



Celebrate Your Life

PICTURES AND PROMPTS
FOR CONVERSATIONS
ABOUT ART ADHERENCE &
PSYCHOSOCIAL SUPPORT

FOR YOUNG PEOPLE (AGED 12-18 YEARS)

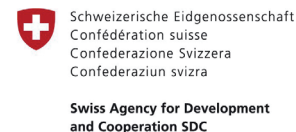
AND FOR ADULTS



REPSSI (the Regional Psychosocial Support Initiative) is the leading African psychosocial support organisation. REPSSI's vision is that all girls, boys and youth enjoy psychosocial and mental wellbeing. REPSSI has strong partnerships with regional economic blocks, governments (particularly the ministries responsible for social services, education and health), development partners, international organisations and NGOs in thirteen countries of East and Southern Africa. The best way to support vulnerable children and youth is within a healthy family and community environment. For fifteen years REPSSI has provided technical capacity enhancement to its partners to strengthen communities' and families' ability to promote the psychosocial wellbeing of their children and youth.

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Email: knowledge@repssi.org Website: www.repssi.org Telephone: +27 11 998 5820 Postal address: PO Box 1669, Randburg, 2125, Johannesburg, South Africa



Acknowledgements

Thank you to Sipelile Kaseke, Malineo Matsela, Mandla Mazibuko, Virgilio Suande, Karesma Mushi, Clever Ndanga, Tabeth Mary Mhonde, David Gwasira, Alex Tigere, Julio Mutemba, Lynette Mudekunye and Carmel Gaillard. Thank you also to Lynette Mudekunye, Makananelo Makape and Ntoli Moletsane for their contributions. Thank you also to Marnie Vujovic, Hayley Ronald and Julia Turner of Right to Care, and to Precious Robinson from EQUIP Health.

Thank you finally to Cedric Niniahazwe and Georgina Caswell for peer reviewing the toolkit.

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Illustrations: Carole Howes

Layout: Candice Turvey-Green, Spiritlevel Studio



Introduction

To end AIDS by 2030, UNAIDS is calling on the world to make sure that:

- 90% of all people that are living with HIV have been tested and know their status
- 90% of those that know their status are on anti retroviral therapy (ART)
- 90% of those on ART are adhering to their treatment and have their viral load suppressed

In 2015, just over half of those that were living with HIV had been tested and knew their status. For us to reach 90% testing we need psychosocial support to help individuals to overcome their fear of knowing their status, communities to address stigma and discrimination, and all of us to celebrate the wonderful opportunity for life that anti retroviral treatment (ART) has given to us.

This conversation prompted by pictures is mostly about adherence and aims to help communities to understand HIV and how ARVs (anti retroviral medicines) work so that they are motivated to be tested to access ART to be able to live long and healthy lives. It encourages community and family members to support one another psychosocially so that those that are living with HIV can take their ARVs, are not afraid to disclose their status, and are confident that they will be safe and cared for.

The conversation accepts that there are many barriers to adhering to treatment but also encourages community members to appreciate how precious anti retroviral medicines (ARVs) are. If we understand and value ARVs we can be inspired to take our treatment regularly, every day, or to adhere to treatment.

Many people have not been tested and do not know their HIV status. These people are not even accessing ART. Many people who are on ART struggle with **adherence** (taking their medicines in the right quantities and at the right times). Many people also struggle with **retention** (remaining in treatment).

This intervention aims to provide psychosocial support to patients, their families and communities to ensure more people get tested, enrol for treatment, are adherent and remain in treatment.

Psychosocial support is a continuum of love, care and protection that enhances the cognitive, emotional and spiritual wellbeing of a person and strengthens their social and cultural connectedness. Effective psychosocial support enhances individual, family and community wellbeing and positively influences both the individual and the social environment in which people live.

(REPSI Glossary of Terms, 2016)

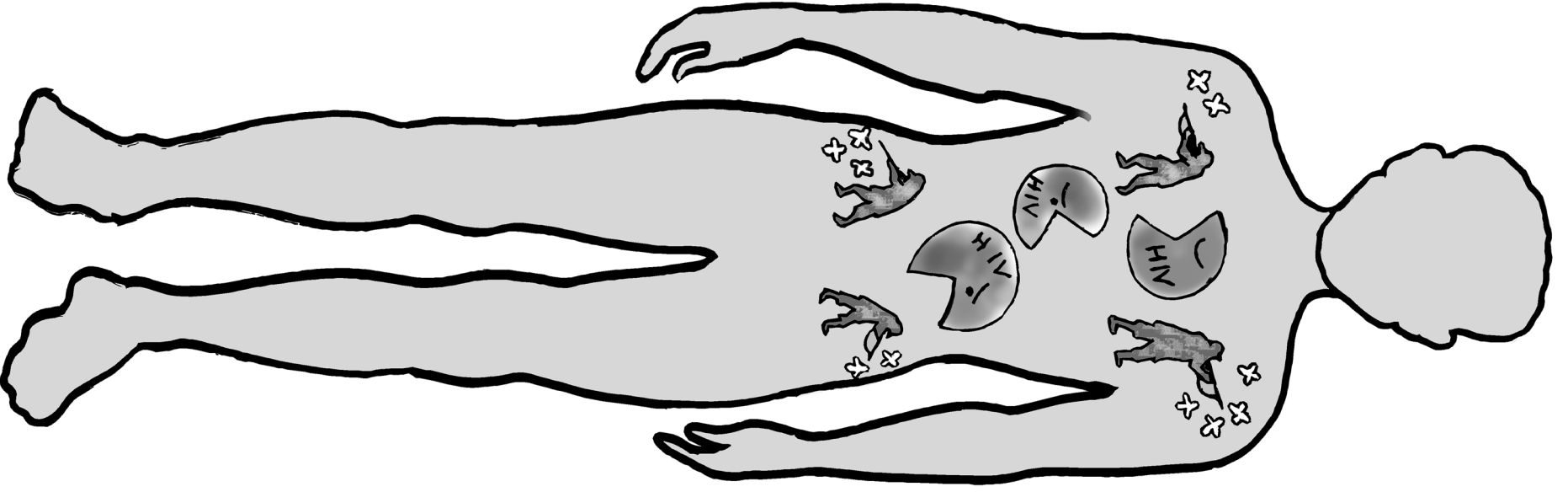
How to use this tool

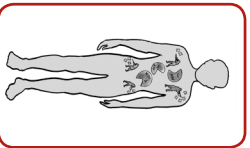
This tool is made up of 16 pictures. Each picture has:

- 1 A main theme
- 2 Questions and prompts for discussion
- 3 Further information / Issues for further discussion

How to facilitate the discussion and to use the pictures

- Depending on the group that you (the facilitator) are working with, select the pictures (plus the questions and points for further discussion) suited to that group (for example, one of the pictures relates to teenage pregnancy and this picture plus questions is only relevant for teenagers)
- Hold up the first picture
- Briefly introduce the theme
- Read out the questions at the back of the picture (one at a time) beginning with "what is going on in the picture?"
- Facilitates discussion which should follow the main theme
- Read out the main messages (contained in the section entitled "Further information / issues for further discussion) and allow for further discussion
- Summarize the discussion thus far
- Move on to the next picture and repeat all the above steps for each picture





Understanding HIV

Introduction:

It is important to understand HIV. This picture and the discussion will help us understand this virus.

