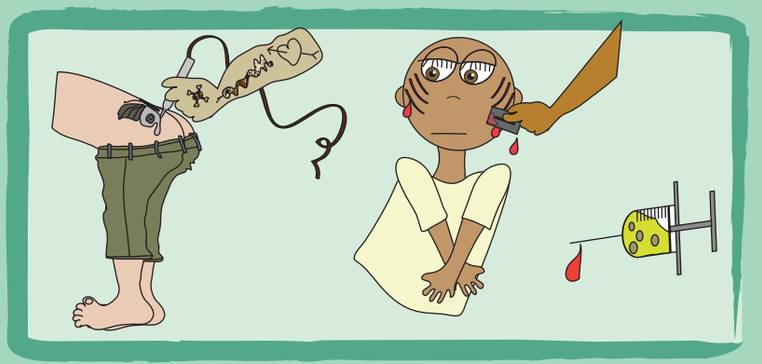


How HIV is NOT transmitted



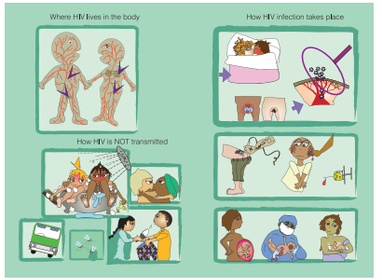
How HIV infection takes place







NOTE: You are teaching the child about HIV, but you **HAVE NOT** told them they have HIV yet, so just talk about HIV in general, **do not refer to them having HIV!**



9 "How can people get HIV?"

"People can get HIV through unprotected sex or from blood or it can be passed from a mother to her baby during pregnancy or breastfeeding. You can see in the pictures the ways HIV can be spread and ways it cannot."

10 "Is there treatment for HIV?"

"Yes, there is a medicine that works well, it cannot yet cure HIV but it controls it. This means that people who take their medication every day are well and fit and live completely normal lives. You won't be able to tell if a person has HIV. They don't look sick and they don't feel sick because the medicine makes sure the army of soldier cells stays strong."

11 "How long can people with HIV live?"

"People living with HIV (PLHIV) can live just as long as people without HIV if they take their treatment everyday."

12 "Can people with HIV do any job?"

"Yes, people with HIV can do whatever job they want! Living with HIV does not prevent people from living a completely normal life."

13 "Can people with HIV get married and have children?"

"Yes! PLHIV can have relationships and have children, and if they are taking their treatment and have a suppressed viral load, their sexual partner and children will not get HIV."

14 "Are people with HIV bad or different?"

"No! definitely not! These days HIV is so common that anyone can have HIV, and it does not make them different or bad. Many people around you have HIV and you do not know because they are just as healthy as those without HIV."



15

"Many people have HIV: people of all different ages and races, and people who have all different jobs. You can't tell who has HIV or not, because they are all happy and healthy and completely normal."



NOTE: If it is the parent/caregiver using this tool, they can omit the rest of this page.

16

"Could I (the healthcare worker) have HIV?"

The child generally says no.

17

Then "So you think I can't have HIV because I am healthy and strong, but remember we said that there is very good treatment for HIV, that works so well that people with HIV live just as long and healthily as anyone without HIV".

"If I had HIV would it mean I am a bad person? No, it wouldn't, remember lots of people have HIV these days and it is not their fault, they did nothing wrong! If I had HIV could I still get married and have children? Yes, I could and if I was taking my treatment well, my husband/wife/partner and children would not get HIV! Could I still be a health care worker? Yes of course, people with HIV can do any job they want! Would it change who I am? No! Would you still be my friend? I hope so!"

If the child agrees with all the answers above then proceed to ask about the mother/father. If the PCG did not agree to disclose their own status, or is not living with HIV, leave out number 18 and move on to 19.



NOTE: If it is the parent/caregiver leading the disclosure process they can speak in first person i.e.

"Could I have HIV?"

Could I have HIV and be healthy and strong ...



18

"Could your mother have HIV?"

*The child generally says no, then you should say "*Could she have HIV and be healthy and strong because she is taking medicine every day? Yes! If she had HIV would it mean she is a bad person? No, of course not, remember lots of people have HIV these days and it is not their fault, they did nothing wrong! Would it change who she is? No! Would you still love her? Yes definitely."

If the child agrees with all the answers above then proceed to ask:

If it is the parent/caregiver leading the disclosure process, say "Do you want to ask me if I have HIV?"

19

"Do you want to ask your mother If she has HIV?"

Let the child ask their parent and let the parent answer. Then encourage the child to tell the parent they still love them and give them a hug.

If the child coped with finding out that their parent has HIV, proceed to the next questions.

As the discussion becomes personal monitor and manage emotions



FULL DISCLOSURE

20

"Do you think you could also have HIV?"

"Could you be healthy and strong because you are taking your medicine everyday? Yes. Would it mean you are a bad person? No, of course not!
Could you still get married and have children? Yes! Could you do any job you want? Yes!
Would it change who you are? No! Can you still have the same friends? Yes."



If it is the parent/caregiver leading the disclosure process, say "Do you want to ask me if you have HIV?"

If the child agrees with all the answers above then proceed to ask:

