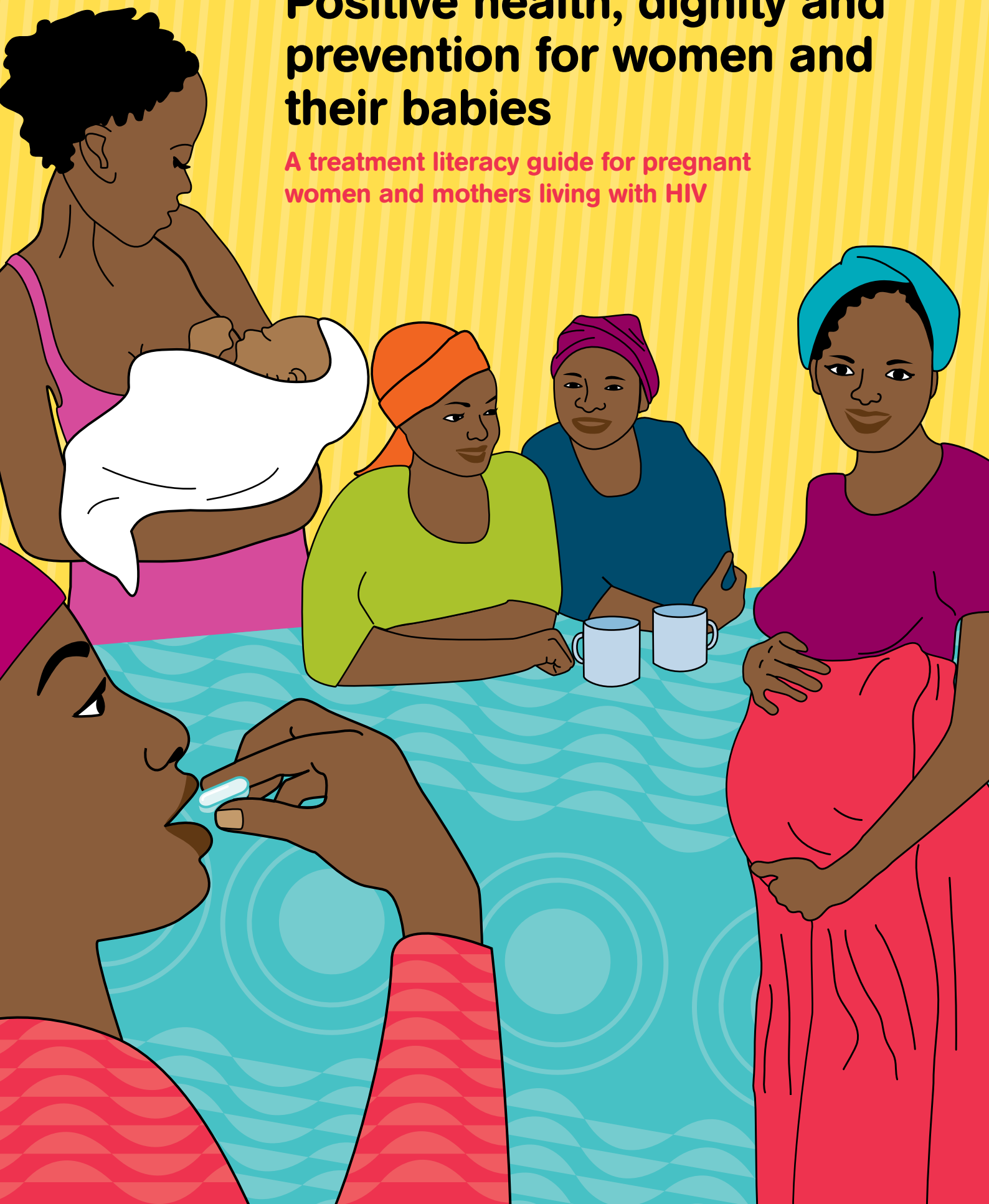


FACILITATOR'S MANUAL

Positive health, dignity and prevention for women and their babies

A treatment literacy guide for pregnant women and mothers living with HIV



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For more information on the IATT, please visit:
www.emtct-iatt.org/about/

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Introduction

Positive Health, Dignity and Prevention for Women and their Babies: A treatment literacy guide for pregnant women and mothers living with HIV is intended for use by networks of women living with HIV, women's groups, peer educators and others wishing to help guide women living with HIV through the decisions they will need to take before, during and after their pregnancy. It is not intended as a substitute for going to a health facility and seeking information from a healthcare worker.

The guide contains three elements:

- facilitator's manual
- flipchart
- poster

They are designed to offer a package of guidance for a woman living with HIV who is considering having a child.

About the facilitator's manual and accompanying flipchart

The facilitator's manual and flipchart are intended to be used by leaders of support groups, peer educators or lay counsellors to facilitate small groups or community sessions with women living with HIV. Together, they provide accurate and comprehensive information to enable pregnant women and mothers living with HIV to know their rights and make informed decisions about their health, and the health of their baby.

The manual is made up of 12 modules. Key messages from each module are also represented more graphically in the flipchart.



About the poster

The third element of the package is a poster that summarises the key messages from this guide.

This poster can be displayed anywhere that it will be seen by women living with HIV and their families, for example: clinic rooms, a church hall, waiting rooms, community education spaces, and places where support group meetings are held.



Global guidelines are regularly updated. Make sure you are up to date by visiting these web links www.who.int/publications/guidelines/hiv-aids/en/ and <http://emtct-iatt.org/resource-categories/guidelines>

Tips for the facilitator

- As you talk through each section of the module, you should show the corresponding flipchart that represents the key messages graphically for the participants to follow.
- It is important to get the group to actively participate throughout the sessions by sharing what they already know, the challenges they face as well as any solutions to these challenges.
- Ideally all the modules should be followed in sequence to give a woman the full set of guidance that she will need for her pregnancy, labour and when caring for her new baby. If this is not possible you will need to ensure that the women in your group are given key related information from other modules. Throughout the modules you will see prompts to include information from other modules where this is necessary.
- As the facilitator, you should check if any of the information needs to be adapted to reflect differences in your national care and treatment guidelines.
- Throughout the module, some of the more technical words are written in bold. It is important that you take time to ensure that the group understands the meaning of these words and adapt the language where necessary.

In the modules you will find:

Handouts: there are two handouts included within the manual, each one is two-sided. You will need to photocopy these to give one to each member of the group during the relevant modules. These contain more detailed information that the women may find helpful to take home with them.

Facilitator's guidance: this section is for the facilitator only, to give additional guidance on how to conduct the session and in particular highlight areas where you may need to provide further information or refer to other modules.



This icon is used to indicate there is a corresponding flipchart page for the section. Make sure you turn to the relevant flipchart page each time you see this icon.



Notes: there is space in the margin of the manual to add your own notes. This can be anything you find useful such as information specific to your setting or issues that arise during sessions.

Activity: the activities are designed to be interactive elements of the sessions. You should adapt them to the group and carry them out in whatever way you think will work best. Please look at these in advance to ensure you are fully prepared and have all the materials you need. You will need male and female condoms for the activity in Module 5.

Following up with your healthcare team: each module ends with this section. At this stage you should check the group has understood the information covered in the module and allow time for questions. You should then talk through the 'Questions to ask your Healthcare team'. You could photocopy these and hand them out to the group.

Finally, it is important to emphasise the human rights listed at the end so that women leave the session empowered to seek more information and stand up for their rights.

1

Human rights in healthcare settings

This module will discuss:

- Rights in healthcare settings and what to do if they are not respected
- Specific issues surrounding the rights of young pregnant women and mothers



Notes

1.1 Health rights

Facilitator's guidance



Use **Flipchart 1: Knowing your rights** to complement this section.

Every human being has the right to enjoy the highest attainable standard of health. You also have the right to control your own body. In practice, this means you have the right to:

- confidentiality and privacy
- equal and non-discriminatory treatment
- access to acceptable, quality healthcare services
- access to justice and redress
- be free from all forms of violence (including gender-based violence).

Critically, you also have the right to all the information that is required to enable you to take informed decisions about your healthcare. You should not be coerced into making any decisions. For example, you should not be offered treatment on the condition that you use a certain form of contraception, or be given something of value if you follow a certain procedure.

In particular, you have the right to choose, free from coercion:

- whether or not to be tested for HIV
- whether to take HIV treatments, when to start and whether to stop
- whether to have a child or choose to have an abortion or be sterilised
- whether to use contraception and what contraception to use
- whether to breastfeed and for how long.



Healthcare providers are obliged to uphold these rights. In particular:

- They must fully explain all treatments and tests you are prescribed; how they are given; what they do; and any potential benefits and harms of these treatments. They should seek your understanding and free consent to the treatment, procedure or process.
- They should never force or coerce you into undertaking a particular treatment, procedure or test.
- They must never treat patients rudely or in a threatening manner. They should never abuse patients either verbally or physically.

Problems in healthcare settings

Many healthcare providers are caring, supportive and respectful of the women in their care. Unfortunately, there are some who may not have received the right training and support, or who do not follow the guidelines. As people living with HIV, we sometimes receive worse care, treatment and support than we deserve and are entitled to.

If you feel your rights have not been respected you can:

- contact other women living with HIV for support or contact an HIV organisation to get help with making a complaint
- raise your concerns with the clinic's director, if you feel you can, or ask someone to help you do this
- if all else fails, contact a legal aid organisation, if one is available, to file a complaint.

Activity

Briefly outline the scenario below to the group:

Grace attended her antenatal clinic in the early stages of pregnancy. A nurse told her she needed some routine tests. After the tests had been carried out, the nurse returned to the waiting room where Grace was sitting with her mother-in-law and told her that one of the tests showed that Grace was HIV positive.

First, encourage the group to discuss what was wrong with the nurse's behaviour. Make sure the group understands that the nurse should have sought Grace's informed consent for the test and should have kept the results confidential.

Then ask the women in the group if they feel they understand their rights – do any of them have questions about what their rights are in specific situations or what kind of behaviour is acceptable?



1.2 Know your rights, if you are below the legal age to consent to medical care

Facilitator's guidance



Use **Flipchart 2: Young pregnant women's rights** to accompany this section.

Ensure that you know what the legal age to consent to medical care is in your country. You will need to adapt the section below to reflect the legal position in your country, in particular: whether young pregnant women are considered to be emancipated or mature minors; what rights they have in your country; and whether the law requires healthcare providers to share information about a woman's health without consent.