Questions for Discussion:

- What is going on in the picture?
- What is HIV?
- What is the difference between HIV and AIDS?
- What does HIV do to one's body?
- How is HIV transmitted from one person to another?
- Do you know what CD4 count is? How is it checked?
- Do you know what viral load is? How is it checked?
- Can a person with HIV be well and more healthy than a person who does not have HIV?
- What kind of psychosocial support will help a person living with HIV better understand this condition?

Further information / Issues for further discussion:

- HIV is transmitted from one person's body fluids to another person's body fluid. This is most often sexual fluids (vaginal fluids for women and semen for men), or blood or breast milk (from a mother to a baby).
- HIV is a virus which attacks a person's immune system which is made up of CD4 cells. The immune system is the body's soldiers who protect the body from illnesses.
- In the picture we see the body's soldiers defending the body against diseases. These soldier cells are called CD4 cells.
- HIV kills soldier cells. Without enough soldier cells to fight disease, germs can make the body sick.
- When the immune system is attacked it becomes weak. It can not defend the body and it is easy for other illnesses like TB to attack the body.
- We can do a blood test to count the number of soldier cells (CD4 cells) in 1 ml of blood. A normal CD4 count is between 500-1000. If a person has a very low CD4 count e.g. 75, they can easily become sick from many different germs.
- People living with HIV have low CD4 cell counts and that is why they need ARVs to help them strengthen their immune system and fight diseases.
- We can also do a blood test to count the number of HIV viruses in 1 ml of blood. This is called a "viral load". If a person's viral load is high, it means they have lots of HIV viruses in the blood.
- A viral load test helps provide information on one's health status and how well antiretroviral therapy (ART – treatment with HIV medicines) is controlling the virus.
- HIV is not transmitted by touching, hugging, kissing or sharing eating or cooking utensils.
- We now know what HIV is but what is the difference between HIV and AIDS? HIV stands for human immunodeficiency virus. AIDS stands for Acquired Immune Deficiency Syndrome and refers to an advanced stage of HIV, when the immune system is weak and a person has other illnesses such as TB, diarrhoea and so on. One can be HIV positive and very healthy (if one takes one's ARVs as they are supposed to be taken) but if a person has AIDS they are sick.
- A person with HIV can be well and more healthy than a person who does not have HIV. This is possible if they reduce their viral load (amount of HIV virus in the body) to a very low level by





The only way to know if one is living
with HIV is to be tested

Introduction:

This picture and the discussion that follows will explore the importance of testing.

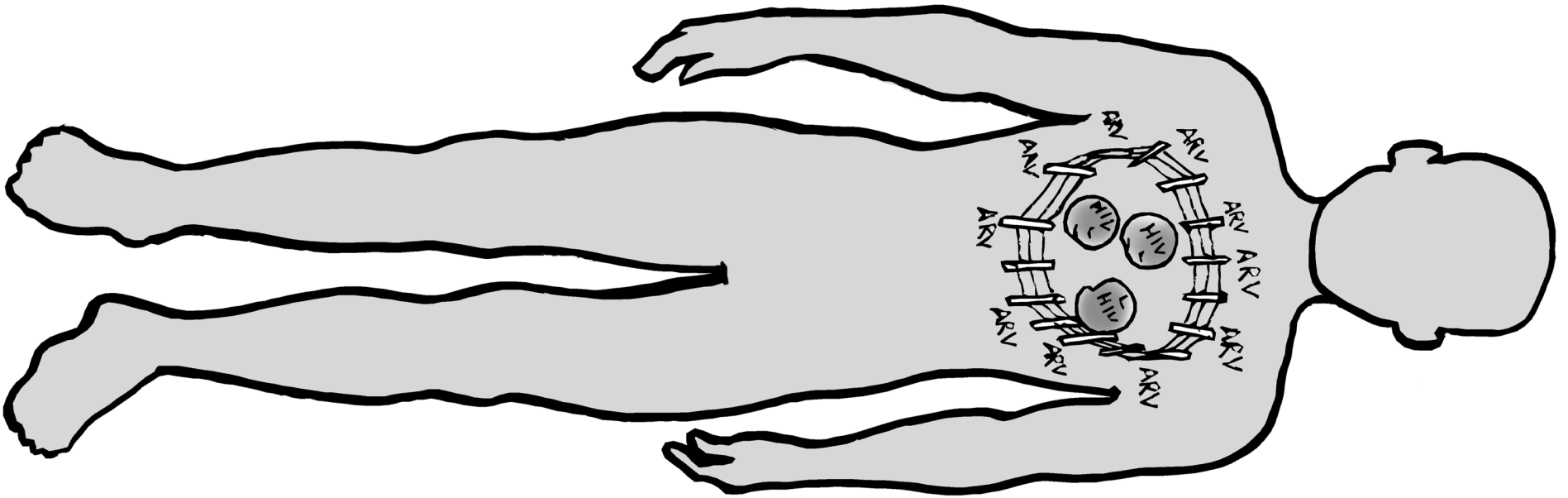
Questions for Discussion:

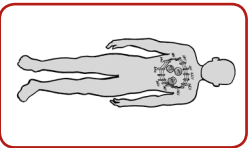
- What is going on in the picture?
- Which of these people are living with HIV?
- Can one tell if someone has HIV by looking at them?
- Do we want to know if we are living with HIV? Why? Why not?
- Why is it important to have support when one goes for an HIV test?
- Who can give us this support and how?

Further information / Issues for further discussion:

- It is not possible to know who is living with HIV just by looking at them.
- The only way to know is to be tested for HIV.
- Most of us are afraid to know if we have HIV, we are afraid just to know and we are afraid of what other people will say about us.
- There is no cure for HIV but it can be managed. One can be HIV well (very healthy even though one has HIV).
- It is important for all of us – men and women, girls and boys - to be tested to know if we are living with HIV. If we are negative we can prevent HIV. If we are positive we can begin the treatment and reduce the possibility of getting sick and developing AIDS.
- We need support from our family, friends and community to be tested.

3
CYL





What is ART?

Introduction:

This picture and the discussion that follows will help us understand ART.