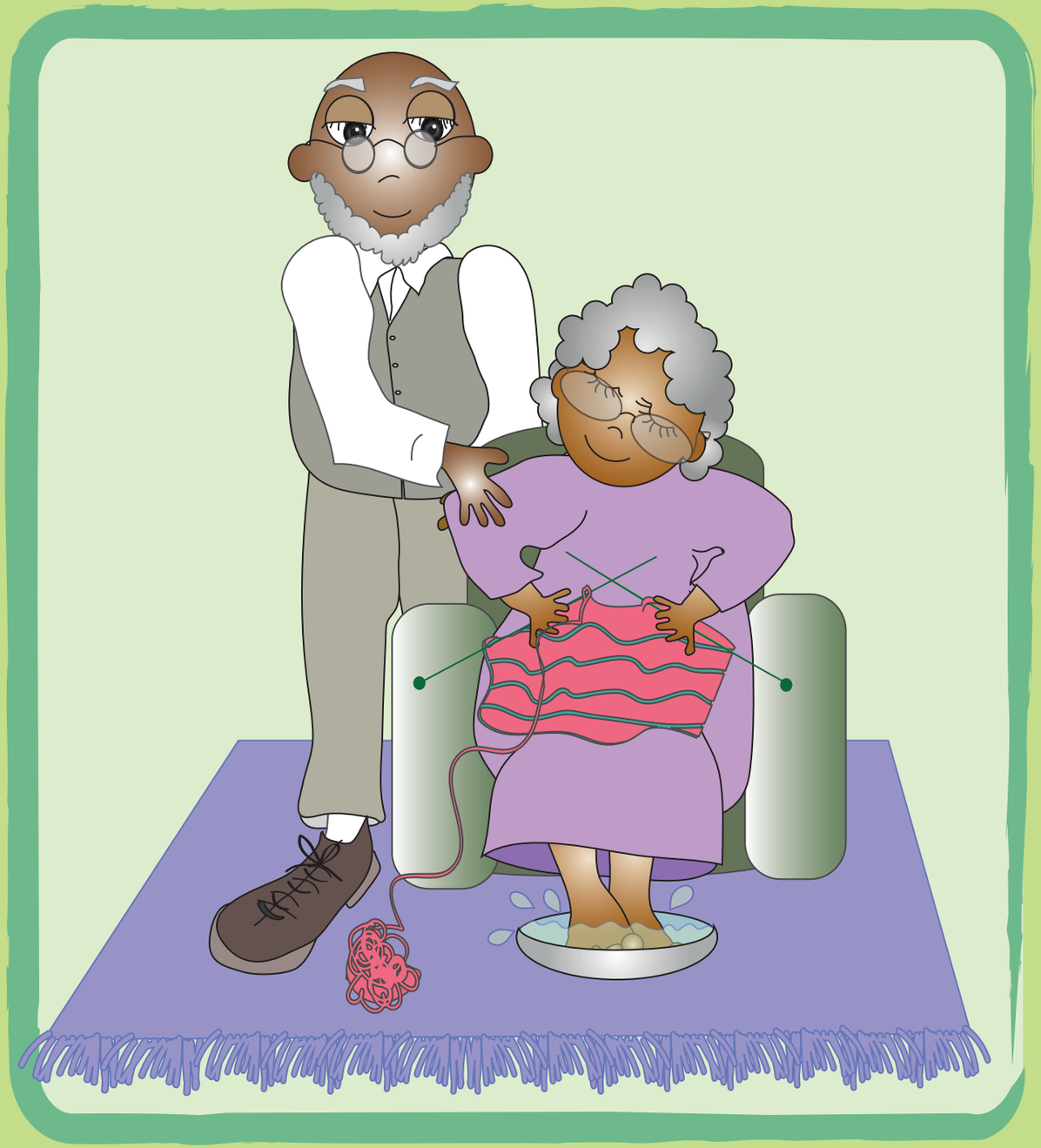
21

"Do you want to ask your mother/ father if you have HIV?"

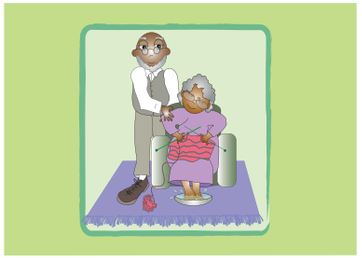
Let the child ask their parent and let the parent answer. Then encourage the parent to tell the child they still love them and give them a hug.

NOW the child knows that they have HIV

Ask the child how they are feeling and normalise and contain their emotions. Remember that according to the South African Guidelines, the final disclosure should be done by the caregiver/parent. If the caregiver/parent is comfortable, support him or her to tell the young person that he or she has the HIV virus and is taking medication to keep him or her strong and healthy.
The healthcare provider can undertake the disclosure if the caregiver or parents requests it. If no caregiver or parent is present and consent to disclose was obtained, the healthcare provider can confirm that the young person has the HIV virus. In this case disclosure to a trusted adult should be discussed. Whatever the case, it is always important to contain and reassure the young person and give them time to take the information in and respond with empathy.



FULL DISCLOSURE



22

"Today you have learned that the virus called HIV Is living in your body. You might feel scared, angry, shocked, or sad. It is normal to have these feelings."

If the caregiver or parent is present, give them an opportunity to interact with the young person, and to take lead in the disclosure process. Explore the feelings/emotions (Ask how the child feels). Observe the body language and emotions that may arise whilst engaging the child.

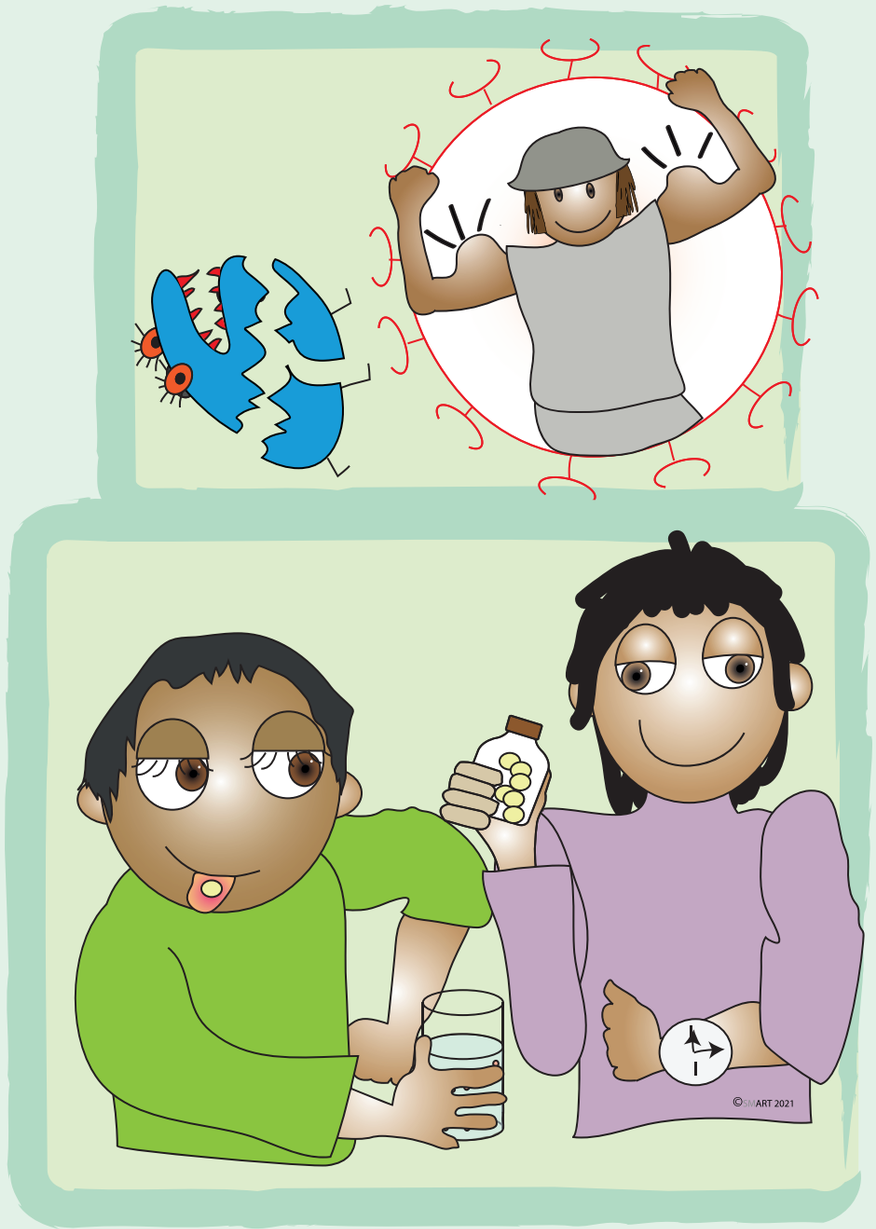
23

"Even though it might be hard to think about right now, it is important to know that you have HIV and that the medicine can keep you well."

Invite input from the caregiver or parent.

24

"Do you know that people used to be very scared of HIV?
People used to think it was a very strong virus and that people with HIV would not live long.
But now we know that is not the case. These days people can live until they are old (Gogos or grandfathers) as long as they take their medicine."

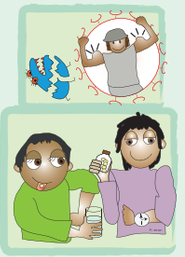

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FULL DISCLOSURE

25

"Do you know how HIV makes people sick?"

"HIV kills off the soldier cells, the white blood cells we spoke about that protect us from germs **(such as flu germ or TB germ etc.)**. When the soldier cells in the body become too few they can't protect us from germs then we might get sick."



NOTE: *If it is the parent/caregiver leading the disclosure process, say "It is important to remember that it isn't my fault that you got HIV."*

NOTE: *If it is the parent/caregiver leading the disclosure process, say "We didn't have such good medicine in those days when I was pregnant with you".*

26

"It is important to remember that it wasn't your mother's fault you got HIV."