You can skip Section 1.2 if none of the women in your group are below the legal age to consent to medical care.

The right to consent to your own treatment and that of your baby

In some countries, even though you have not reached the legal age to consent, you may be considered an **emancipated** or **mature minor**. This means that you are able to give consent for your own treatment and the treatment of your baby during pregnancy, childbirth and breastfeeding. In this case, you are entitled to:

- a full explanation of all treatments you are prescribed, how they are given, what they do, and any potential benefits and harms of these treatments
- decide whether or not to choose the treatments recommended to you by the healthcare provider
- choose who your health information can be shared with
- decide whether or not you want to have a baby or keep the baby.

The right to choose who your health information is shared with

You should reasonably expect that any information about your health will not be reported to anyone without your consent or permission. This includes parents, legal guardians, and school or religious authorities, except when the law requires it. For example, the laws in some countries may require healthcare providers to report when underage pregnant women have experienced illegal sexual behaviour.

You should also expect the same care and respect as any other pregnant woman.

Choose a friend or relative to be your treatment supporter

If you feel you would like some support, bring a trusted friend, relative, community healthcare worker or someone from a peer support group with you to your clinic appointment. This person can act as a **treatment buddy**. You may find it helpful to discuss the decisions you face with them. They could also support you to choose strategies to help you to adhere to your medication and keep your clinic appointments.



Notes

1.3 Follow up questions

Questions to ask your healthcare team or women's support group

- Can I refuse treatment recommended by a healthcare professional?
- How can I ensure healthcare workers respect my right to choose if and when to start treatments?
- If a healthcare provider's behaviour is stigmatising or abusive, who can I complain to? Are there groups that can help me?

Remember you have the right to:

- the highest attainable standard of health
- be treated the same as any other pregnant woman, free from stigma and discrimination
- confidentiality and privacy
- make voluntary decisions about healthcare for you and your baby.

2

Staying engaged in healthcare during pregnancy and after delivery

This module will discuss:

- Why it is important to be active in your healthcare
- How to work with your healthcare team



Notes

2.1. The importance of engaging in your own healthcare

Facilitator's guidance



Use **Flipchart 3: Take control of your own care** to accompany this section.

Attend the clinic during pregnancy and after your child is born

It is essential for your health and for your baby's health that you take your **antiretrovirals** (ARVs) but good healthcare goes far beyond this. You and your healthcare team need to monitor all aspects of your health (e.g. your nutrition, blood pressure etc.) to ensure you are well and your baby is thriving. If you have other health conditions besides HIV, these also need to be monitored and managed. Your healthcare team can support you through this.

A healthy baby needs a healthy mother. After your baby is born, you should continue to seek support for your own health from your healthcare team. It is also important to take your baby to his/her appointments so that your healthcare team can monitor your baby's health.

Be active in your healthcare

Your healthcare team includes many professionals such as your doctor, midwife nurse, pharmacist, community healthcare worker and others at the hospital, clinic or even in the community. Often, we are used to doing as we are told by those in authority, but it is important not to simply follow instructions from your healthcare team – you also need to share your opinions and play an active part in shaping your healthcare.



- **You too are an expert** – You know your body and are in the best position to say how you feel and describe any changes you are experiencing. This will help your healthcare team give you the right support.
- **Be in control** – You need to make sure you understand as much as possible about your treatment and take control over your own care.
- **Engage** – The better relationship you have with your healthcare team, the more able you will be to make informed choices about your treatment

Activity

Ask the women to split into small groups. Ask them to think about whether there are particular healthcare professionals that they feel they have a good relationship with. In particular, ask them to discuss questions like:

- Why do they feel supported by this healthcare professional or healthcare team?
- Do they feel comfortable talking openly to them? If so, why do they think this is?

Then gather the women back together and ask each group to share the main points that came up in their discussion.

2.2 How to establish a good relationship with your healthcare team

Facilitator's guidance



Use **Flipchart 4: PREPARE** to accompany this section.

As you are following this section, wherever possible refer back to the comments that came up during the activity. Try and point out positive examples of discussions and relationships with healthcare professionals.

The best way to make the most of your time spent with your healthcare team is to be prepared. Thinking about what you want to get out of your appointment will help you and your healthcare team meet your needs. An easy way to remember this is using the acronym PREPARE:

- **Plan**
- **Research**
- **Explain**
- **Prioritise**
- **Ask questions**
- **Return**
- **Explore other options**



Plan

Put your appointment in your diary or phone so that you don't forget.

Think about:

- Any questions you have
- Any symptoms you have and how often you experience them
- The main things you would like to discuss with your healthcare provider

Make sure you know or find out:

- your **CD4 count** and/or **viral load**
- the names of the medications you are taking – both ARVs and any other medications you are taking for other conditions (including any herbal remedies or contraceptives).

Research

If you are experiencing symptoms for the first time, ask other people living with HIV if they have experienced similar symptoms. Ask how they were able to cope with them.

If you have access to a computer, you can use well-known reputable web sites to get basic HIV information (e.g. HIV i-base <http://i-base.info> or The Body www.thebody.com). Remember, that although these sites can give you some useful information, always talk to your healthcare team – you should not use web sites to diagnose yourself.

Explain

If you are experiencing any symptoms or side effects, explain how often they occur, how severe they are and to what extent they affect your quality of life.

Talk to your healthcare provider about what is happening in detail, no matter how embarrassing it may be. It is very likely that they have heard it before.

Prioritise

Most appointments only last for a few minutes, if there is something that really concerns you, talk about this first. Try to focus on just one or two complaints per appointment to allow time for them to be dealt with effectively.

Ask questions

It is important that you understand about your medication and your condition. If there is anything you are unsure about do not be embarrassed to ask. If the healthcare provider says something that is unclear, ask for it to be repeated or explained in more detail.

Write down anything that is said that you think you may forget.

Give feedback. If things go wrong or you are not happy about your care, then let your healthcare provider know. Equally, give positive feedback if you feel well supported.



Return

If things don't improve, go back. Don't ignore any symptoms. Some medications can have side effects that last for a short period of time, but if they persist, let your healthcare team know.

Explore other options

If you are unhappy with any explanation, you can question your healthcare team. Try to do this in a non-confrontational way. For example, if they don't think that your persisting headaches are a side effect of your ARVs, then ask them to explain why they think this is so, and what else could be causing them. If you remain unconvinced by their explanation, you can ask for a second opinion.

Peer support is extremely important. It can be especially helpful if you are a young person moving into an adult clinic. You may find it helpful to take someone you trust with you to your next appointment. Also speak with other women living with HIV to find out what works for them.

2.3 Follow up questions

Questions you may want to ask a peer counsellor

- I feel alone in this process. Who can I talk to?
- I don't like attending the clinic because I don't feel comfortable with my healthcare team. What should I do?
- I am concerned that whatever I share with my healthcare team will not remain confidential. I do not want it to be reported back to my partner, my parents or family etc. What should I do?

Remember you have the right to:

- make voluntary decisions about any healthcare you receive.
- the same quality of care as any other pregnant woman, free from stigma and discrimination.

3

Talking about HIV

This module will discuss:

- Reasons for disclosing your HIV status
- How to talk about HIV



Notes

3.1 Advantages and disadvantages of disclosure

Materials

Flipchart paper and marker.

Facilitator's guidance

Remember, some women in the group may have only recently discovered their HIV status. The aim of this module is to give them guidance on how to begin to talk about their HIV to others – they should not feel under pressure to disclose their status.

During Section 3.1 you will discuss non-disclosure. Make sure you know the legal situation in your country. In particular, whether non-disclosure leads to criminal charges.

Conduct the activity on page 13, before you turn to Flipchart 5. After the activity you should go on and look at the lists below to ensure you have discussed all the main pros and cons of disclosure.



Use **Flipchart 5: Reasons to tell people your HIV status** to complement this section.

As a person living with HIV, you are no different to other people. You have the right to be loved and to have relationships, sexual and intimate, with other people. However, you may feel this is difficult if people know your HIV status.



Activity

Put a large piece of paper up on the wall and draw two columns on it. At the top of one column write the heading “disadvantages” on the other write “advantages”. Ask the women to share with the group some of the pros and cons of disclosing their HIV status and write them up on the paper. You may find it better to split the women in to small groups for this activity.

We have discussed some of the many reasons why you may be reluctant to disclose your status to partners, family members or friends, including:

- Fear of stigma or rejection, due to others’ lack of knowledge about HIV
- Fear of intimate partner violence (also known as domestic violence)
- Fear of loss of economic and social support for you or your children

However frightening it may be, telling people that you are living with HIV can bring many benefits:

- It gives you control over how other people learn about your HIV status, rather than them being told by someone else.
- It can reduce the stress of having to hide your medical condition.
- It may allow you to get support from your partner(s) and family member(s) to help cope, and to manage your HIV.
- You can choose to start **antiretroviral treatment** (ART) when it is right for you, without worrying about hiding the medicine. It also increases the chance that you will adhere to your treatment. You won’t have to take your **antiretrovirals** (ARVs) in secret and others can support you to remember to take your medicines and attend the clinic.
- It allows you to begin talking with your partner(s) about HIV prevention methods (e.g. condom use).
- It may also be a signal to your partner(s) to be tested.

3.2 How to talk about your HIV status

Guidance for facilitator



Use **Flipchart 6: Disclosing your HIV status** to accompany this section.

It is very important that a woman does not feel pressured into sharing her HIV status with anyone, particularly if she is concerned for her safety. Make sure you reiterate throughout this session that it is the woman’s right to disclose if, when and to whom she chooses. She is in the best position to decide what is safe for her and her family.

While you have a responsibility to protect yourself and others from HIV, you should not feel driven by fear but rather empowered to take your own decisions with dignity. You should never feel pressured to share your HIV



status unless you want to and feel ready to do so. The key thing is to always seek support. When you are ready to talk about your HIV status with your partner(s) or family member(s) you should consider the following:

Be prepared

- Think about how you will share information about your HIV status. Plan what to say and how to say it
- Gather materials about how HIV is transmitted and HIV treatment, for your partner(s) or family member(s) to read. Helping them to understand the facts about HIV may stop them reacting negatively.
- Have the names of doctors, counsellors, and, if possible, other people in the same situation who your partner(s) or family member(s) can speak to.
- Practise talking through what you might actually say in the situation so that you don't forget anything and you feel comfortable with what you are going to say.