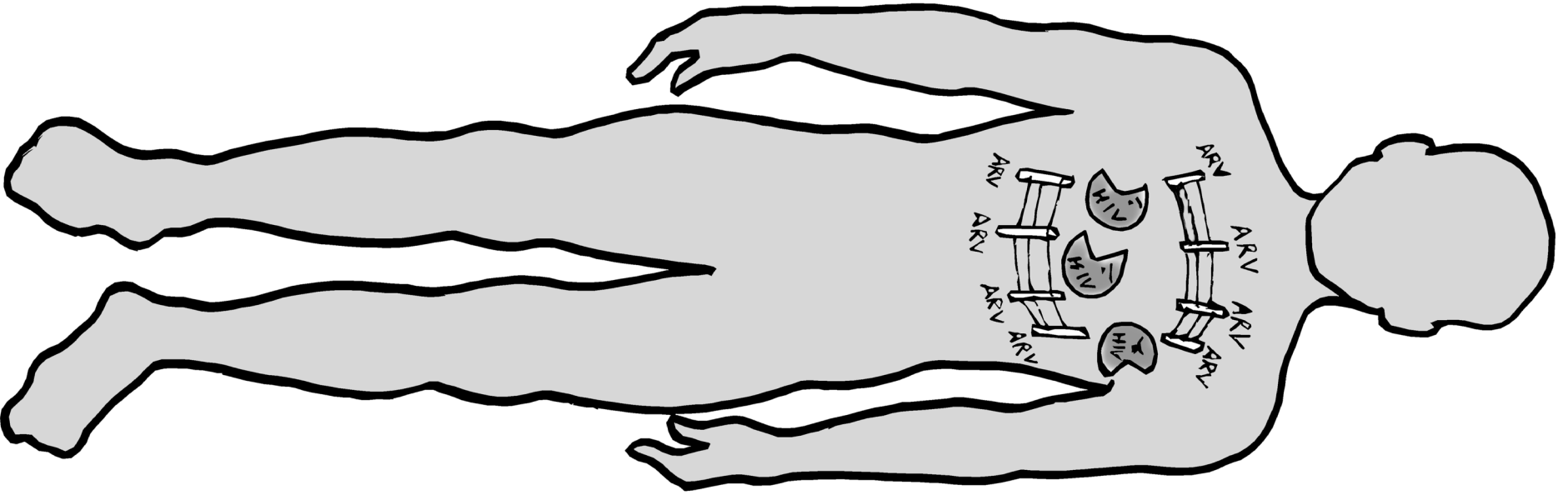
Questions for Discussion:

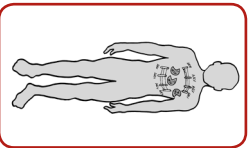
- What is going on in the picture?
- What has happened to the HIV?
- What are ARVs?
- How do they work?
- Are they a cure for HIV?

Further information / Issues for further discussion

- ARVs (anti retroviral medicines) are a wonderful way to manage HIV.
- ARVs stop the HIV virus from attacking one's immune system.
- In the picture we see the HIV fenced in - HIV is held back by ARVs but it is still there.
- ARVs do not cure one of HIV.
- ARVs must be taken every day for the rest of one's life.

4 CYL





Adherence

Introduction:

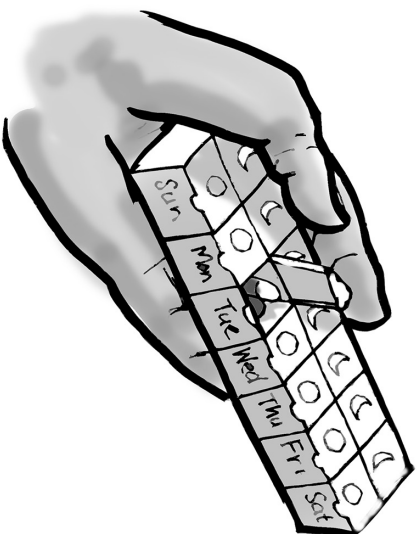
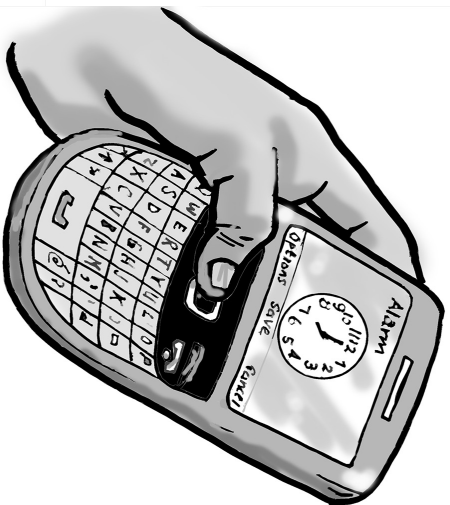
This picture and the discussion that follows will help us understand the concept “adherence”.

Questions for Discussion

- What is going on in the picture?
- What is adherence?
- Why must we be adherent?
- What is 100% adherence?
- What is 80% adherence?
- What must one aim for if we want to be healthy and adherent?

Further information / Issues for further discussion

- ARVs cannot kill the HIV viruses but they can build a fence around the HIV viruses so that they cannot multiply and spill out into the blood.
- If one takes one’s ARVs every day, the fence will keep the HIV viruses out of one’s blood.
- If one takes one’s ARVs every day and go for a viral load blood test, the virus should be undetectable in the blood (even though they are there in very low quantities “in the fence.”)
- Adherence means taking one’s ARVs in exactly the way they are meant to be taken – every day and forever.
- In the picture we see that part of the fence - that holds HIV in place and prevents it from attacking one’s body - is broken. It is broken because the person did not take their ARVs every day. When the fence is broken it is possible for HIV to escape and attack the immune system again.
- 100% adherence means one never misses a dose.
- 80% adherence means one misses 1 out of 5 doses
- If one takes them 80% of the time that is not good enough. ARVs have to be taken 100% of the time - as they are supposed to be taken. One must try not to miss any doses at all.
- When one is on ARVs it’s extremely important to have 100% adherence. Anything less means the virus can multiply.
- One does not have to take one’s ARVs at exactly the same time every day but if one takes them every night then one must take them every night. And if one takes them every morning and night then one must take them every morning and every night. It does not matter if it is at 6 or 7 or 8 or 9 o’ clock.
- It usually helps to choose a certain time to take one’s ARVs so that one can set an alarm clock or have something to remind one to take one’s ARVs, but remember that if one is late it does not matter, one must still take one’s ARVs. Our motto is “better late than never”. Even if one is up to 6 hours late one should still take one’s ARVs. If one is more than 6 hours late, wait till the next day to take them but do not get into the habit of missing doses or one’s ARVs will stop working.
- If one misses some doses of one’s ARV’s, the level of ARV in one’s blood becomes too low to work, so the HIV starts multiplying again.
- A person that is living with HIV needs much support and care to adhere and keep taking their ARVs every day





What can we do to be adherent?

Introduction:

This picture and the discussion that follows will explore what one can do to be more adherent.

Questions for Discussion:

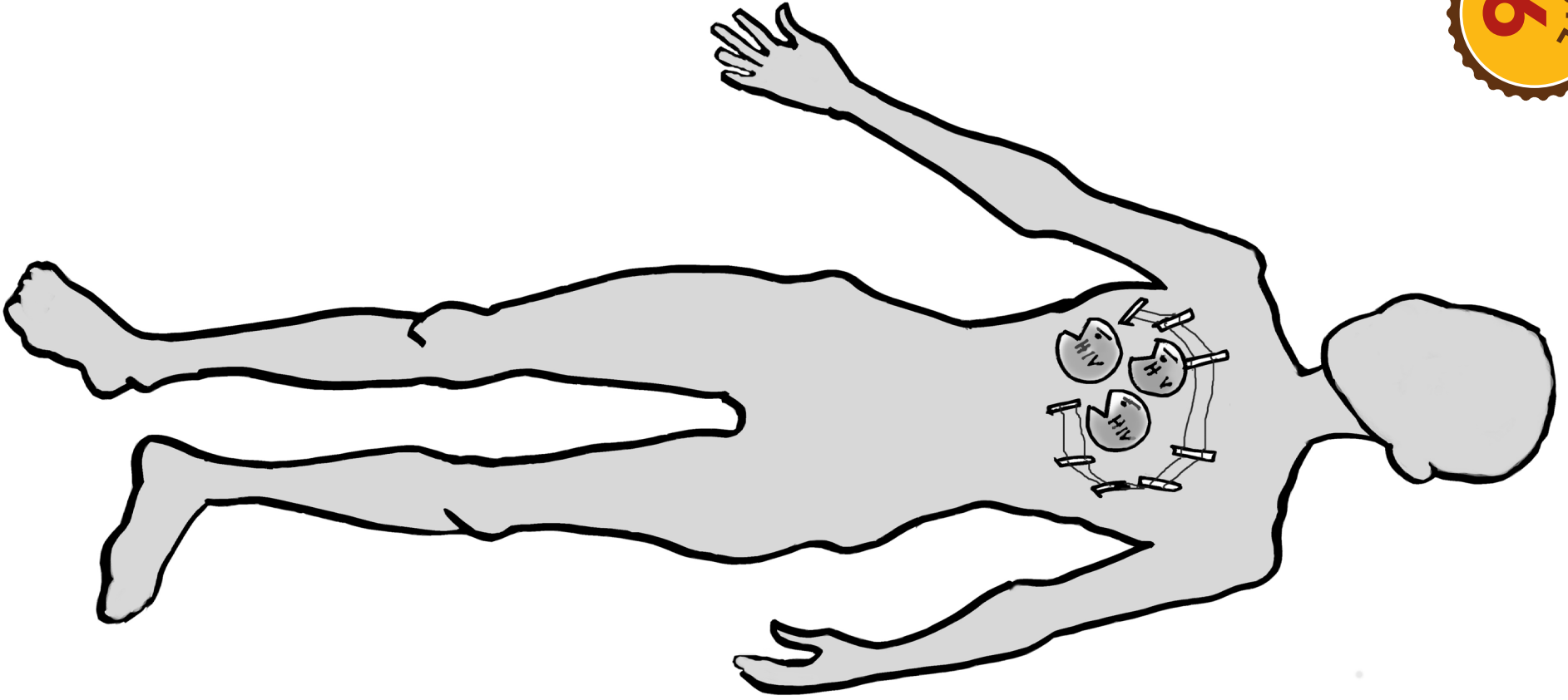
- What is going on in the picture?
- What can one do to increase and maintain one's adherence?

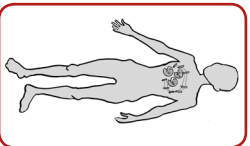
Further information / Issues for further discussion

To be adherent one can:

- Get into small groups even just 2 or 3 people who live close to each other and support each other to take one's ARVs every day.
- Use a pill box where one puts all the pills for a whole week into a different partition for each day.
- Set one's phone alarm to remind one to take one's pills.
- Keep an adherence diary.
- If one tells other people in one's household or others that one trusts that one is HIV positive (disclosure), they can support a person to take their ARVs every day (adherence) as well as support them more generally.
- If a person living with HIV asks someone they trust to watch them take their medicine each day, it becomes more difficult to be uncertain if they have taken their pills or not.
- Discuss other ways in which people remind themselves or are reminded to take their medication every day at the correct time.

9
CYL





Drug resistance

Introduction:

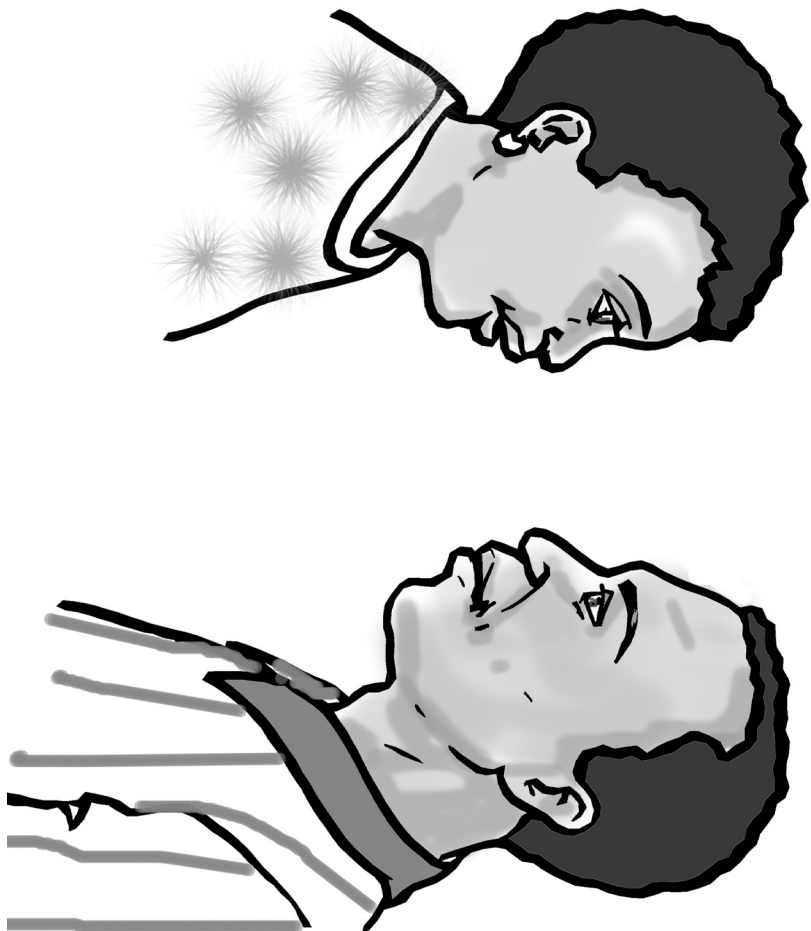
This picture and the discussion that follows will help us understand “drug resistance”.

Questions for Discussion:

- What is going on in the picture?
- What is drug resistant HIV?
- How does one get drug resistant HIV?

Further information / Issues for further discussion:

- If one does not take one’s ARVs every day, they do not control HIV any more (the fence breaks) and one develops what is called drug resistant HIV (HIV that cannot be controlled by the drugs that we are getting in our clinics).
- Drug resistant HIV can also be spread to other people (via sex or other forms of transmission) which means ARVs will not help them either.
- When HIV escapes it becomes even stronger than it was before (it is resistant to the ARVs) and starts to attack the soldiers (CD4 cells) again.
- If one develops drug resistant HIV, the ARVs one is on no longer work and one has to change one’s medicines (ARVs) to what is called “second line ART”.
- If one goes onto second line ART, one has to take many more pills, for example, from one pill (first line) to six pills (second line).
- Second line ART is much more expensive than first line and it is not as easily available compared to first line ART in many countries.





**Disclosure between couples and how
it is good for adherence**

Introduction:

This picture and the discussion that follows will help us understand the concept of “disclosure” especially disclosure amongst couples.