"We didn't have such a good medicine in those days when she was pregnant with you.""

27

"It wasn't your mother's fault you got HIV. It also isn't your mothers fault that she got HIV"

"HIV is so common, anyone can get it."

28

"It is important to decide who you should tell that you have HIV or not. Do you think you should tell everyone at school?"

"It might not be a not a good idea. HIV is a sickness like any other sickness, but some people might treat us differently if they think we have HIV. We call this "stigma". For this reason it might not be a good idea to tell everyone that you have HIV. It is a decision you can make with your parents to decide who you should tell or not. We will discuss this more next session. We can also discuss how and when to tell your boyfriend or girlfriend."



FULL DISCLOSURE

29 “Now that you understand better, do you see how good your parents/caregivers have been to make sure you came to clinic and took your medication all these years to make sure you stayed healthy, even when you might not have wanted to take medicine. Aren’t they wonderful parents/caregivers?”

Allow child to answer



30 “When you visit next time we will talk some more about the medicine, but today what is important is that you know the name of the virus that you have, and how you can stay healthy and strong.”

Emphasize that the young person is not alone and there are many people who care and want to make sure that she or he is a winner against HIV.

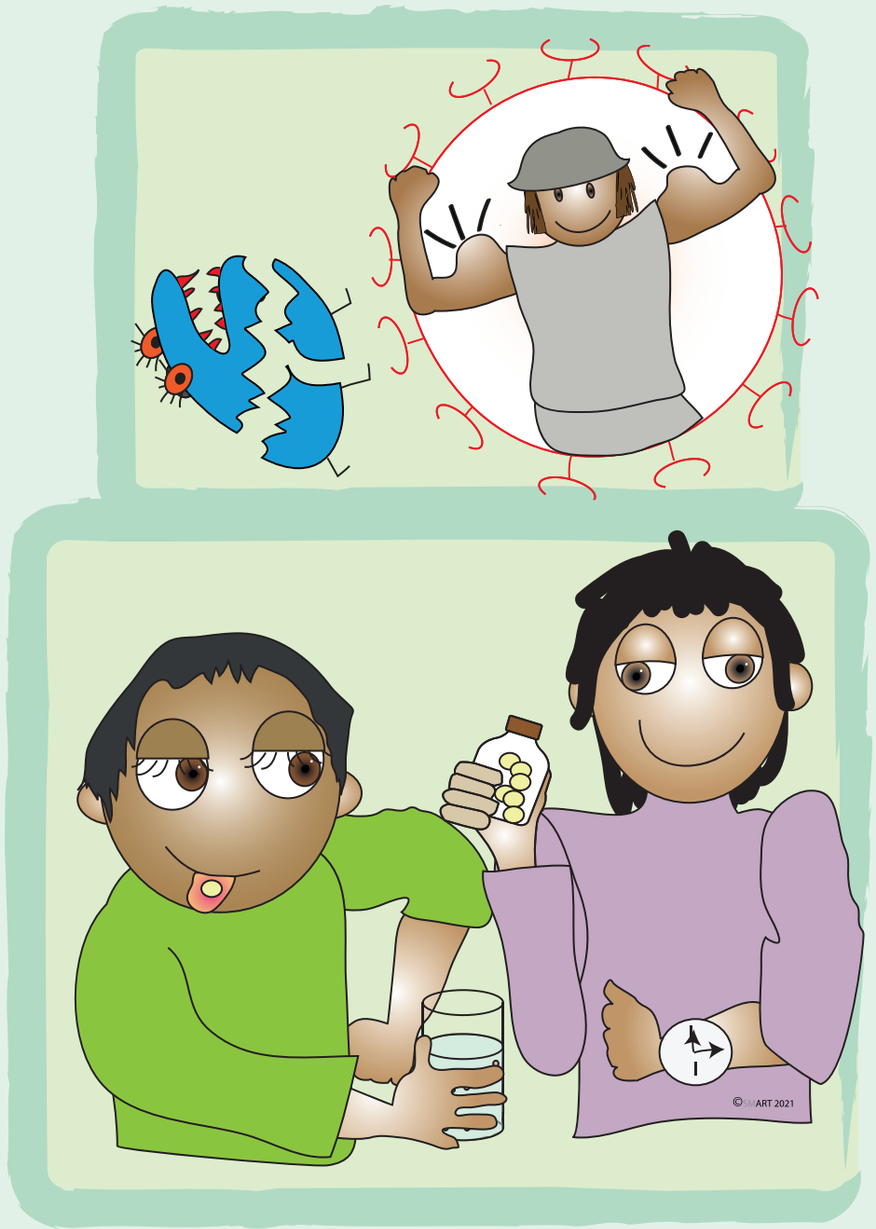
If the caregiver or parent is present, involve them in the conversation to reinforce the message of care and support. The caregiver should be asked to observe the behaviour patterns of the child after the session and identify any unusual behaviour that might arise post disclosure.

31 "We have spoken about a lot today, how are you feeling about it?"

32 “Do you have any questions?”

33 “We are going to end now. But I will see you again soon.
In the meantime remember that there is always someone to talk to if you want to chat or there is anything you want to know more about.”

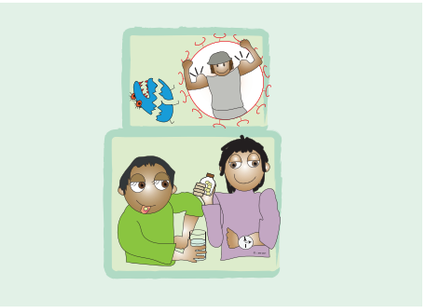
Ask parent/caregiver to confirm this. Inform child and parent/caregiver that they can return anytime if they are struggling or if the parent/caregiver notices any emotional or behavioural problem


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POST DISCLOSURE

Session One

Healthcare provider / Social Service Practitioner



POST DISCLOSURE SESSION 1 and 2 should preferably be done by the health care provider or social service practitioner, unless the parent/caregiver requests to do it.

- *Prepare for this session by ensuring that you are familiar with the content and follow "Guidance for all sessions".*
- *Greet the young person warmly.*
- *Explore what has happened since the full disclosure session and do a feelings check.*
- *Review the previous session.*
- *Ask the parent/caregiver how the child is adjusting after the disclosure, and whether there is anything that concerns them (such as withdrawal issues/isolation, anxieties, stress, eating disorders etc.) If so, refer as appropriate.*

1

"Do you remember some of the things we spoke about when we met last time?"

Allow the young person to respond.

2

"We said you had a germ in your blood that was killing the soldier cells or white blood cells that keep you well and healthy.

We said the proper name for the germ is the HIV virus.

Remember we talked about medicine and how this fights the virus so that your army of soldier cells can grow bigger and stronger, so you won't get sick.

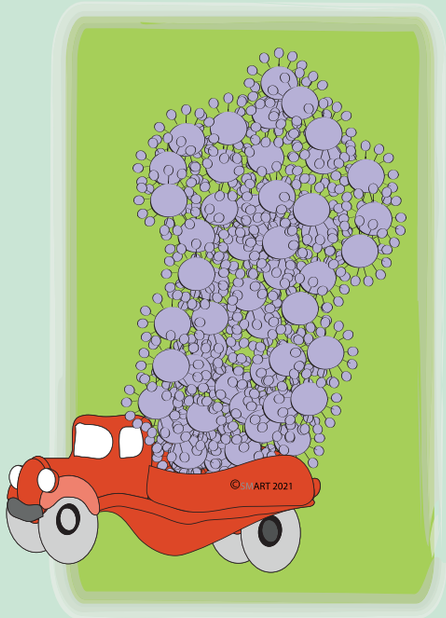
Do you know the name of that medicine?"