Be safe

- Choose a quiet and private place to talk. But, make sure it is safe for you in case your partner(s) or family member(s) become upset.
- Consider having someone close by who can help you, if necessary.
- Do not pick a time when your partner(s) or family member(s) is drinking alcohol, using drugs, or is in a stressed state of mind.
- If your partner(s) or family member(s) have a history of violence against you or anyone else, you may not feel safe to share your HIV status while in the relationship. In that case, consider sharing your HIV status with others who can help you leave the relationship and find shelter before doing anything. If you want to share your status while in the relationship, consider doing so at your healthcare provider's office or in a counselling environment where you feel safe.
- If you have children, plan for their safety and have someone look after them for you.
- In case it is necessary to leave after disclosing your HIV status, have access to money or transportation and have a prearranged place to go.

3.3 Follow up questions

Questions for your healthcare team/support group

- How can I tell my partner(s) and family members about my HIV status?
- How can I protect myself from violence and abuse when I share my HIV status?
- Are there healthcare providers, counsellors, or other community groups who can help me to share my HIV status with others?
- What are my legal responsibilities to "disclose" to a sexual partner? How do I protect myself from a claim that I did not "disclose"?

Remember you have the right to:

- have relationships, including sexual and intimate ones
- decide if and when to disclose your HIV status.

4

Understanding HIV

This module will discuss:

- Your immune system and how it is weakened by HIV
- The signs that show HIV is affecting your health



Notes

4.1 How your body protects itself from infection

Materials

Sheets of plain paper and a box or hat to put questions in.

Facilitator's guidance



Use **Flipchart 7: What is HIV?** to accompany this section.

Some of the scientific terms in this module may be new to some women in your group. Make sure you take time to ensure they understand the words you are using and the explanations of HIV and AIDS. If you require any further information, you may find the following websites useful: www.thebody.com and www.avert.org

Your immune system

- Your immune system protects your body from diseases. It is made up of immune cells, proteins, and chemicals. These different parts of the immune system work together to identify and fight foreign **organisms**, like bacteria, viruses, and fungi that can cause infections.
- Some of your immune cells have a marker on them. The cells with a CD4 marker on them are called **CD4 cells** and are the most important cells in your immune system.
- The CD4 cells fight infections like HIV, when they come into your body.

How HIV affects your immune system

- When you are infected with the **human immunodeficiency virus** (HIV) we say that you are HIV positive or you are living with HIV.
- The HIV virus attacks your CD4 cells and uses them to make copies of itself. As it does this, it destroys your healthy CD4 cells.



- The more HIV continues to attack your CD4 cells, the less you are able to fight off other organisms that cause infections. As a result, you are more likely to get infections like tuberculosis (TB) or thrush. These are called **opportunistic infections**.
- Once in your body, HIV will move in your blood to other parts of your body, including the spleen, liver, lymph system, brain, sperm and vaginal fluids.
- HIV usually targets your gut first and kills off a lot of your CD4 cells there. This causes many people living with HIV to have stomach and intestinal illnesses.
- **Antiretrovirals** (ARVs) are medications that help to stop the HIV from making copies of itself and helps your body fight the infection.
- Remember, you can live well, take medications, and be healthy for many years even though you are living with HIV.

What is AIDS?

- Just because you are living with HIV does not mean you have AIDS.
- AIDS stands for **acquired immunodeficiency syndrome**. Over time, as HIV continues to attack your CD4 cells, your immune system gets weaker and weaker. AIDS only develops when HIV has caused serious damage to your immune system.
- AIDS describes the collection of illnesses that you get when you have almost no CD4 cells left and your immune system is too weak to fight off infections. It is a complex condition with symptoms that vary according to the individual.
- You can live many years with HIV. However, if you do not get treatment for your HIV, eventually you will get AIDS. This will take, on average, up to ten years from initial infection to AIDS. Even if someone has progressed to AIDS, it is possible for a person to live for many years if they start and continue taking ARVs.
- ARVs can never completely get rid of the HIV in your body. However, if taken correctly, ARVs can stop the harm that the HIV causes to the immune system and enable you to continue being healthy for many years.

Activity

Give the women pieces of paper. Ask them to write down any questions that they still have about HIV and AIDS. Ask them to put the questions in a box or hat.

Take the questions out one by one and encourage the woman themselves to try and answer them. Gently correct any misinformation (e.g. *Many people say that but actually ...*) and provide answers where they are unable to.

This activity can also be carried out without writing down the questions. Instead the women can be encouraged to ask their questions aloud.



4.2 How do I know that HIV is affecting my body?

Facilitator's guidance



Use **Flipchart 8: Understanding viral load and CD4 count** to accompany this section.

Viral load

- The amount of HIV in your blood is called **viral load**. When you have an **undetectable viral load**, it means that the HIV in your blood is very low.
- A viral load test is the best way of knowing if your ARVs are working well for you. If your viral load is undetectable your ARVs are helping your immune system to fight HIV.
- With a low viral load, there is less chance that you will pass HIV onto your baby, as well as to your partner(s).

CD4

- A CD4 test measures the number of CD4 cells in your blood to see how well your immune system is working. The test is called a **CD4 count**.
- The CD4 count helps you know when the body needs help to build and maintain the immune system. The higher your CD4 count is, the stronger your immune system is.
- Although global guidelines now recommend treatment is given to everyone living with HIV, in your country you may still find that your CD4 count is used to decide when to start treatment.

4.3 How is HIV transmitted?

Facilitator's guidance



Use **Flipchart 9: How HIV can be transmitted** to accompany this section.

- HIV is transmitted by coming into very close contact with the blood, semen, and cervical or vaginal fluids of someone who has HIV.
- The most common way people get HIV is by having sex with someone who has HIV (and does not have an undetectable viral load) without using a condom.
- Women living with HIV can pass HIV onto their baby during pregnancy, delivery and breastfeeding. This is called vertical transmission or mother-to-child transmission of HIV.
- HIV can also be passed from person to person by using needles or syringes that are contaminated with blood from someone with HIV.
- HIV can be transmitted through blood transfusions.
- HIV CANNOT be passed from person to person by hugging, eating together or sharing living space.



4.3 Follow up questions

Questions to ask your healthcare team

- What is my CD4 count?
- What is my viral load?
- When should I start taking ARVs? What are the risks of taking ARVs?
- What is the best way to keep my viral load low and my immune system functioning well?

Remember you have the right to:

- know and understand your medical condition, including your CD4 count and viral load
- choose whether to take HIV treatments, when to start and whether to stop.

5

Importance of sexual and reproductive health and rights

This module will discuss:

- How you and your partner(s) can have a healthy sex life
- Your choices around whether or not to have children



Notes

5.1 How to protect yourself and your partner(s) during sex

Materials

Female and male condoms for demonstration.

Facilitator's guidance



Use **Flipchart 10: How to protect you and your partner(s) during sex** to accompany this section.

It is important to acknowledge to the group that they may find it difficult to take some of the steps below, or feel they have little control over these decisions. Begin with discussing the steps and then you can move on to talking about possible barriers to taking these steps and ways of accessing help.

If you have not followed Module 3 in this session, you will need to give extra information from that module in addition to the summary below about how to safely talk about HIV.

Talk to your partner(s) about HIV

- If you feel safe to do so, it is important to talk to your partner(s) about your HIV status. This will help you both decide what steps to take to have a healthy sexual life.
- Talking about HIV together may encourage your partner(s) to consider having an HIV test. If he has HIV, he will need to go to an HIV clinic. If he does not, you may choose to use male or female condoms to reduce the risk that he will get HIV.



Take your ARVs on time

- You can reduce the risk that you will pass on HIV to your partner(s) by taking **antiretrovirals** (ARVs).
- Having an **undetectable viral load** dramatically reduces the risk of you passing HIV onto your partner(s). The only way you can achieve an undetectable viral load is by taking your ARVs on time and as prescribed by your healthcare professional.

Always use a condom and protect against STIs

- It is important that you or your partner(s) have no open sores from any other **sexually transmitted infections** (STIs).
- Male and female condoms help protect you from getting other STIs, like syphilis or herpes. These infections are harder to treat in people living with HIV.
- If your partner does not have HIV, condoms can help reduce the risk that he will get HIV.
- Both male and female condoms provide **dual protection** because, in addition to preventing sexually transmitted infections (including HIV), they can also prevent you from getting pregnant if you do not wish to be.
- Ideally, it is good to use condoms and another form of **contraception** (e.g. the pill).
- You can get condoms from your healthcare team as part of your visit to the HIV clinic or antenatal clinic.

It can be difficult for women to negotiate to use their preferred method of contraception with their sexual partner(s). If your partners do not wish to use condoms (male or female) you can still protect yourself against unwanted pregnancy with other forms of contraception while you attempt to encourage your partner(s) to use condoms.

Activity

Show the women both male and female condoms. Explain how to use both. As women tend to be less familiar with female condoms focus especially on these and encourage anyone who has used a female condom to talk about their experience.

Flipchart 10 shows how to use a female condom.



Seek treatment for STIs

- HIV is one type of STI. Other common STIs include syphilis, herpes, and gonorrhoea.
- Symptoms of an STI include: a smelly discharge from your vagina, pain when you urinate, a sore in your genital area, and/or pain in your abdomen.
- If you have any of these symptoms, you should let your healthcare team know right away. It is important you get treatment for these infections so you can remain healthy and so you can protect the health of your baby.
- It is also important that your partner(s) sees a healthcare provider so that he can also get treatment. If you have an STI, he is also very likely to have it. And vice-versa.

Cervical cancer

- Women living with HIV are at greater risk of cervical cancer, particularly those with advanced HIV disease. Cervical cancer screening is usually not offered to women who are pregnant as the results can be difficult to read, so it is important to try and be screened before you become pregnant.
- If a woman living with HIV, has cervical cancer and becomes pregnant she will face difficult decisions about whether to continue with her pregnancy and whether to treat her cancer. She will need a great deal of support and advice from her healthcare team.

5.2 Deciding whether to have a baby

Facilitator's guidance



Use **Flipchart 11: What to do if you want to have a baby** to accompany this section.

If you know there are problems in your area with health workers not supporting the rights of women living with HIV to have children, you should discuss this. Also, if there are specific groups that offer support and advice outside formal healthcare settings you should tell women about these.