Questions for Discussion

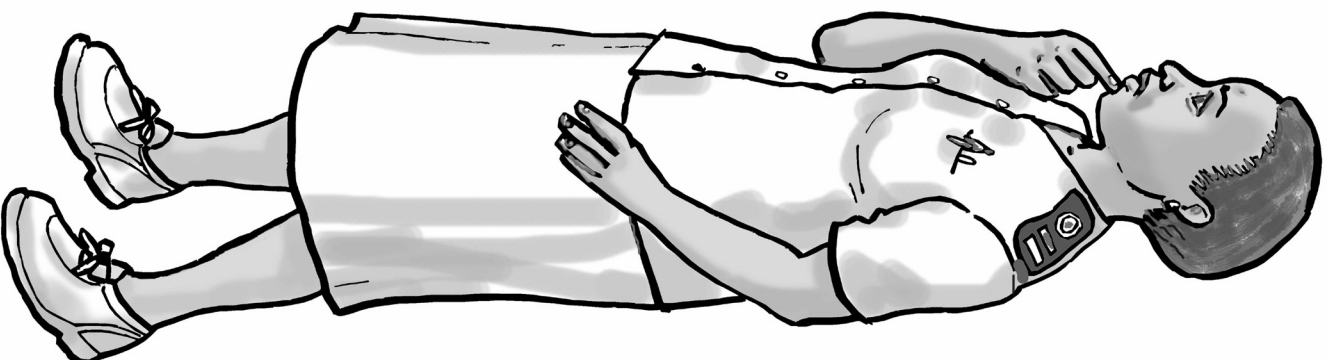
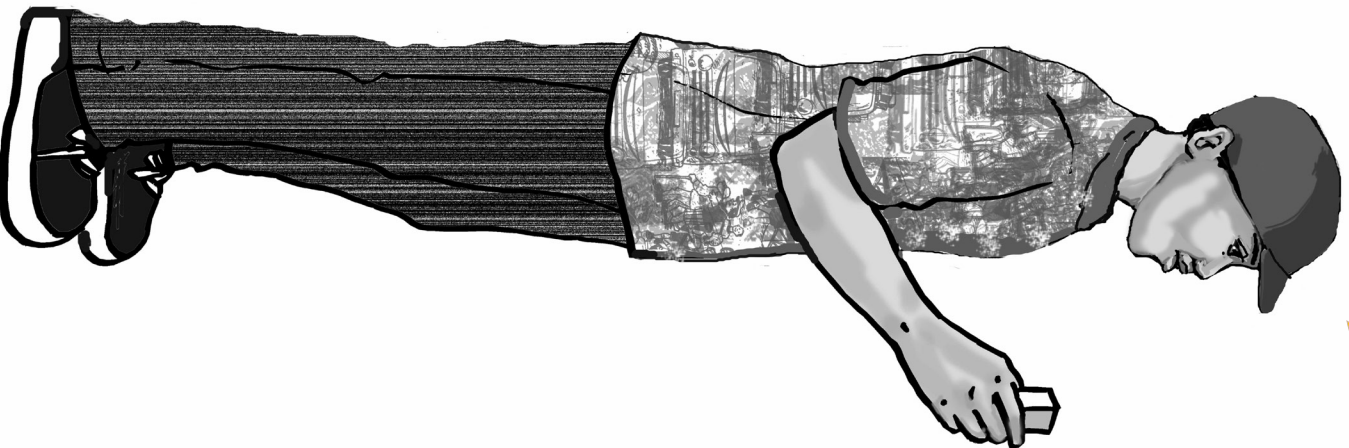
- What do we mean by “disclosure?”
- What is going on in the two pictures?
- What issues can prevent disclosure between couples?
- Why is disclosure between couples important?
- What are the advantages of mutual disclosure between a couples?
- How can we support disclosure between couples?

Further information / Issues for further discussion

- Disclosure related to HIV means sharing with others that one is HIV positive.
- Disclosure between couples can lead to increased support and increased adherence.
- The top picture shows good open communication between a couple in which disclosure is more likely than in the bottom picture which shows mistrust.
- Lack of disclosure might lead to conflict e.g., one partner might blame another for contracting the virus through being unfaithful.
- It is more difficult to take one’s medications regularly and in secret if one’s partner does not know about one’s HIV.
- Disclosure is important for a healthy, trusting relationship within a couple and to build support within the couple.



*These medicines make me
nauseous, give me diarrhoea,
and make me tired.*





Medicine side effects

Introduction:

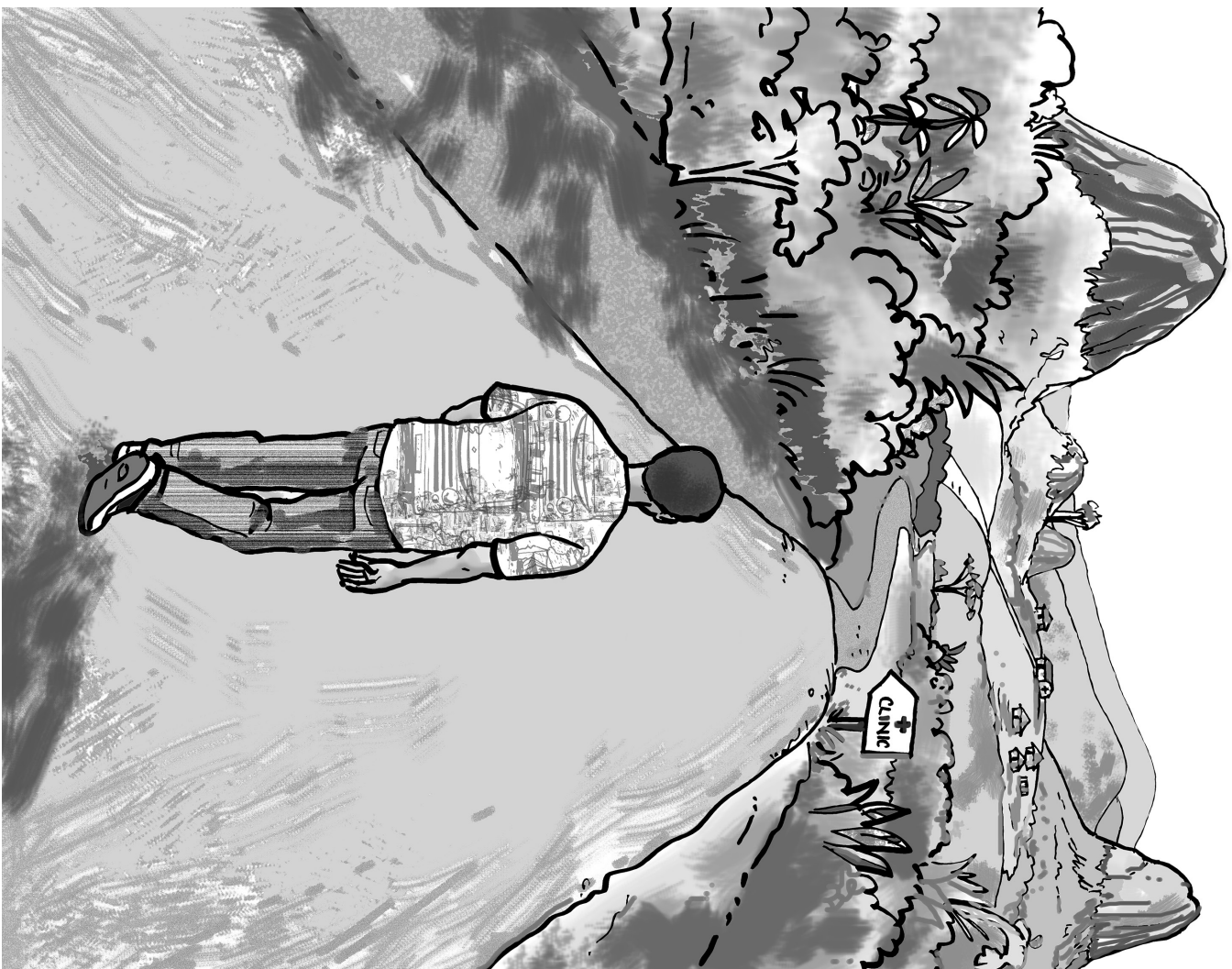
This picture and the discussion that follows will help us understand the side effects that a person may feel with ART.