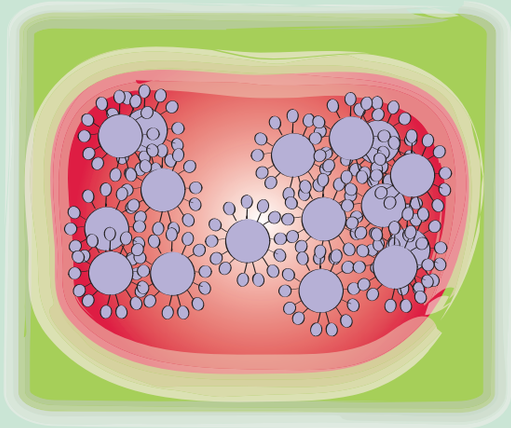
Allow the young person to respond, provide answer if necessary.

Without pills



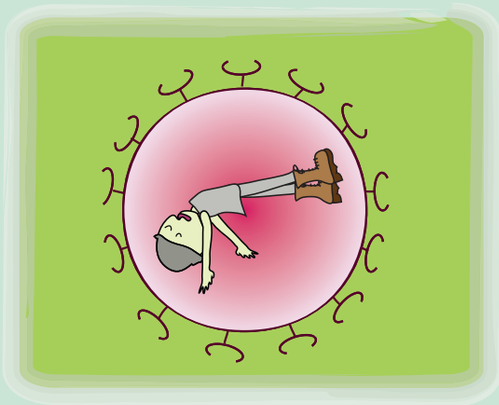
High viral load

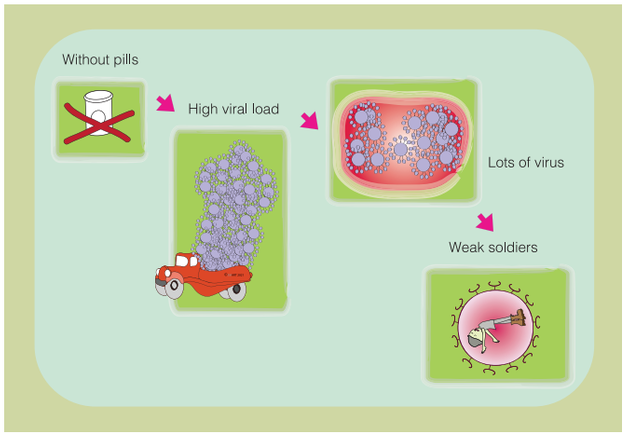




Lots of virus

Weak soldiers





3

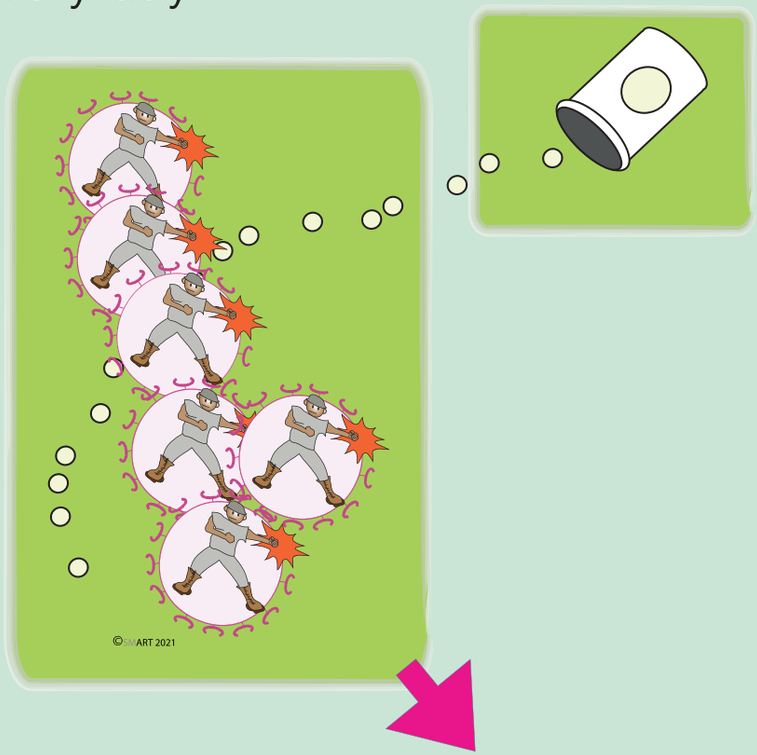
Your medicine is called anti-retroviral medication or ARVs for short. It stops the HIV virus from multiplying and attacking the soldier cells in your blood.
Thousands of young people in South Africa take this medicine every day so they can stay healthy.
You are proof that this medicine works well. You are healthy.
What do you think would happen if you didn't take your medicine very day?

Allow the young person to respond:
he/she might become sick

4

The soldiers can only do their work as long as you take the medication.
When you don't take your medicine HIV can easily win against the soldiers.
When there is lots of HIV virus in a person's blood we say that a person has a high viral load. A high viral load means that the HIV virus is making more and more viruses, it is multiplying.
All of us, doctors, nurses and others at this clinic don't want you to have a high viral load because that means the HIV is killing your soldier cells and you are in danger of becoming sick.

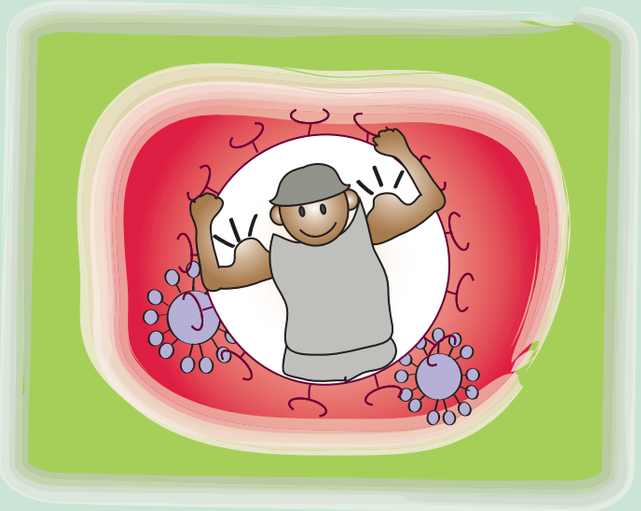
Pills every day

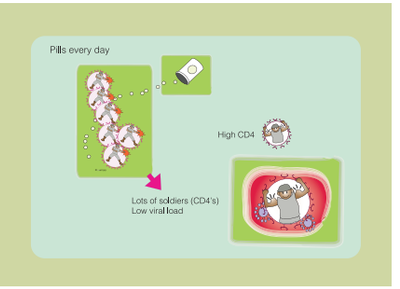


Lots of soldiers (CD4's)
Low viral load

High CD4







5

Rather you must have lots of soldier cells. The soldier cells we have been talking about have another name too, they are called CD4 cells. What the doctors/nurses want to see is a high CD4 count because that means you have lots of strong soldiers to keep you well.
You can make sure your CD4 count is high if you take your medicine every day.

How long do you think that a person who has HIV can live?

Allow young person to answer.
Remember that young people may have a family member or parent who has died from AIDS, so check the reason for their answers and provide information if necessary.
e.g."Sometimes a person does not find out until it is too late that they have the virus in their blood. When this happens the medicine might not work."