Look for support and advice

- If you want to get pregnant, you should talk to your healthcare team. They can give you information on how you can safely get pregnant and advise whether you are healthy enough to get pregnant.
- If you do not feel able to talk to your healthcare team you will still need advice and support. Try to talk to someone from a women's group or HIV support group.
- Remember, it is your right to decide if and when you want to have children.

Make sure you are healthy

- Pregnancy will not make your HIV any worse. However, you need to make sure that you are healthy enough to get pregnant. This includes making sure your **CD4 count** is high enough, that you are stable on your ARVs,



and that you do not have any symptoms of other STIs or **opportunistic infections** such as tuberculosis (TB).

Talk to your partner and family members

- It is important that your partner gets tested for HIV so that your healthcare team can help you and your partner get pregnant safely and have a healthy child.
- You may need a lot of support during your pregnancy and when you are breastfeeding. Ideally, your family members and partner will know that you have HIV so that they can support you and help you take your medicines and get to the clinic on time.

Get pregnant safely

If your partner does not have HIV, there is a risk that he could get HIV while you are trying to get pregnant. However, there are things you can do to reduce this risk:

- Always take your ARVs on time. This reduces the amount of HIV in your blood and the risk that you will pass HIV onto your partner.
- Know when in the month you are the most **fertile**. If your period comes every 28 days, you are the most fertile around the 13th day after your monthly bleeding starts.
- To increase the chance of becoming pregnant, you and your partner should stop using condoms two days before your most fertile day and continue sex without condoms until two days after your fertile day. This means you should not use condoms from day 11 to day 15 after the start of your monthly bleeding to increase your chance of getting pregnant. (Flipchart 11 shows the fertility cycle.)
- You and your partner should use condoms on all other days of the month to reduce the chance that he gets HIV.
- If your partner does not have HIV he can also take a daily pill called a **pre-exposure prophylaxis** or PrEP for short. This will reduce the risk that he gets HIV. Your healthcare team can advise whether this is available in your setting.

Do ARVs affect your fertility?

- Women living with HIV who are not on ARVs are between 25% and 40% less **fertile** than HIV-negative women. However, women living with HIV on ARVs have the same fertility rates as women who are not living with HIV. ARVs improve the fertility of women living with HIV because they help our bodies to become healthy enough for pregnancy and because our sexual desire returns when we feel healthy.
 - There is some evidence that certain ARVs may negatively affect the sperm in men. If your partner is on ARVs and you want to get pregnant, you should talk with your healthcare provider in the HIV clinic. They will then carry out certain tests to make sure you are both healthy enough for pregnancy.
- Discuss your plans with your healthcare team as they can support you to get pregnant safely.



What you should do if you do not want to get pregnant

- Condoms are the best form of **contraception**. Not only do they prevent unwanted pregnancy but they also offer you and your partner protection from HIV and other STIs. No other contraceptive method offers this dual protection. You should always try to negotiate to use a male or female condom alongside any other contraceptive method that you choose.
- There are a number of other contraceptive methods that you can use if you do not want to get pregnant. The most common are **oral contraceptive pills** that you take every day or **injectables** that you can get every 2 or 3 months. There are also longer acting methods of contraceptives called **implants** or **intra-uterine devices** (IUD) that can last up to five years.
- Most women living with HIV can safely use all these methods of contraception. Some contraceptives include hormones, these can interact with your ARVs and reduce the efficacy of the contraception. It is important that you talk to your healthcare provider to discuss which form of contraceptive is best for you given the specific ARV regimen that you are taking. There are also concerns that some hormonal contraceptives may increase the risk of acquiring or transmitting HIV but the evidence is unclear, ask your healthcare team to update you on the latest advice.

5.3 Follow up questions

Questions to ask your healthcare team

- Am I healthy enough to get pregnant?
- What ARVs or other medications are safe to use during pregnancy?
- How can I safely get pregnant while protecting myself and my partner from getting or passing HIV and other STIs onto each other?
- I don't want to get pregnant, what contraceptive methods are available at this clinic?
- Which contraceptive methods are safe for me to use?

Remember you have the right to:

- a healthy sex life
- choose whether, when and how many children you wish to have
- give your consent before any test or medical procedure is carried out (e.g. sterilisation)
- use contraception to avoid unwanted pregnancies.

6

HIV transmission during and after pregnancy

This module will discuss:

- Understanding how HIV affects your pregnancy
- Protecting your baby from HIV



Notes

6.1 Managing your HIV

Facilitator's guidance



Use **Flipchart 12: Managing your HIV** to accompany this section.

Even if you have covered Module 4 with this group of women, you should still reinforce the key points about understanding HIV here. You could ask the women to recall the key points themselves, rather than outlining them again.

Even though you have HIV, the virus will not necessarily be transmitted to your baby. In the absence of any interventions, transmission rates range from 15% to 40%. This rate can be reduced to below 5% with effective interventions, such as taking **antiretrovirals** (ARVs) every day and delivering your baby in a health facility. It is important that you understand how to manage your HIV in order to reduce the chances of the virus being transmitted to your baby. The aim of HIV treatment is to have a very low or **undetectable viral load** and a **high CD4 count**.

Viral load

- If your **viral load** is high, you have a lot of HIV in your blood. This increases the risk that you will pass HIV onto your baby.
- Taking ARVs can lower your viral load and reduce the risk that you will pass HIV onto your baby. Viral load is considered undetectable when there are under **40–75 copies** in a sample of your blood.
- Having an undetectable viral load doesn't mean that the virus is completely gone from your body. It is important to start ARVs early in your pregnancy and to take the medications on time to allow the ARVs to fight the HIV.
- While viral load tests are not always available or accessible, it is recommended that they should be performed every six months to support better adherence to ARVs and prevent treatment failure.



CD4 count

- HIV attacks and destroys CD4 cells. Measuring your CD4 cells is called a **CD4 count** and is a way of testing how strong your immune system is.
- Generally the higher your CD4 count, the healthier you are. Taking ARVs can increase your CD4 count. Anything between **500** and **1,200 cells/mm³** can be considered a healthy CD4 count.
- If you have a higher CD4 count, there is less chance you will pass HIV onto your baby. Having a higher CD4 count will also help you stay healthy enough to carry your baby to full term and help prevent the risk of miscarriage.

Having an opportunistic infection

- **Opportunistic infections** (e.g. tuberculosis (TB), hepatitis B and C, thrush and kaposi's sarcoma) usually occur when your CD4 count is low. They can also be a sign that your viral load is high.
- If you have an opportunistic infection, you may be at higher risk of passing HIV onto your baby. It is very important to let your healthcare provider know if you have a symptom of an opportunistic infection. Your provider can give you treatment for the infection and may also need to adjust your ARVs.

6.2 How HIV can be transmitted from mother to child

Facilitator's guidance



Use **Flipchart 13: How HIV can be transmitted from mother to child** to accompany this section.

As many women living with HIV are unsure whether to breastfeed their babies, make sure that throughout this module you reinforce the current global guidelines that advise women living with HIV in low-resource settings to breastfeed.

If you are not planning to cover Module 10 with this group of women you will need to explain the term **balanced diet** and provide some further information on nutrition during Section 6.2 below. Similarly, if you are not following Module 12, further information on nutrition for the baby may be needed during the breastfeeding section.

HIV transmission during pregnancy

- Your baby is surrounded by **amniotic fluid** in your womb. This fluid protects your baby during pregnancy.
- Your blood travels through the **placenta** and **umbilical cord** to feed your baby. Usually, HIV will not cross through the placenta from mother to baby. This is because the placenta protects the growing baby from many different infections, including HIV.



- Protection from the placenta can be reduced if you have an infection in your **uterus**, have a high viral load or are **malnourished**.
- Again, it is really important to take your ARVs to reduce your viral load and the risk of passing HIV onto your baby.
- You should also try to eat a balanced diet to make sure your body has the nutrition it needs during pregnancy and you do not become malnourished.

HIV transmission during labour and delivery

- Most babies that acquire HIV get it during labour and delivery. It is important that you deliver your baby in an equipped health facility so that the healthcare providers can make sure you deliver your baby in a safe and timely manner.
- During labour, as your uterus contracts, some of your **membranes** may break. This may expose your baby to fluid containing HIV. The risk of transmission increases by 2% for every hour after membranes have broken.
- A sore or tear in your **vagina** or **cervix** can act as a door through which HIV can pass from you to your baby during childbirth. If you have sores or tearing in or around your vagina, you should let your healthcare provider know.
- During delivery, when your baby is passing through your **vaginal canal**, there may be friction (or rubbing) between your baby's thin skin and your vaginal wall. This may expose your baby's immune system to your maternal fluids and blood containing HIV.
- Remember, taking your ARVs can also lower the viral load in your blood and vaginal fluids and reduce the risk that you will pass HIV onto your baby during labour and delivery.
- Previously, women living with HIV were advised to deliver by caesarean (C-section) but this is no longer the case.
- Global guidelines recommend that all babies born to mothers living with HIV are given a course of ARVs from the day they are born for up to six weeks to reduce the risk of HIV infection.

Activity

Ask the women to discuss whether they think a woman living with HIV should breastfeed or not. Ask them to try and come up with a list of pros and cons. They may feel more comfortable talking about this if you split them up into smaller groups. At the end bring the groups back together to share their thoughts on breastfeeding. As you follow the next section on HIV transmission during breastfeeding, refer back to any of the questions that arose where it is helpful.



HIV transmission during breastfeeding

- HIV can be transmitted to the baby during breastfeeding if the baby has mouth sores.
- HIV can also be transmitted to your baby if your nipples become cracked and let out blood containing HIV. It can also be transmitted if you develop **mastitis** (an infection in your breast where it becomes swollen, red and sore). If you develop sores on your breasts or nipples, or you think you may have mastitis you should seek treatment right away.
- Previously, it was thought that **mixed feeding** (giving your baby a combination of breastmilk and any other food or liquid) in the first six months of your baby's life led to a greater risk of HIV transmission. It is now recognised that if a mother is adherent to ARVs the medication works to reduce the risk of transmission even when mixed feeding. However, mixed feeding in the first six months is still associated with an increased risk of your baby contracting other diseases (such as diarrhoea and pneumonia) so is best avoided.
- Women living with HIV are now advised to breastfeed their babies. It is important to remember that taking your ARVs will lower the viral load in your breastmilk and reduce the risk that you will pass HIV onto your baby in any of the circumstances described above.

6.3 Follow up questions

Questions to ask your healthcare team

- How can I protect my baby throughout my pregnancy?
- How can I protect my baby during childbirth?
- What can I do to protect my baby during breastfeeding?