Questions for Discussion:

- What are some of the side effects of ARVs?
- What happens when someone has side effects?
- How can we support someone with side effects to keep on taking their ARVs?

Further information / Issues for further discussion

- ART can result in side effects, e.g. feeling sick, diarrhoea and tiredness but these should only last a few weeks.
- In spite of side effects there are long term benefits which have to be weighed against the side effects and consequences of not being on ART.
- A person that is experiencing side effects needs a lot of support to keep taking their ARVs until the side effects become less pronounced.
- They should be encouraged to speak to their health care provider about the side effects, and speak to other people that are on ARVs who have also experienced side effects.
- These problems arise mainly when a person starts treatment or changes treatment.
- One should NOT stop taking medication when one experiences side effects but should consult with one's health care provider.





Travelling long distances to collect medicines

Introduction:

This picture and the discussion that follows will help us overcome the problem faced by people who live far from the clinic.

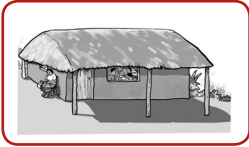
Questions for Discussion:

- What is going on in the picture?
- How can the challenge of travelling long distances to the clinic to collect medicines be addressed?

Further information / Issues for further discussion

- Long distances to collect medicines and having to wait in queues are barriers to adherence.
- Solutions to this challenge include:
 - forming support groups
 - members take turns to collect medicines for the whole group
 - being given medicines for a longer time e.g. 3 months rather than 1 month.
 - A person who is getting more than one month's supply may need support to keep remembering to take their medication, even when they are not seeing a health professional.





Stigma from the family / household and stigma in the community

Introduction:

This picture and the discussion that follows will help us understand the concept of "stigma".

Questions for Discussion:

- What is going on in the picture?
- What is stigma?
- What are some examples of stigma?
- Is there stigma in our community?
- What can we do to address stigma?

Further information / Issues for further discussion

- Stigma is discrimination, negative attitudes and abuse of people, in this case of people living with HIV.
- Examples of stigma are:
 - A person experiencing discrimination. e.g., having to eat outside or separately from the rest of the family, or a losing friends or support.
 - A person not being accepted for a job because of their HIV status.
- Stigma can lead to a person living with HIV feeling lonely and isolated and can decrease hope and adherence.
- Stigma can be addressed by raising awareness about HIV and by people living with HIV mobilising into support groups.
- When we love and care for each other we will do our best to not stigmatise each other. If we hear our family members and friends saying things which can hurt others we will try to explain to them why we need to care for everyone.





Abandoning treatment following health improvement

Introduction:

This picture and the discussion that follows will help us understand why people who feel well on ART decide to stop taking their medicines.

Questions for Discussion:

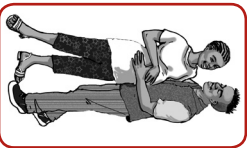
- When a person on ARVs begins to feel much better, can they stop taking their ARVs?
- When a woman who is on ARVs gives birth to a HIV negative child can they stop taking ARVs?

Further information / Issues for further discussion

- When a person on ARVs begins to feel much better, they may think that they do not need to continue to take their ARVs.
- REMEMBER that the ARVs have only fenced the HIV. HIV is still there. If a person stops taking their ARVs the fence will break down and HIV will be able to come out again.
- So when people begin to feel better they need to continue their ARVs – if they stop they may become sick .
- When a woman who is on ARVs gives birth to a child they must continue taking ARVs forever.
- A person who feels better and is not sick may need a lot of support and encouragement to keep on taking their medication

CY1
12





Pregnancy and HIV

Introduction:

This picture will help us think about pregnancy and HIV.

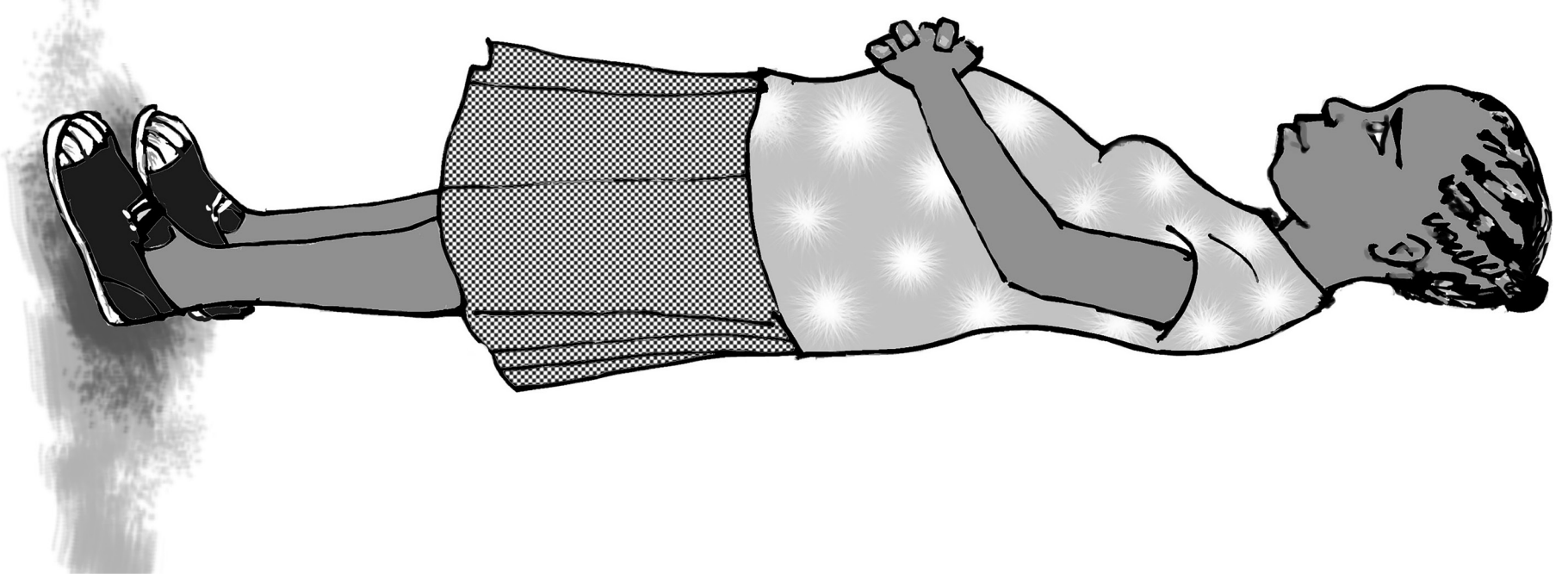
Questions for discussion:

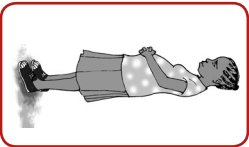
- What is going on in this picture?
- What do you think the father and mother of this unborn baby are feeling and thinking?
- If you have a child what did you feel before your child was born, and if you are having a child soon, what are you feeling now?
- How can the community help parents who are expecting a new baby?
- What do parents need to do to love, care for and protect their baby even before the baby is born?