6

People used to be very scared of HIV. They used to think it was a strong virus and that people who had it in their blood would die. But that is not true. If you take your antiretroviral medicine every day you can live a long and normal life.

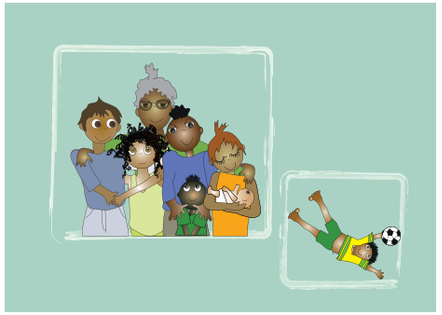
Young people like yourself would also worry that they could not become mothers and fathers one day because maybe the baby would get the HIV virus. These days a person with HIV can have a family of their own if they want. As long as a person is taking his/her medicine properly, he/she cannot pass the virus onto their partner or to the baby. A nurse/doctor can guide a person on how to safely have a baby without HIV.





POST DISCLOSURE

Session One



7

Do you remember from the last time that we talked about support?

What kind of support do you think is important?

Encourage the young person to respond.

*Explain that it is **good to have support** so she or he can remember to take their medicine. Discuss the importance of having a **winning team** where everyone works together to make sure that the soldier cells (white blood cells) stay strong.*

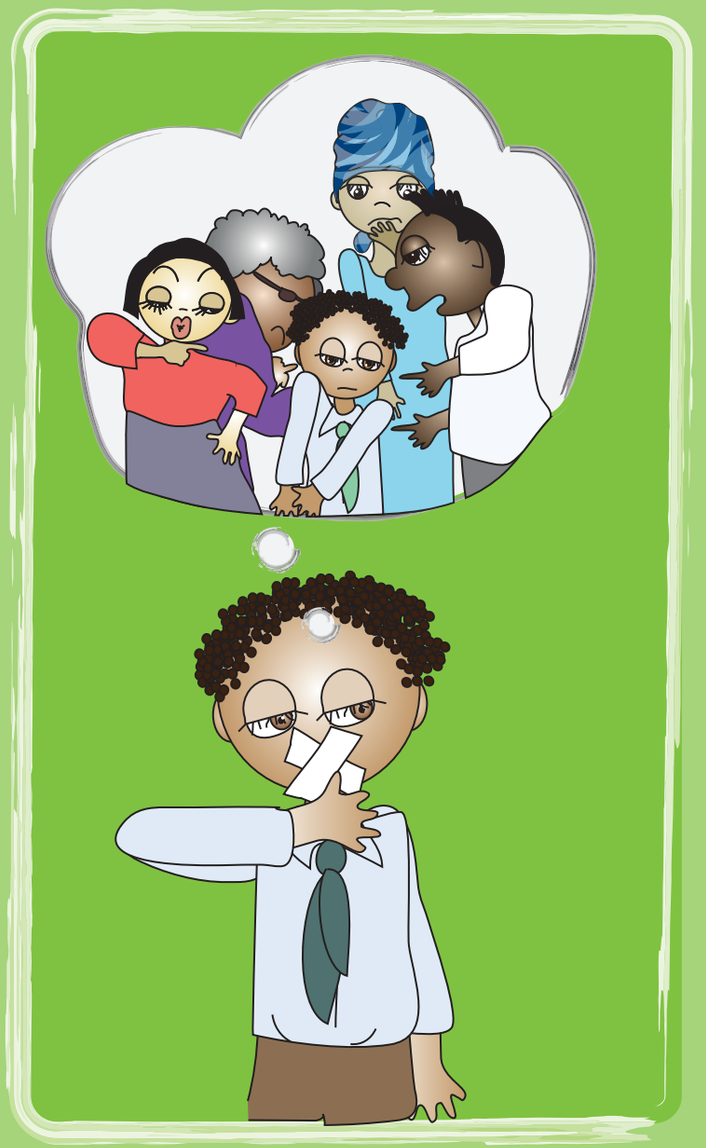
Ask the young person for their ideas on who might be part of their team.

Older family members are usually good people to have on their team to support them.

Team Approach

You can ask the young person which soccer team they support, and ask them what will happen if the coach is not there when the team is playing. Usually the young person thinks that the team won't play as well. Tell them that even though the coach is not playing, the team will not play as well if the coach is not there. In the same way, they (the child) are playing the match of their life. Their treatment buddy/parent/caregiver is their coach and if they're not there then the young person will not take their medicines as well. It is important that their treatment buddy is there to make sure that they take their medicine every day and score goals for the right team!

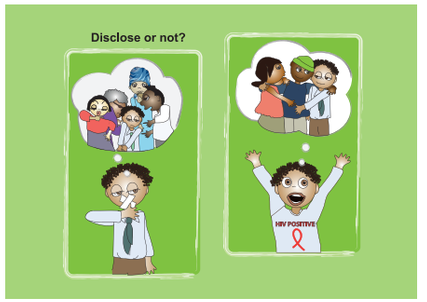
Disclose or not?





POST DISCLOSURE

Session One



8 Have you thought about whether you want to tell anyone else about your HIV status?

9 It is up to you and your parents/caregivers to decide together who you should tell that you have HIV. Many people do not understand HIV and might not know that there is very good treatment these days, so they might think that you are going to be very sick if you have HIV. Some people also treat people with HIV badly, this is called stigma. So it is important that you think very carefully and discuss with your parents/ caregivers before you tell people that you are living with HIV.

Note:

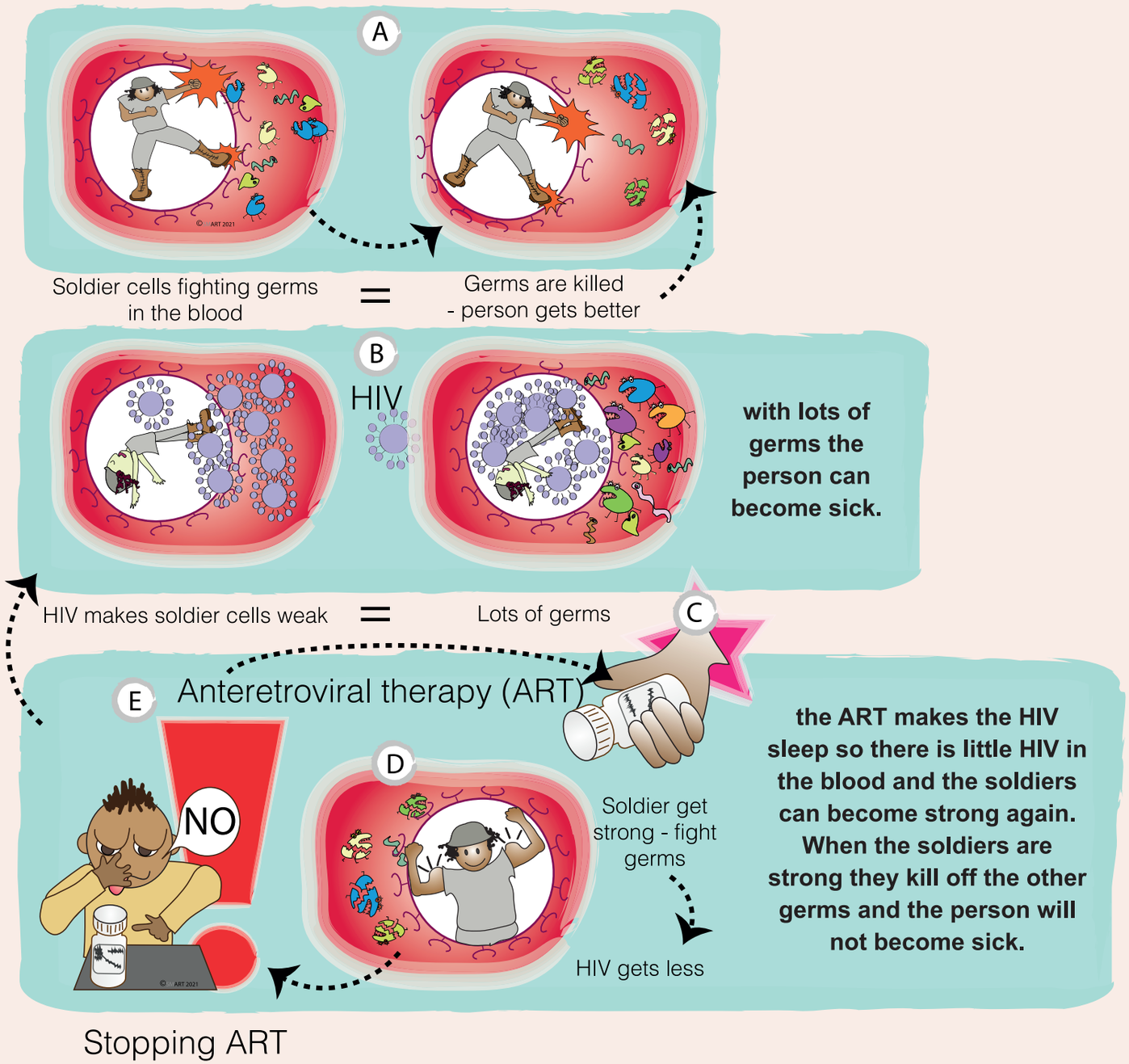
If the young person says there is nobody else he or she would like to share this information with, ***affirm that he or she has the right to decide who should know his/her status*** *and nobody can make a person tell their status if they do not want to.*