Remember you have the right to:

- antenatal care throughout your pregnancy
- healthcare during labour
- healthcare after delivery and during breastfeeding
- support from a trained healthcare team while caring for and feeding your baby.

7

HIV treatment for pregnant and breastfeeding women

This module will discuss:

- ARVs and how they work
- What treatments are available and when to start them
- The importance of adherence to ARVs



Notes

7.1 What is HIV treatment?

Materials

Copies of **Handout A: Antiretrovirals and side effects** on page 51, one for each participant.

Flipchart paper.

Facilitator's guidance



After reading the introductory paragraphs, carry out the activity. After the activity is completed, display **Flipchart 14: Antiretroviral treatment** and give a copy of **Handout A: Antiretrovirals and side effects** to each of the woman in the group. If you are following Module 9 with the women later you can ignore the column on side effects on the handout at this stage. If not, you will need to make time to discuss them with the group during this module.

Although World Health Organization (WHO) guidelines now recommend that all pregnant women are offered HIV treatment as soon as they are diagnosed with HIV, this is not always the reality. Make sure you know whether treatment is offered to all pregnant women in your country before you carry out this module.

- **Antiretrovirals** (ARVs) are medicines that stop HIV making copies of itself. By stopping the virus from making copies, there is less HIV in your blood and your immune system remains stronger and is more able to fight diseases.
- There are different **classes** or groups of ARVs. Each class targets a different part of the process of HIV replication and attack on the immune system. This is why a combination of three or more ARV medicines is used for HIV treatment – often contained in one pill. For example, Atripla or Viraday, contains **efavirenz** (EFV), **emtricitabine** (FTC) and **tenofovir** (TDF) – the recommended **regimen** for all adults.



Activity

Explain that each country has its own guidelines that determine which combinations of ARVs (often called **regimens**) are offered to people living with HIV. Ask the women to call out the names of the regimens that they are taking and write them all up on a big piece of paper. When you go through the table of ARVs in Handout A, make sure you explain which regimens are offered in your country and what class they fall into.

What HIV treatment is recommended and when should you begin?

- WHO sets global HIV treatment guidelines. It currently recommends that:
 1. **Antiretroviral therapy** (ART) – the use of a combination of antiretroviral medicines to treat HIV infection – should be started among all adults with HIV regardless of WHO clinical stage and **CD4** cell count.
 2. Pregnant women should start taking ARVs as soon as they are diagnosed with HIV. WHO also recommends lifelong treatment for them (sometimes referred to as **Option B+**). In other words, once you start, you keep taking these medicines for the rest of your life. It recommends a pill once a day that has a combination of three medicines, for example, **EFV**, **TDF** and **3TC** or **FTC**.
 3. Any baby born to a mother living with HIV should be given a course of ARVs from birth for up to six weeks (this is usually **nevirapine**).
- While there are clear health benefits to beginning treatment early, choosing to take ARVs for the rest of your life is a big decision. Regardless of what the health authorities or your healthcare providers recommend, remember, it is always your choice to decide whether you are ready to start treatment or not. You should make sure you have all the information you need before making the decision, and discuss it with your healthcare provider, partner, family and anyone else that you trust to help you decide.
- If you are below the legal age of consent in your country, you should discuss with your parent(s), guardian(s), or healthcare team what is best for you.

7.2 Adherence

Facilitator's guidance



Use **Flipchart 15: Adherence to ARVs** to accompany this section.

Adherence means taking your ARVs every day exactly as advised by your healthcare provider. It includes taking them at the right time, in the right doses, and following any dietary and storage instructions.



It is important to adhere to your treatment in order to:

Improve your health and stay healthy

As ARVs stop the HIV destroying your CD4 cells, you will have more CD4 cells and therefore your immune system will be stronger. It will be better able to fight off diseases and infections, including **opportunistic infections** such as tuberculosis. Your health will improve and you will stay healthy for longer.

Avoid developing HIV that is resistant to available ARVs

- If you do not take your ARVs on time, there will not be enough medicine in your blood to fight HIV. This gives HIV a chance to continue to make copies of itself.
- As it makes copies of itself, the HIV can change its form so that the specific ARVs you are taking will no longer work to control the HIV. This is called **drug resistance**.
- If you develop resistance to the ARVs you are currently taking, you will need to switch to different kinds of ARVs (called a **second-line** or **third-line regimen**).
- If you develop resistance to all available ARVs you may not have any treatment options. This is called **treatment failure**.

Prevent passing HIV onto your baby or partner(s)

- ARVs lower the amount of HIV in your blood, vaginal fluids and breastmilk. This reduces the risk that you will pass HIV onto your baby during pregnancy, childbirth and breastfeeding.
- It also reduces the risk that you will pass HIV onto your partner(s) during sex – if they do not have HIV.

7.3 Some tips to support your adherence

Facilitator's guidance



Carry out the activity below with the women in the group and then turn to **Flipchart 16: Adherence tips** to accompany the rest of this section.

Activity

Ask the women what they do to help them to adhere to their treatment? Do they have any tips that help them to remember to take their ARVs on time, every day?

It is best to start ARVs when you are ready to make it a part of your life and are committed to taking your medications at the same time, every day.



Here are some suggestions for how you can remember to take your ARVs:

- Connect taking your pills to another activity that you do at the same time every day, such as waking up, eating a meal, or going to bed (if these activities happen at the same time every day/night).
- Divide up each day's medicines every morning and use a pillbox. Then you can check if you have missed a dose.
- Take extra ARVs with you if you are going away from home for a few days.
- Always have some ARVs in a small container in your handbag.
- Set a reminder or alarm on your cell phone. You could also have a little calendar with your medication to help you remember each day.
- If you like using computers, you can use an online calendar service. Some online calendars, like Google's, can SMS or text you at the same time every day.
- Have someone remind you to take your medications and keep your clinic appointments. The person could be a treatment buddy, partner, family member or friend.
- Get peer support – ask other women or people living with HIV who are already on treatment how they remember to take their medications.

If you forget to take your ARVs, just take them as soon as you remember. Do not be too hard on yourself – we all forget to take our medication at times even after years of practice. Just try to think of other ways to remind yourself to take them regularly in the future.

If you are having trouble taking your ARVs, talk with a nurse or counsellor. They can help you develop a plan to remember to take your medications. Most treatment centres can also connect you with someone who is taking the same treatment, who can talk you through how they manage, if you feel this would help.

7.4 Follow up questions

Questions to ask your healthcare team

- What are the advantages and disadvantages of taking ARVs for life?
- What do we know about how these medications affect women including my future **fertility**?
- If my baby is born with HIV, will s/he also need to take the same ARVs?
- Will taking ARVs affect my growing baby? Will my baby develop resistance to these ARVs if I take them during pregnancy and breastfeeding?
- As a young woman, do I have the same rights as adults to make my treatment decisions?
- Where can I get support to adhere to my medications?
- How can I find out if I have developed resistance to certain ARVs?
- What other ARVs are available if I develop resistance?

Remember you have the right to:

- consent to decisions about your own healthcare
- choose whether to take HIV treatments, when to start and whether to stop.

8

Antenatal and postnatal care

This module will discuss:

- The care that you and your baby will need
- The tests you are likely to have and what they mean



Notes

8.1 The type of care you need during your pregnancy

Facilitator's guidance

This section contains many technical words and names for tests. Make sure the women in the group understand all the terms you use. You will need to make sure you are familiar with the tests that are offered to women and their babies in your country as part of HIV, antenatal and postnatal care.

Do not use the flipchart at the beginning of this section. Begin with the short introduction below and then move on to the activity. Only after you have completed the activity should you use **Flipchart 17**.

It may seem like your healthcare team is carrying out a lot of tests during and after your pregnancy, but they are needed to monitor everything that is happening in your body. In general, they check to make sure that:

- You are adhering to your **antiretrovirals** (ARVs)
- Your body is processing the ARVs
- Your immune system is responding to the ARVs
- Your body is responding as expected to any treatment for other infections
- Your pregnancy is progressing without complications and your baby is developing well

The tests you take will depend on your country's national guidelines and recommendations.



Activity

Ask the women to stand up in the middle of the room. Ask them if they can remember what tests they have had so far in their pregnancy or the tests they had in previous pregnancies.

Get the women to call the name of the tests out one by one. After each test ask the women to move to the right hand side of the room if they believe the test is done to monitor their HIV or to the left if they believe it is monitoring their pregnancy/baby.

Before moving on to the next test tell the women the real reason for the test.

8.2 Antenatal care and HIV monitoring

Facilitator's guidance



Use **Flipchart 17: Antenatal care and HIV monitoring** to accompany this section.

The need for viral load and CD4 count testing is explained in full in Modules 4 and 6. If you have not covered those modules with these women you will need to explain both CD4 count and viral load testing here.

Antenatal care

You will need routine care to make sure you stay healthy during your pregnancy. This is called **antenatal care**. As part of your antenatal care, your healthcare provider will:

- Monitor how the baby is developing, and help you address any problems. It is particularly important for you to receive routine care if you have had problems with past pregnancies such as a **premature** child, a **stillbirth**, **high blood pressure** or **seizures**.
- Check if you have any high-risk conditions like **high blood pressure**, **diabetes**, or **kidney disease**. These medical conditions could affect your health and the health of your baby.
- Detect and test for any other problems that may complicate your pregnancy (e.g. **anaemia**, **eclampsia**, bleeding).
- Encourage interventions to prevent health problems arising. This could include **tetanus immunisation**, anaemia prevention (through iron and folic acid supplements) or anti-malarial treatment.
- Treat any health conditions that you have or pregnancy complications that arise.
- Provide information and counselling on nutrition, healthy lifestyle, safer sex etc.
- Discuss the birth and help you plan and prepare for it.



HIV monitoring

Throughout your pregnancy you need to continue to have your HIV monitored. In addition to monitoring your **viral load** (to see if your ARVs are working) and your **CD4 count** (to see how strong your immune system is) you are likely to be offered other tests to see how HIV is affecting your health and pregnancy. These include:

- A complete **blood count** measures the kinds and number of cells in your blood, especially red blood cells, white blood cells and **platelets**. This test helps your healthcare provider diagnose conditions, such as anaemia and infections, including malaria and **bacterial infections**. It also gives information about the strength of your immune system.
- **Sexually transmitted infections** (STIs) tests will check for other STIs like syphilis, gonorrhoea and herpes. It is important that you get treatment for these STIs so you can remain healthy and you do not pass them onto your partner(s) or baby.
- **Kidney and liver function** tests will detect any previous damage to the kidneys or liver as this may affect the **ARV regimen** you take. In some rare cases, ARVs may have an effect on your kidneys or liver. This test helps to determine if they are healthy and functioning properly and whether you need to avoid or change your ARVs.