Further information / Issues for further discussion

- Most parents feel hopeful, excited, happy while the mother is pregnant before their child is born.
- It is also normal to feel anxious and worried.
- Parents should make sure that the mother goes to the clinic as soon as possible after she thinks she may be pregnant. This is so the clinic checks her health including blood pressure and testing her for HIV. If she is HIV + and not yet on ARVs she will probably be given ARVs.
- The mother should do her best to look after her health. This includes eating nutritious food, resting, trying to prevent any illness including avoiding HIV re-infection by using condoms. It also includes not drinking alcohol or smoking.
- The mother should go to the clinic at least 4 times during her pregnancy. She should try to deliver her baby at a clinic with a trained nurse.
- Parents should try not to argue or get angry with each other. Stress is dangerous for both the parents and the baby.
- Family members can support couples who are stressed and help them to appreciate what is positive in their lives, including being excited about the baby.
- The community and community members can encourage parents and support them to look for treatment especially if they are HIV+.

CY1
13





Teenage pregnancy and PMTCT

Introduction:

This picture will help us explore and think about teenage pregnancy.

Questions for discussion:

- What is teenage pregnancy?
- What does PMTCT stand for?
- What can one do to prevent Mother to Child Transmission of HIV (MTCT)?

Further information / Issues for further discussion:

- Teenage pregnancy refers to teenagers (girls aged 13-19) who are pregnant.
- A teenager who is pregnant (or any pregnant woman) and who is living with HIV can pass on the HIV virus to her child. PMTCT stands for Prevention of Mother to Child Transmission (of HIV). It is also known as prevention of vertical transmission, and refers to interventions to prevent transmission of HIV from an HIV-positive mother to her infant during pregnancy, labor, delivery, or breastfeeding.
- What can one do as a teenager living with HIV to prevent mother to child transmission?
 - Do **your** best to only get pregnant when you have planned to be pregnant.
 - Use Family Planning and condoms to avoid becoming pregnant until you plan to be. That way one can reduce the risk of passing HIV to a baby.
 - When one becomes pregnant and while breastfeeding one's baby one is less likely to transmit HIV if one's viral load is very low.
 - One can keep one's viral load low by taking one's ARVs every day, eating healthily, getting enough rest and not being stressed or managing stress (The latter part is good advice for anyone that is living with HIV, or pregnant, or just dealing with every day!)
 - Use condoms to avoid re-infection which can increase your viral load.
 - After the baby is born it is good practice to exclusively breast feed the baby for six months. Look after one's nipples. If they crack and are bleeding ask for advice. One may be advised to stop breast feeding until they heal or one may be advised that instead of not breastfeeding due to sore nipples, a nipple shield can be used.
 - Take the baby to the clinic as soon as possible and follow their advice about testing the baby and about medicine for the baby.
 - Join a support group for young mothers or for mothers living with HIV.





Infancy and HIV

Introduction:

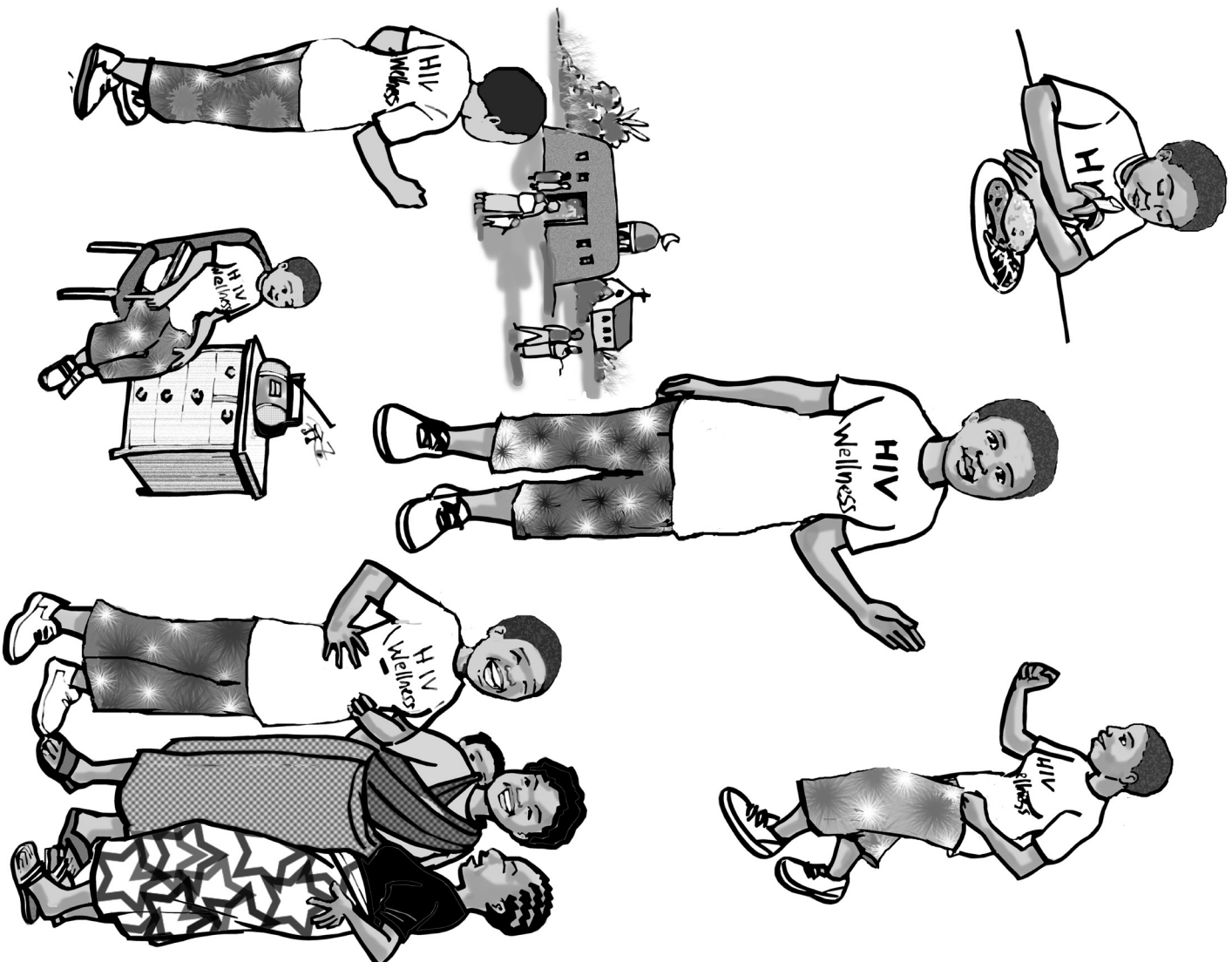
This picture will help us think about young babies and HIV.