If the young person indicates that ***there is someone*** *they would like to tell explore the reasons and decide together if* ***this is a person they can trust*** *- a person who will understand and help.*

See page 57 for tips on partner disclosure.

Bring the session to a close:

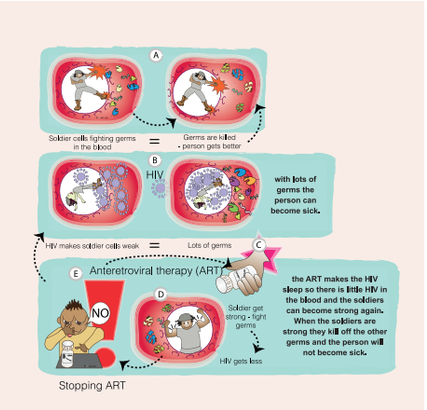
Ask if the child has any questions.
Make an appointment for a second post disclosure session.


A
Soldier cells fighting germs in the blood
=
Germs are killed - person gets better
B
HIV
with lots of germs the person can become sick.
HIV makes soldier cells weak
=
Lots of germs
C
E
Anteretroviral therapy (ART)
NO
D
Soldier get strong - fight germs
HIV gets less
the ART makes the HIV sleep so there is little HIV in the blood and the soldiers can become strong again. When the soldiers are strong they kill off the other germs and the person will not become sick.
Stopping ART

POST DISCLOSURE

Session Two

Healthcare provider / Social Service Practitioner



- *Healthcare worker or social service provider should prepare himself / herself for the session by ensuring that he/she is familiar with the content and follow "Guidance for all sessions".*
- *As per Session One, greet young person warmly. Explore what has transpired since the last session and do a feelings check. Refer back to the previous session.*
- *Ask young person what she or he remembers from the last session.*
- *Praise young person whenever the opportunity arises.*

1

(Recap, depending on how much the young person remembers).

- In the last session we talked about the HIV virus that is in your blood. We spoke about how HIV wants to kill the body's soldier cells which are also known as CD4 cells.
- When this happens you get sick.
- We said there is medicine that works very well.
- It is called **antiretroviral medicine (ARVs)** and if you take it every day the body's army of CD4 cells or soldier cells will become very strong and the HIV virus will get very weak.

With a strong army of CD4 or soldier cells you will not get sick.

2

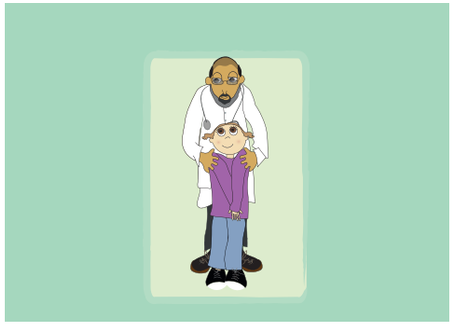
Did you know that the doctor or nurse can tell how much HIV virus there is in your blood?
Do you know how they do this?

Allow the young person to respond.



POST DISCLOSURE

Session Two



3

The doctor or nurse will take some blood - usually once a year - to see what is happening.
If they can't find the virus they will say the virus is undetectable. This is the best that can be - It means your ARV medications are working and the HIV can't do any damage to your body.
But if they see lots of the HIV virus they know that the HIV virus is strong. They will tell you that you have a high viral load. That is not so good.

Why do you think a person has a high viral load?

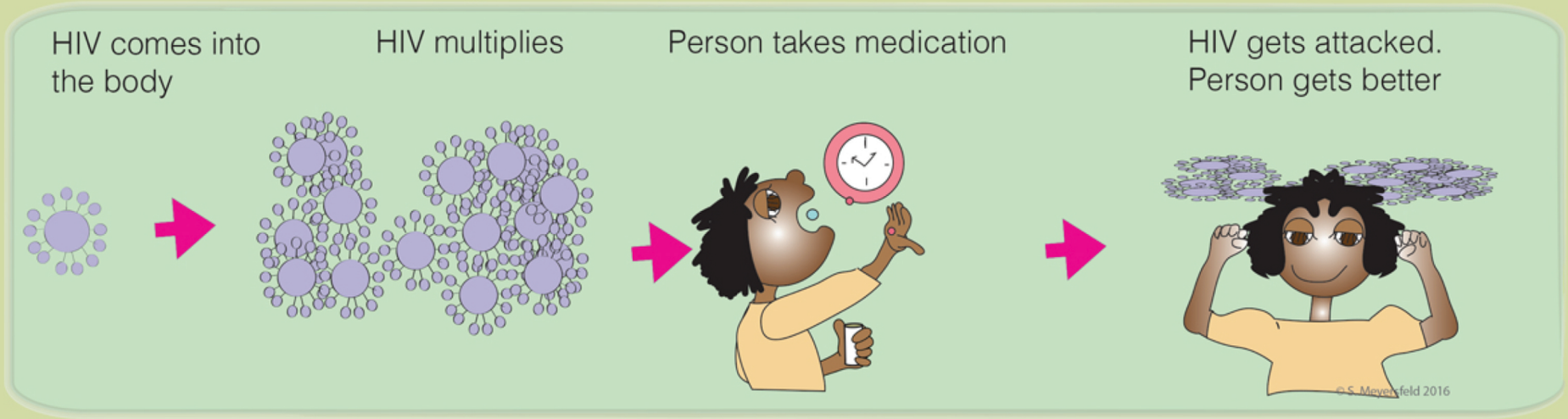
Allow the young person to respond.