8.3 Postnatal care

Facilitator's guidance



Use **Flipchart 18: Monitoring your baby's health** to accompany this section.

If you are not planning to cover Module 12 with these women you will need to provide further information on nutrition during this session. Module 11 has more information on postnatal monitoring

After your baby is born he or she will need routine care to stay healthy. This is called **postnatal care**. Your baby will need:

- Immediate postnatal care (ideally within one week of birth) to monitor and address any danger signs.
- Routine immunisations according to the guidelines in your country.
- **Prophylaxis** medications to prevent infections as prescribed by your healthcare provider(s). All children born to mothers living with HIV should receive **cotrimoxazole** from 4–6 weeks after birth as it protects against common bacterial infections, toxoplasmosis, and malaria.
- Clinical and laboratory examinations and active monitoring for possible infections.
- It is very important for your baby's health and development that he/she is fed appropriately, this includes your breastmilk.
- The healthcare provider will also monitor the growth and development of your baby to make sure your baby is developing normally.



HIV-related postnatal care

In addition to this post-natal care your baby will also be offered the following treatment and tests that relate specifically to HIV:

- **Prophylaxis ARVs** – Your baby will be given a course of antiretroviral medicines (usually **nevirapine**) from the day they are born for up to six weeks to reduce the risk of HIV transmission.
- **HIV DNA PCR** – Early infant diagnosis (EID) of HIV is extremely important and refers to the practice of testing babies within the first 4–6 weeks of life. It is very important that you take your baby back to the healthcare provider for this test. The test is very sensitive and can identify whether your baby has HIV in his or her blood. It helps to determine whether your baby got HIV during pregnancy or childbirth. If your child has a positive DNA PCR test, it means he or she has HIV.
- **HIV rapid test** – Your healthcare provider will conduct a rapid HIV antibody test when your baby is 9 months old and again at 18 months or after you stop breastfeeding. This test will detect if your baby's immune system has produced any antibodies to fight HIV. If your child tests HIV negative on this rapid test and you have stopped breastfeeding, then your baby is considered **HIV free**. It is very important that you take your baby to your healthcare provider to have this test.
- If your child is found to be living with HIV, your healthcare provider will discuss starting your child on ART to protect his or her health.

Remember!

- In general, your test results should not be a source of stress, anxiety, or worry. Your healthcare team will be able to recommend a care plan that is based on your test results.
- All test results are important for the successful management of your pregnancy, your health and your baby's health.

8.4 Follow up questions

Questions to ask your healthcare team

- How often will I need to come back to see the healthcare provider?
- What should I do if I cannot stick to the monitoring schedule?
- How are antenatal and postnatal care different for a pregnant woman who is also on HIV treatment?
- What tests will I need during my pregnancy? What additional tests will I need to manage my HIV during pregnancy?
- If my baby tests negative for HIV at 6 weeks, why would we need another HIV test at 9 and 18 months (or after I stop breastfeeding)?

Remember you have the right to:

- make decisions about your treatment and care
- make decisions about the treatment and care of your baby, including feeding choices
- the same quality of care as any other pregnant women, and care that is free from stigma and discrimination.

9

Recognising, understanding and reporting side effects

This module will discuss:

- What side effects are
- What to do if you experience side effects



Notes

9.1 Explaining side effects

Materials

Copies of **Handout A: Antiretrovirals and side effects** on page 51, one for each participant. (If you have covered Module 7 with the same women they will already have this handout.)

Facilitator's guidance



Use **Flipchart 19: Side effects of ARVs** to accompany this section.

- **Side effects** are unintended, usually unpleasant, reactions to taking a medicine. Many medications, not just **antiretrovirals** (ARVs), can cause side effects. When you take ARVs you may experience side effects.
- Some side effects are mild, others can be more serious, including potentially unsafe reactions to the medications that you are taking.
- Some side effects are obvious and can be examined physically by your healthcare team. Other side effects are more hidden and can only be detected with blood tests.
- Some ARVs may cause different side effects in women than in men.

When do side effects occur?

- It varies. Side effects can occur after a single dose, a few days after you start taking ARVs, or after the medicine has built-up in your blood.
- Most side effects from ARVs are mild and usually get better by themselves or reduce after a few weeks of taking ARVs.
- However, some side effects can last longer. Others can be serious if they continue for a long time.
- Some side effects can be permanent.



Activity

Ask the women in the group what kind of side effects that have experienced. Have they lasted for long? Were they severe?

9.2 What types of side effects can be caused by commonly prescribed ARVs?

Facilitator's guidance



Make sure all the woman in the group have a copy of **Handout A: Antiretrovirals and side effects**. Allow the women some time to look at the handout and give them an opportunity to ask any questions they may have about it.

9.3 How to manage side effects

Facilitator's guidance



Use **Flipchart 20: What to do if you have side effects** to accompany this section.

- Whenever you start taking any medicine for the first time you should ask your healthcare provider what side effects you may experience. Also ask what you should do if they occur so that you are prepared.
- Once you start taking your ARVs, if you experience a side effect that affects your ability to carry out your normal duties, or if a side effect continues for a long time, you should visit or contact the clinic as soon as possible. Do not wait for the symptoms to improve, or until your next clinic appointment.
- Your healthcare provider will work with you to determine how best to manage the side effect or decide if you should change your ARV regimen.
- It is important that all your side effects are clinically monitored and managed by your healthcare team for the best outcomes for you and your baby.
- Some side effects, particularly if they are milder, may be managed by modifying your diet, exercising and taking medications.
- Some side effects will require that you change your ARVs as soon as possible.
- Regardless of how severe the side effect, do not stop taking your ARVs for any reason without consulting with your healthcare team first. Instead, you should go to the clinic as soon as possible.



9.4 Follow up questions

Questions to ask your healthcare team

- What side effects can be associated with my prescribed ARVs? How quickly can side effects occur with this medication?
- Are they permanent or temporary?
- What can I do to manage these side effects?
- What are the consequences of stopping my treatment because of severe side effects?
- Do my prescribed ARVs have any effect on bone health, my menstrual cycle or sexual desire?
- How do I know if a side effect is because of my ARVs, other treatments I am receiving, or just a symptom of my pregnancy?
- If I have a side effect during pregnancy, will this be harmful to my baby?
- What side effects could my baby get from taking ARVs?
- If my baby has a side effect from taking the ARVs, will this be harmful to him or her?

Remember you have the right to:

- choose whether to take HIV treatments, when to start and whether to stop such treatments. This includes the right to request to change your medication if side effects are serious or persist.

10

Your health and nutrition

This module will discuss:

- Links between HIV and nutrition
- The importance of good nutrition and a healthy lifestyle



Notes

10.1 What is nutrition and why is it important?

- Nutrition is the process of taking in, absorbing and using nutrients through the foods we eat.
- Proper nutrition allows our bodies to perform essential tasks such as to:
 - develop and grow
 - produce energy to stay warm, move and work
 - fight infection
 - repair and recover from injury.
- Our bodies need water, **macronutrients** (carbohydrates, proteins and fats) and **micronutrients** (vitamins and minerals) to function properly.
- Eating a variety of safe and nutritious foods, in the right quantity, is the best way to get these nutrients and meet the body's needs. It is vital for good health.
- When we do not eat a good, balanced diet on a consistent basis, we become weak and more susceptible to infections and disease.

10.2 Nutrition and HIV

Materials

Pens and blank circles of paper

Facilitator's guidance



Use **Flipchart 21: Nutrition and HIV** to accompany this section.



- Nutrition and HIV are linked.
- Malnutrition (a lack of good, balanced nutrition) can occur as a result of HIV. When the immune system breaks down, we are more likely to get other infections and diseases. These infections can result in diarrhoea, poor absorption of nutrients, loss of appetite, and weight loss.
- Malnutrition can also weaken the immune system. A person who is malnourished and then acquires HIV is more likely to develop AIDS faster because the body becomes weak and is less able to fight other infections.
- So, malnutrition can contribute to and be a result of HIV disease progression. On the other hand, a person who is well-nourished is more likely to maintain a strong immune system. This helps the body fight HIV and overcome infection. It can also help prevent weight loss and delay disease progression.
- Proper nutrition also helps your **antiretrovirals** (ARVs) work well.

Illnesses caused by HIV that can affect your nutrition

Some illnesses caused by HIV can affect your nutrition. It is important to take steps to treat these conditions and make sure you are still getting all the nutrients you need. If you suffer from any of the following you should seek medical help:

- Anorexia
- Diarrhoea
- Fever
- Nausea and vomiting
- Thrush

10.3 Good nutrition

Facilitator's guidance



Conduct the activity below before you use **Flipchart 22: Taking care of yourself** alongside this section.

Activity

Split the women in to small groups. Give each group a blank circle. Ask them to think of the main food groups that are important in a balanced diet. They should then decide how much of the diet each food group should represent and mark it on the circle.

At the end, their circle should be divided in to a number of varying sized segments each representing a different food group.

For each food group ask them to give some examples of foods in that group. Then follow the section below and at the end of the section ask them to compare their answers with the correct answers.



Taking care of your health

It is particularly important for you to try and have a healthy life during your pregnancy (for both you and your baby). You should try to avoid any unnecessary risks to your physical and mental health. In particular:

- Avoid smoking, alcohol and **non-prescribed** drugs. Tobacco and some drugs can cause serious health problems for you and your baby. Drinking too much alcohol can affect your body's ability to absorb your ARVs and may affect your ability to remember to take your medications on time.
- Try to avoid stress and anxiety, not only for your mental well-being but also because these can lead to physical health problems.
- Be aware of your safety. Sadly, pregnant women and those living with HIV are at increased risk of domestic violence. If you are concerned for your safety, seek support as soon as you can.
- In general, it is good to take plenty of exercise while you are pregnant. You may wish to avoid sports that involve a particular risk of falling or knocks but regular exercise (such as brisk walking or swimming) will help you stay healthy during your pregnancy and can help to reduce the chances of depression.
- Make sure you are getting enough rest.