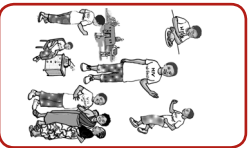
Questions for discussion:

- What is going on in this picture?
- What do you think the mother and father feel?
- Would you agree that they feel happy and hopeful for their baby?
- What can parents do to love, care for and protect their baby after the baby is born?
- How can the community help parents that are living with HIV to care for their baby?

Further information / Issues for further discussion:

- Parents need to do their best to feed the baby well. Breast milk is an ideal food for babies. It has all the nutrients that a baby needs and also antibodies to protect the baby from getting sick. Feeding the baby only breast milk for 6 months is good for the baby who also bonds with the mother. Parents should get advice from the clinic on whether to breast feed or not.
- Parents need to take the baby to the clinic when the nurses tell them to come. This is so the baby is checked, weighed and immunized. If the mother is HIV+ the baby should be tested for HIV as well. If the baby is negative parents should try to keep them negative. If positive, parents should talk to the nurses about the baby also having ARVs.
- Parents should do their best to protect children and give them shelter.
- Young babies need stimulation e.g. singing talking and playing with the baby, celebrating with the baby as they learn to smile and make sound, sit, crawl, stand and walk. Parents need to talk to their babies to soothe them, to stimulate them and so the baby can learn to talk.
- Community members can encourage parents to love and care for their baby. Especially if the baby cries a lot and parents are worried. Community members can help parents to care for the baby and not show them stigma or discrimination. They can invite them to join community activities and support groups.





HIV wellness

Introduction:

This picture and the discussion that follows will explore the concept of “HIV wellness”.

Questions for Discussion:

- What is going on in the picture?
- We all know what illness is, what is HIV wellness?
- Can one be HIV +ve and healthy?
- Can one be HIV+ and healthier than someone who is HIV –ve?
- What might one do to become more well?

Further information / Issues for further discussion:

- HIV wellness is about more than just medication – it is about eating healthy food, fitness, spiritual health, finding time to rest and relax, having friends, laughing and celebrating life.
- HIV wellness can also be defined as low viral load and high CD4 count.
- We can all support HIV wellness by being supportive to those that are HIV positive.
- In the picture we see a woman who is HIV positive who eats healthily, who has friends, who attends church, who exercises, who enjoys relaxing and listening to the radio. She is HIV positive but is HIV well.
- One can be HIV positive and healthier than someone who is HIV negative. The person who is HIV negative might have diabetes, high cholesterol, cancer etc. A HIV positive person who takes their ARVs every day, whose viral load is undetectable and who eats healthily, exercises and has social support, can certainly be healthier than the unwell HIV positive person.
- Be honest with yourself and discuss what you can do to be HIV well.





Psychosocial Support

Introduction:

This picture and the discussion that follows will help us understand psychosocial support.

Questions for Discussion:

- What is going on in the picture?
- What kind of support is most valuable to a person who has HIV?
- Try and think of 5 forms of support?

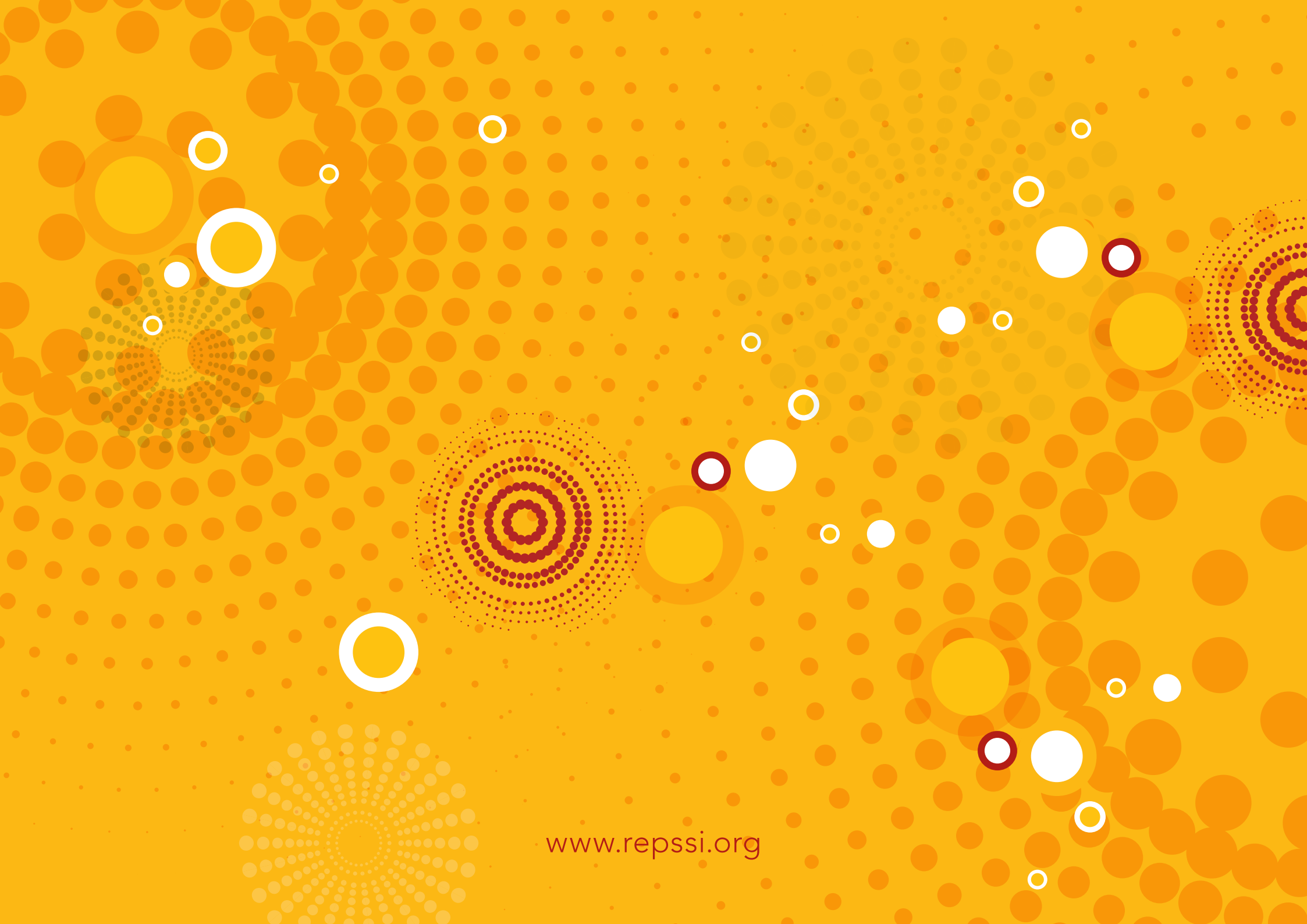
Further information / Issues for further discussion:

- Psychosocial support is emotional and social support, or the love, care and protection people provide to one another.
- It is easier to take one's medicines every day and to achieve HIV wellness if a person living with HIV is supported by others.
- This support can be:
 - reminding them to take their ARV
 - not blaming them for contracting HIV
 - encouraging them to keep healthy
 - encouraging them to have enough rest and eat nutritious food
 - other acts of kindness.



Psychosocial Wellbeing For All Children

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