4

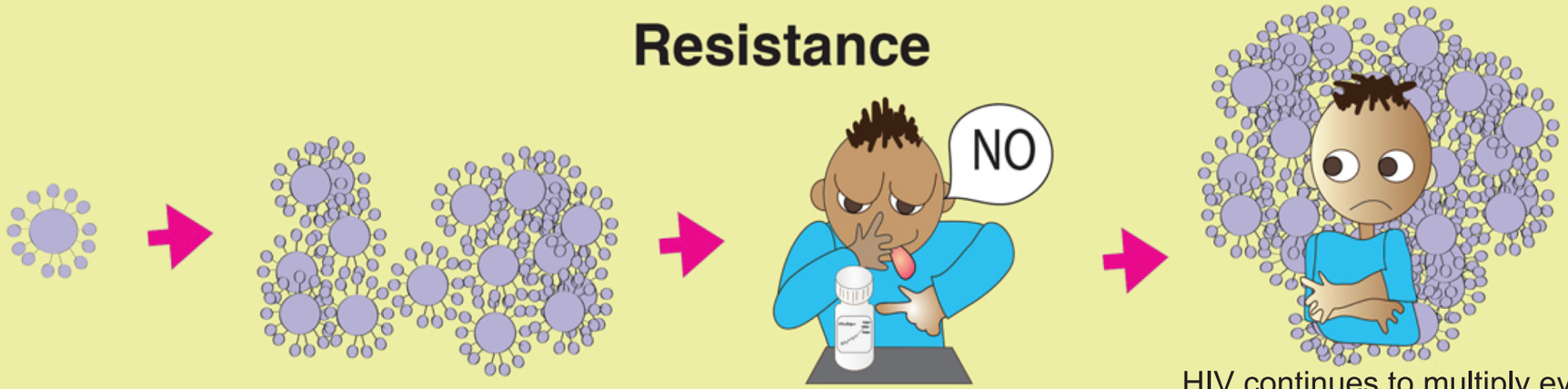
When a person does not take his or her medicine the HIV virus starts to multiply (makes many, many more copies). When there is a lot of virus in your body and your viral load is high, there is a chance you will get sick.
Another thing that can happen if you do not take your medicine is that you can get something called **resistance.**

Do you know what resistance is?

Allow the young person to respond.


HIV comes into the body
HIV multiplies
Person takes medication
HIV gets attacked. Person gets better
© S. Meyersfeld 2016

Resistance


NO
HIV comes into the body
HIV multiplies
Person stops medication or does not take it properly. HIV becomes **resistant**.
HIV continues to multiply even if they take their medication, because the medication does not work any more the person will eventually become sick.
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POST DISCLOSURE

Session Two

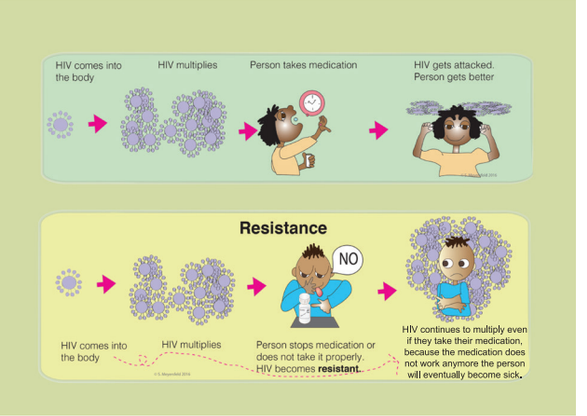
5

Resistance means that the antiretroviral medicine does not work any more so it can't help the soldier cells, CD4 cells, to fight the HIV. Resistance happens when a person does not take their medicine every day.

When a person's HIV becomes resistant the doctor/nurse will change their medication to another medicine. Usually this means that they will have to take more pills than before.

This is why you must remember to take your medicine every day so that your HIV does not become resistant and you can stay on this nice medicine and not have to take more and more pills.

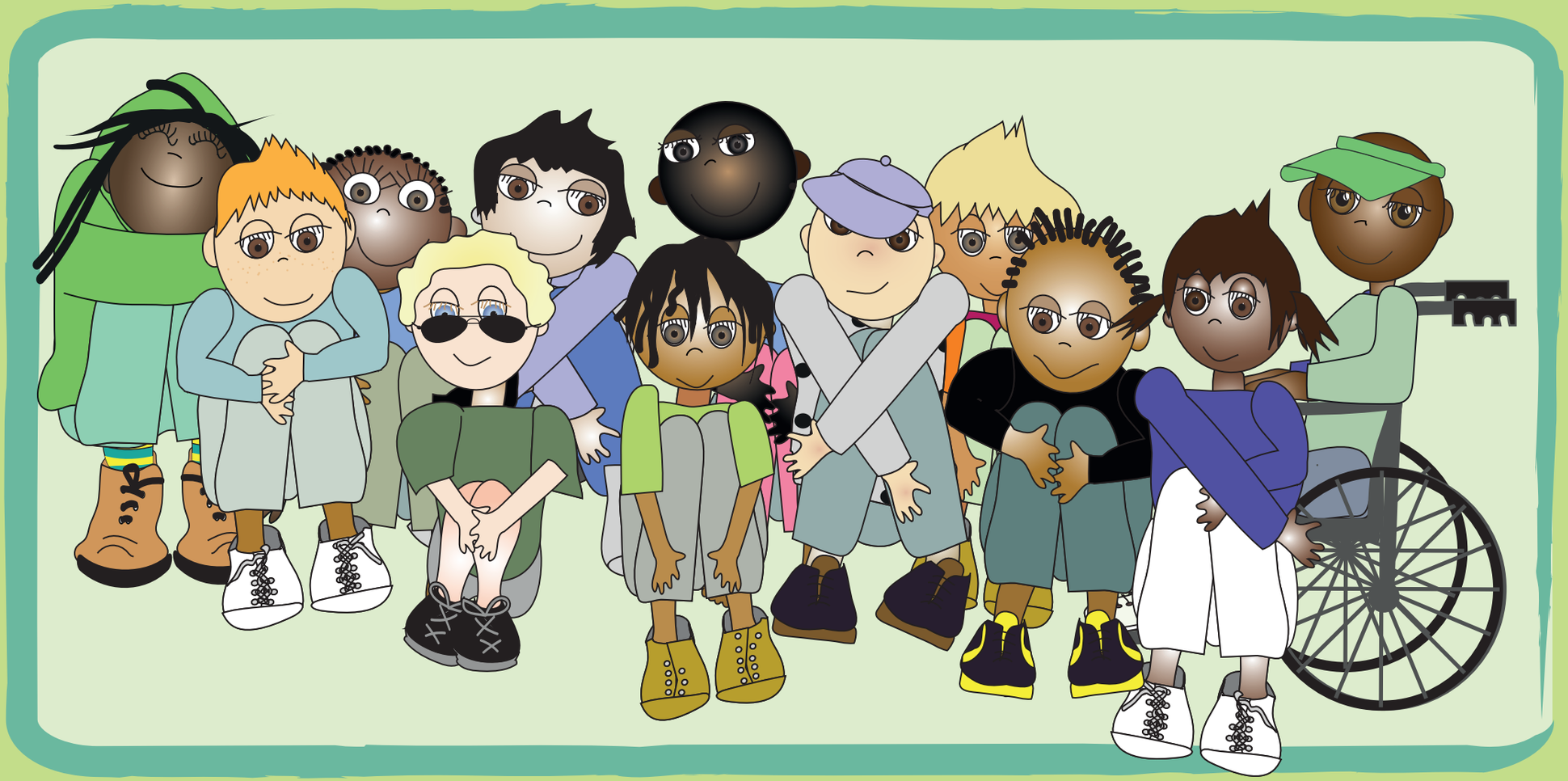
Do you remember why you <u>can be happy</u> when the doctor or nurse tell you that you have an undetectable viral load and a high CD4 count?