Nutritional needs

Good nutrition is always important to prevent weight loss, maintain **muscle mass** and allow the body to have a strong, well-functioning immune system. Pregnant women living with HIV have specific nutritional needs to bear in mind:

- There is NO need to eat for two. However, you will have slightly increased energy needs. Women in the early stage of HIV or stable on **antiretroviral therapy** (ART), need approximately 10% more energy a day. This is equal to about 150–250 extra calories per day, the food equivalent of one additional snack. For example, a serving of porridge with sugar, milk and oil, or a slice of bread with a handful of groundnuts.
- Women with advanced stage HIV need approximately 20–30% more energy a day. This is equal to about 300–450 additional calories per day, the equivalent of two or three additional snacks or a small meal.
- You should drink plenty of clean water. Water helps move the nutrients from your blood to your baby and helps keep you hydrated. If you are breastfeeding you should drink an extra 2 to 3 litres of water each day.
- You should try to avoid or reduce the amount of salt and sugar that you eat or drink. Eating too much salt or sugar can increase your risk of getting **diabetes** or **high blood pressure**.
- In general remember to:
 - eat a wide variety of foods, including fruit and vegetables
 - eat foods rich in nutrients
 - eat frequent meals and avoid skipping meals.
- Remember that while good nutrition and supplements are very important, they do not replace the need for you to take your ARVs on time, every day. Instead, proper nutrition helps your ARVs work more effectively.
- It is equally important to continue eating well after your baby is born. You will need energy and strength to look after your baby, particularly if you are



breastfeeding. Do not try to lose weight quickly after the birth. Just eat a good, balanced diet and drink plenty of water.

10.4 Follow up questions

Questions to ask your healthcare team:

- Is it important to take my ARVs with food? Is any kind of food better than another?
- Is it important to take medications with water or other liquids? How much?
- I will need food assistance or food support during my pregnancy and while I am breastfeeding. Is any support available at this clinic?

Remember you have the right to:

- adequate food and clean water.

11

Labour and delivery

This module will discuss:

- Preparing for labour and delivery
- What to expect before and after the birth
- Keeping your baby healthy after the birth



Notes

11.1 How to prepare for labour and delivery

Facilitator's guidance



Use **Flipchart 23: Be prepared for the birth** to accompany this section.

During labour and delivery you have the right to:

- ask for information about your health and your baby's health
- express concerns about your environment if you do not feel comfortable
- have your privacy respected
- have your partner or other family member there to support you, if you wish
- give informed consent before any procedure is performed. Unless you are incapacitated or unconscious you are the only person who can give consent for a medical procedure. Sterilisation is not an emergency procedure and should always be discussed in advance. You should NEVER be forced or coerced in to sterilisation and even if you are incapacitated, your partner cannot consent to sterilisation on your behalf.

Preparing for the birth

- To best prepare for your baby's birth you need to regularly attend the antenatal clinic and take your **antiretrovirals** (ARVs) on time. You should attend at least four antenatal care visits during your pregnancy to make sure you and your baby are healthy. Some women may need more visits.
- It is important that you give birth in a health facility with a midwife or nurse. These healthcare providers are trained to deal with problems that may arise during labour that could affect your health or the health of your baby, such as heavy bleeding, infections, **prolonged rupture of membranes**



and **high blood pressure**. They will also make sure your baby gets the medicines needed after birth to remain HIV-negative.

- If you live far away from the health facility, you will need to make a plan for getting to the clinic during your labour. You should talk to your partner, family members, and your healthcare team to get their help and advice on how you will get to the clinic. You may also want to have a written plan for how you and they will handle any unexpected emergencies.

11.2 What to expect during labour and delivery

Facilitator's guidance



Use **Flipchart 24: The three stages of labour** to accompany this section.

- Research has shown that most women who are living with HIV and regularly taking ARVs can safely deliver their baby vaginally with a low risk of passing HIV to their babies. A **caesarean section** (C-section) is now only recommended for some women if their health or their baby's health is at risk. Your midwife or nurse will advise if they recommend a caesarean, but it remains your decision and they would need to seek your informed consent.
- You should ask the midwife or nurse at the antenatal clinic to tell you when and how you will know it is time to come to the clinic for delivery.
- When you get to the clinic, tell the nurse or midwife:
 - when your **contractions** began
 - whether your water has broken
 - if your water has broken, what colour it was (clear or green) and how long ago
 - your HIV status (in case they need reminding) and that you need to continue taking your ARVs. Make sure you have your ARVs with you.

You will go through three stages of labour

- **First stage** – begins when labour pains start and ends when the **cervix** is completely open. During this time the nurse or midwife will be checking your cervix and your baby's position frequently. As your labour progresses, your **contractions** will get stronger and closer together. Every labour is different, but if this is your first pregnancy you can expect this to last anything from 8–19 hours or more.
- **Second stage** – involves pushing and delivering your baby and lasts between 20 minutes and 2 hours. You should find a comfortable position for delivering your baby. This can include kneeling, squatting, sitting, or lying back. When the top of your baby's head fully appears (crowning), your nurse or midwife will tell you when to push and deliver your baby. After your baby is born, the **umbilical cord** is cut.
- **Third stage** – lasts about 5–30 minutes and is where the **placenta** is delivered. Once the placenta has been delivered, your labour is finished.
- If you experience heavy bleeding or severe pain after delivery, you should let your midwife or nurse know right away.



- After you have your baby, it is important to continue to attend the HIV clinic and take your ARVs. This will help you remain healthy so you can take care of your baby and reduce the risk that you will pass HIV onto your baby during breastfeeding.

Activity

Explain to the women in the group how difficult it can be to think clearly and take decisions during labour and delivery. For this reason, it is helpful to plan ahead as much as possible and think about what you would like to do in different circumstances/emergencies.

Ask the women to discuss their plans. In particular they could consider questions like:

- What will you need to take with you when you go to the clinic?
- Would you like someone to be with you when you deliver your baby, your partner, a family member, a friend?
- Have you thought about how you might try to cope with the pain?

11.3 The importance of postnatal care

Facilitator's guidance



Use **Flipchart 25: Why postnatal care matters** to accompany this section.

Making sure you and your baby stay healthy

- Even after a safe pregnancy and delivery, it is important that you attend postnatal care with a midwife or nurse.
- During postnatal care, the midwife or nurse will check you and your baby for any danger signs that need to be treated. For the baby these include infection of the **cord stump**, blood infections, chest infections, **malnutrition** and **jaundice**; for the mother they include fever, pain in the **uterus**, chest pains, **mastitis** and depression.
- You will need counselling and support to feed your baby appropriately to keep your baby healthy and minimise the risk of passing on HIV.
- Your baby will need **prophylaxis** medications like **nevirapine** to prevent HIV, and **cotrimoxazole** to prevent other infections..
- Your healthcare team need to check to see if your baby has HIV in the following ways:
 - Early infant diagnosis (EID) of HIV is extremely important. When your baby is 6 weeks old, your healthcare provider needs to conduct a test called a **DNA PCR** test. This is done by taking a drop of blood from your baby's foot. The test detects if there is any HIV in your baby's blood.



Even if your baby is diagnosed HIV negative at this stage, there is still a chance that your baby may get HIV during breastfeeding.

- When your baby is no longer breastfeeding, whether it is at 12 months old or 24 months old, your healthcare provider should conduct a different test, called a **rapid HIV antibody test**. This is done by examining your baby's blood. This test will detect if your baby's immune system has produced any antibodies to fight HIV. If your baby tests HIV negative after you have stopped breastfeeding, then your baby is considered **HIV-free**.
- If your baby has any symptoms that cause you to worry that s/he might have HIV between 6 months and the end of breastfeeding, you can request that your baby is tested.

Understanding postnatal depression

- This is a type of depression that some women experience after they have had a baby. It is a result of changes in your **hormones**.
- It usually develops in the first four to six weeks after childbirth, although in some cases it may not develop for several months.
- There are many symptoms of postnatal depression, such as low moods, feeling unable to cope and difficulty sleeping. Many women are not aware they have the condition.
- It is common to experience mood changes, irritability and episodes of tearfulness after birth, also referred to as baby blues. This does not mean you are a bad mother. For most women, these symptoms clear up within a few weeks. But if you experience persistent and continuous symptoms, it could be the result of postnatal depression.
- If you feel you are experiencing any of these symptoms it is important you talk to your healthcare team, as early as possible.

11.4 Follow up questions

Questions to ask your healthcare team

- What kind of preparations and arrangements should I make for the birth of my child?
- How and when will I know if my baby is HIV-free?
- I might have the baby blues. Is there anything that can help me to feel better?

Remember you have the right to:

- information about your health and your baby's health
- have your privacy respected during labour
- give informed consent before any procedure is performed
- postnatal care for you and your baby
- have your partner or other family member with you to support you during labour, if you wish.

12

Nutrition for your baby

This module will discuss:

- Breastfeeding, other feeding options and weaning



Notes

12.1 What nutrition is best for a baby?

Materials

Set of cards with myths and facts of breastfeeding (see activity on page 48).

Copies of **Handout B: Infant feeding** on page 53, one for each participant.

Facilitator's guidance



Use **Flipchart 26: Reasons to breastfeed** to accompany this section.

If you have not followed Module 10 with this group of women, you will need to discuss the importance of good nutrition for breastfeeding women at this stage.

Discuss breastfeeding using the flipchart and then conduct the activity before moving on to the section on breastfeeding tips.

Breastfeeding

In the past women living with HIV were advised not to breastfeed their babies. Current guidelines now recommend breastfeeding for women living with HIV as the risk of HIV transmission is very low for women adherent to **antiretroviral therapy** (ART). It remains your choice how you decide to feed your baby.

- Breastmilk alone is the best food for a baby during the first 6 months of life because it:
 - provides all the nutrition your baby needs, including energy, fat, carbohydrates, proteins, vitamins, and minerals
 - provides all the water your baby needs
 - is easy for your baby to digest
 - helps your baby grow and develop



- as well as the nutrients in breastmilk, it also contains other ingredients that help protect your baby from diseases including diarrhoea, **pneumonia, meningitis** and ear infections. It can also help prevent your baby contracting other diseases later in life when they are young children, adolescents, or adults
- breastmilk is safe, unlike infant formula it does not need to be mixed with water, which can carry other diseases.
- A baby who is exclusively breastfed does not need any other foods or fluids during the first six months of life. **Exclusive breastfeeding** means a baby receives only breastmilk and no other liquids or solids, not even water, with the exception of any medicines.
- If possible, you should start breastfeeding within the first hour of your baby's life. Breastfeeding can be very rewarding, however it also has its challenges and women often require support to breastfeed successfully.