Allow the young person to respond.

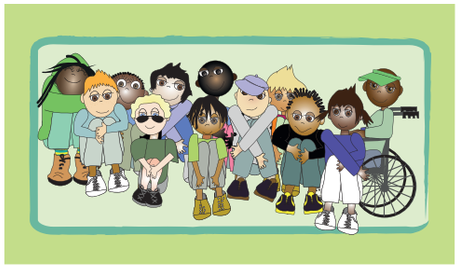
6

An undetectable viral load means your medicine is working and **a high CD4 count,** is good because it means you have lots of very strong soldiers to fight HIV and keep you well.
To keep your **CD4 high** and your **viral load low,** it is important to take your medicine every day.



POST DISCLOSURE

Session Two



7

A person with HIV can live a long and healthy life if they take their medication, eat well and exercise.

Ask the young person what they see for the themselves in the future ***e.g. university, a job, a car. Encourage the young person towards his or her goals.***

8

Yes, as long as you take your treatment HIV can't stop you from having these things. They are all possible. You can be in a relationship, you can have HIV negative babies one day. You can succeed in your studies. You can live until you are old.

Before moving on to the next discussion ask the young person if there is anything else she/he would like to know. Provide information where necessary.

9

Remember that last time we met we talked about support. People need support so they don't feel alone. They need support so they can get advice and information when they need it; so they can share and learn from others and talk about the things that worry them or make them sad.

Ask the young person how he or she is supported.


Facilitator's notes
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POST DISCLOSURE

Session Two



10

There are different kinds of support. The support of a caregiver or parent, or someone you really trust. Another kind of support is a support group. You can get support groups for both children/adolescents and for caregivers.

We can tell you about the support groups which are available in the clinic and in the community.

Ask the young person what they know about support groups.

11

At this clinic/in this community we have a support group where young people of your age can come together to talk about many things.

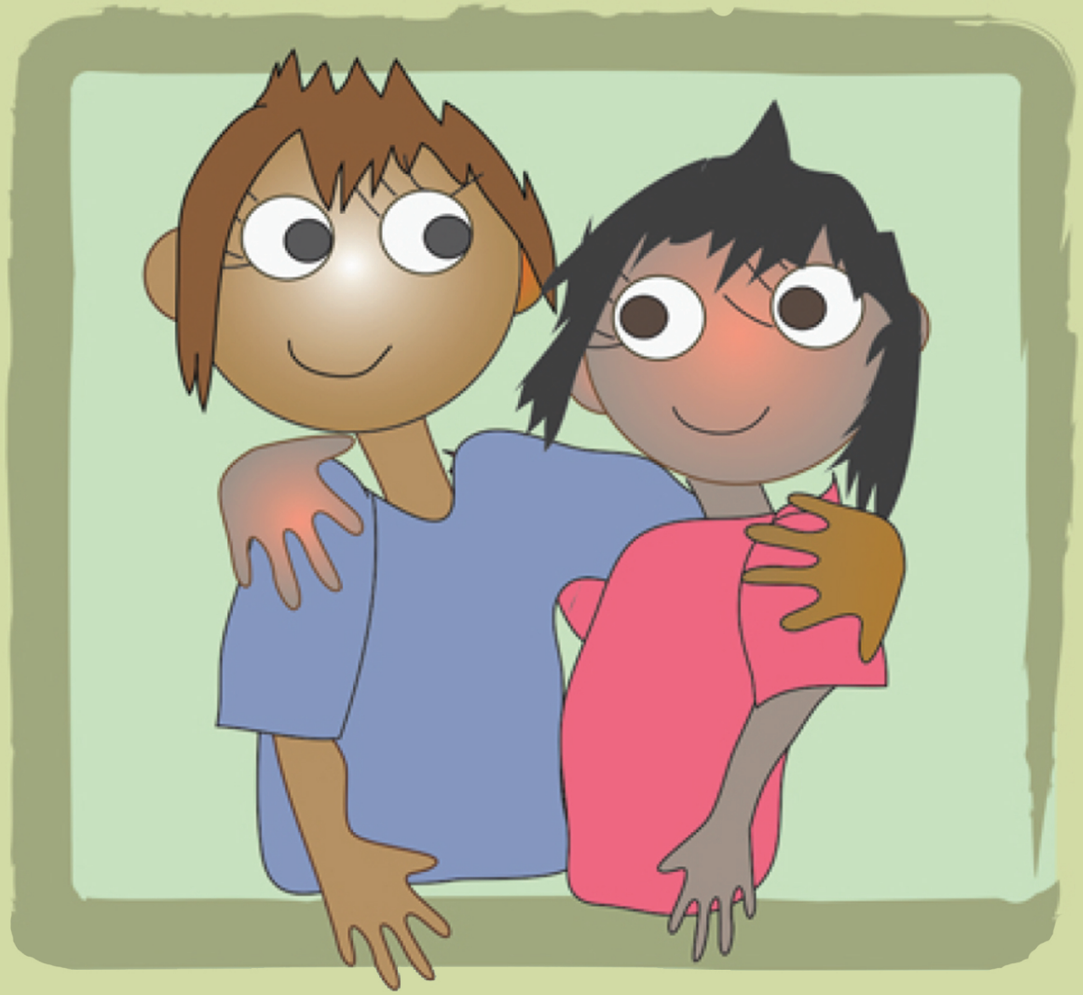
Ask the young person if they would like to hear more about the group. Suggest that they might like to find out more by attending a session. Refer to the group if the young person would like to attend. Ensure that all the necessary information is provided: time, place and so on.

***NOTE:** engage deeply on matters about the support structure of the CALHIV. Facilitate a discussion on identification of the best way to work on having a support structure. If your clinic does not have a group, offer to arrange for one-on-one counselling. If the person would like counselling, make an appointment there and then. Remember to discuss other options for example community-based support and to make the appropriate referral.*

12

we are ready to close the session, how are you feeling about everything you have heard? Please come back to the clinic any day if there is anything you want to ask or talk about or if you are feeling sick or very sad.

Disclosing to a partner



TIPS FOR DISCLOSING TO A PARTNER

Telling a partner about your status is not easy. If you tell them too early in the relationship, they may not want to continue with the relationship. If you tell them too late, they may be angry that you left it so late or possibly put them at risk. For this reason it is important to always use condoms and to make sure that your viral load is undetectable so that you do not pass on your virus. When you reach the stage in your relationship when you feel it is a good time to tell your partner, you can discuss with your counsellor/SSP/ HCW. It may be useful to take your partner with you to the clinic to help disclose to them. This should be arranged first with your SSP/HCW.

It is also important to think about whether you can trust your partner not to tell other people if you don't want them to, especially if the relationship ends.



Advise the young person to choose somewhere safe for this conversation.

- *To have a general discussion about HIV with his/her partner. This will give a clue as to how his/her partner might react.*
- *Advise talking to a trusted friend or family member beforehand or some one they know who has successfully been through the experience.*
- *Important to be clear about why they want to disclose to the person and how they might take it. It is good to think this through beforehand.*
- *Decide what needs to be said and write down some points as a guide.*
- *Suggest support with couple counselling.*
- *Stress importance of feeling emotionally comfortable before disclosing.*
- *Give the facts as they are.*

Thank you for using this tool, we hope that you enjoyed it!



If you have any questions or recommendations for future improvements, please email me at Julia.Turner@righttocare.org