Activity

Split the women into groups. Give each group a set of cards with breastfeeding facts and myths written on them. Ask the women to discuss them and decide whether each is true or false. Then bring the women back together to discuss their answers, making sure you correct any false information. You may wish to use some of the facts and myths below.

Myths

- You cannot get pregnant if you are breastfeeding.
- Breastfeeding is painful.
- The baby is wanting to feed all the time, it can't be getting enough milk.
- Small breasts produce less milk.
- Women living with HIV should not breastfeed.

Facts

- It is important to stay hydrated.
- Breastmilk can help protect the baby from illnesses like diarrhoea and pneumonia.
- Breastfeeding can help prevent postnatal depression.
- Adults who were breastfed as babies perform better in intelligence tests.

Tips for breastfeeding

- Feed your baby as often and for as long as he or she wants, both day and night. This will help you produce enough milk to exclusively breastfeed your baby. It is called **demand feeding, unrestricted feeding, or baby-led feeding**.
- Make sure your baby has **latched** onto your breast properly (see illustration on Handout B).



- Take care of your breasts and get help if any problems occur. Your breasts can become painful or infected, particularly if breastmilk is not completely removed from the breast during a feeding session, breastfeeding does not take place regularly, there is poor breast attachment by the baby, or if you wear tight clothing around your breast(s). If you experience any pain, have cracks or damage to your nipples, or have any other discomfort in your breasts, you must see your healthcare provider right away.

What to do if you have problems breastfeeding

Breastfeeding is not always straight forward. You may need support to enable you to breastfeed your baby. Seek advice from healthcare workers, mother and breastfeeding support groups, friends, older women and traditional birth attendants.

Some women choose **mixed feeding** (giving your baby breastmilk and any other food or liquid) if they feel their baby is not getting enough breastmilk. Previously, it was thought that mixed feeding led to a greater risk of HIV transmission. It is now recognised that if a mother is adherent to ARVs, the risk of transmission is very low even when using mixed feeding. However, mixed feeding in the first 6 months is still associated with an increased risk of your baby contracting other diseases so it is not recommended.

To avoid the need for mixed feeding for the first six months, you can:

- Stimulate your breasts. A baby should suckle as often and for as long as possible. Suckling releases hormones which help you produce breastmilk.
- You and your baby should remain in skin-to-skin contact as much as possible.
- You should put your baby to your breast at least 8 to 12 times every 24 hours, making sure the attachment is good.
- Use a **breastfeeding supplementer** at a health facility. A tube is placed next to your nipple allowing your baby to suck at your breast and receive milk from both your breast and the supplementer at the same time. Your healthcare provider can discuss whether this is appropriate for you.

Other feeding options

If you are not able to breastfeed or choose not to breastfeed, you may wish to **express breastmilk** and then feed it to your baby.

If you choose to use a **milk substitute** (infant formula) you should run through this checklist:

- Are you and your family comfortable with the use of a milk substitute?
- Do you have the time, resources and support you need to feed the baby?
- Can you afford it (the substitute itself, fuel and clean water)?
- Can you sustain the resources and support you need to continue substitute feeding for as long as it is needed?
- Can you ensure the feeds are prepared and stored safely, including using clean and safe water?

For infants over 6 months of age, you should only use animal milk for short times as a substitute for breastmilk, when commercial infant formula is not available.



12.2 How and when to wean your baby

Facilitator's guidance



Use **Flipchart 27: Infant feeding** to accompany this section.

Handout B: Infant feeding on page 53 should also be given to women who attend this session.

- As your baby gets older you will need to add in other foods and liquids as well as continuing to breastfeed. At this stage your baby's nutritional needs will still be mainly met by breastmilk but it is important for your baby's development to begin to introduce solid foods. This is called **complementary feeding**. Generally, complementary foods should be introduced when your baby is over 6 months old.
- When you begin complementary feeding you should make sure you give a good variety, amount and frequency of safely prepared foods. You should also practice **responsive feeding** – feeding your baby directly and responding to their signs of hunger. As babies get older you can then encourage them to feed themselves but still be actively involved and help where needed.
- Feed your baby slowly and patiently, and encourage, but do not force, children to eat.
- If your child refuses to eat, experiment with different combinations of foods.
- Although it can be difficult, try and stay calm during feeding times. Make eye-to-eye and physical contact with your baby, and talk with him/her to encourage bonding between you.
- **Weaning** is the name for the process where you stop breastfeeding altogether and only give your baby other foods. You can consider beginning weaning when your baby is 12 months, but you may wish to wait until 24 months or longer. It can take place over a time period comfortable for both you and your infant (ranging from 2 to 3 days to 2 to 3 weeks).

12.3 Follow up questions

Questions to ask your healthcare team

- Until what age should I breastfeed my baby?
- Should I take ARVs while I am breastfeeding?
- What should I do if I am unable to breastfeed?
- When should I introduce complementary foods for baby? What foods should I give my baby?
- My baby is teething – breastfeeding has become difficult. What should I do?
- When and how should I wean my baby?

Remember you have the right to:

- all the information you need to make informed decisions
- choose the best way to feed your infant, free from coercion
- counselling and support from your healthcare team.

Handout A: Antiretrovirals and side effects

For more detailed explanations of these side effects see:

www.aidsmap.com/side-effects

www.thebody.com

Most antiretrovirals (ARVs) can cause fairly minor side effects. In particular nausea, diarrhoea, vomiting, headaches, rash. The table below shows some of the other side effects that are associated with the different medicines.

This table is for information only. If you are concerned about any side effects, you should seek advice from your healthcare team.

Generic name	Common side effects	Less common side effects
Nucleoside/Nucleotide reverse transcriptase Inhibitors (NRTIs) or 'nukes'		
Abacavir (ABC)	Fever, abdominal pain, tiredness, loss of appetite	Hypersensitivity reaction, lactic acidosis
Emtricitabine (FTC)	Raised creatine kinase levels, skin darkening	Lactic acidosis, liver damage
Lamivudine (3TC)	Abdominal pain, hair loss, fever, insomnia, tiredness, joint pain	Lactic acidosis, liver damage
Tenofovir (TDF)	Flatulence, dizziness, low blood phosphate levels, weakness, stomach pains, fatigue bloating	Kidney problems, bone thinning
Zidovudine (AZT, ZDV)	Fatigue, dizziness, weakness, muscle pain, loss of appetite, fever	Blood disorders, lipoatrophy, lactic acidosis
Non-nucleoside reverse transcriptase inhibitors (NNRTIs) or 'non-nukes'		
Efavirenz (EFV)	Dizziness, sleep disturbance, abnormal dreams, impaired concentration, tiredness, anxiety, depression, suicidal thoughts	Psychosis, severe rash, liver problems
Etravirine (ETR)	Peripheral neuropathy	Severe rash (Stevens Johnson syndrome)
Nevirapine (NVP)	Liver toxicity, allergic reaction, fatigue, stomach pain	Severe rash (Stevens Johnson syndrome)
Rilpivirine (RPV)	Insomnia, raised liver enzymes, depression, dizziness, stomach pains	Changes to heart rhythm
Protease inhibitors (PIs)		
Atazanavir (ATV)	Stomach pain, insomnia, hyperbilirubinaemia, lipodystrophy, liver toxicity, diabetes	Kidney stones, abnormal liver function, changes in heart rhythm
Darunavir (DRV)	Stomach pain, lipodystrophy, liver toxicity, diabetes, fever	Abnormal liver function, changes in heart rhythm
Lopinavir (LPV)	Lipodystrophy, raised liver enzymes, abdominal pain, weakness, heartburn, raised lipids, liver toxicity, diabetes	Changes in heart rhythm

Ritonavir	Raised lipid and liver enzymes, abdominal pain, weakness, numbness around the mouth, bad taste in mouth, lipodystrophy, liver toxicity, diabetes, raised lipid levels	Bleeding in brain, changes in heart rhythm
Integrase Inhibitors (INIs)		
Dolutegravir	Itching, stomach pain or discomfort, insomnia, dizziness, abnormal dreams, fatigue, flatulence, increase in liver and muscle enzymes	Allergic reaction, liver problems
Elvitegravir	Stomach pain, tiredness	Depression, suicidal thoughts, insomnia, problems with digestion (dyspepsia), feeling bloated, flatulence, dizziness, tingling, sleepiness, abnormal taste
Raltegravir	Insomnia	Severe rash, hypersensitivity reaction, extreme thirst

Handout B: Infant feeding tips

For your baby

Look for these signs to make sure that your baby has latched onto your breast properly:

- **Rooting:** Your baby will turn toward your breast when touched on the lips or cheek. Your baby will open his or her mouth, and put his or her tongue down and forward.
- **Suckling:** Make sure that at least half of your areola (the coloured part of your nipple) is in the baby's mouth. Your baby will start to suck when something touches the top and inside of his or her mouth. Your baby's lips should curl around your nipple. Your baby's chin should be pushing into your breast and his or her nose should be lightly resting on your breast.
- **Swallowing:** Your baby swallows when his or her mouth fills with milk. You should see his or her ears moving up and down as your baby swallows.



Good latch

- Baby's mouth is open wide like a yawn.
- Baby's tongue is over his lower gum.
- Baby's lips are curled out like a fish.
- Baby's chin firmly touches your breast.



Poor latch

- Baby's mouth is barely open.
- Baby's tongue is behind the lower gum.
- Baby's lips are curled in.
- Baby's chin barely touches your breast.

For you

It is important that you maintain healthy breasts and get help when problems occur. Problems can occur if breast milk is not completely removed from the breast during a feeding session, breastfeeding does not take place regularly, there is poor breast attachment by the baby, or if you wear tight clothing that causes injuries to your breast(s):

- **Breast engorgement:** Breasts become swollen, look shiny and red, and are painful. There may be a fever that goes away in a day. Nipples may become tight and flat, making it difficult for the baby to attach and remove milk.
- **Blocked ducts:** A tender lump covered by red skin is present in the breast.
- **Mastitis:** There is a hard swelling in the breast covered by red skin, and severe pain.
- **Sore or fissured nipple:** Severe nipple pain when the baby is suckling. There may be a crack across the tip or around the base of the nipple, and it may look squashed from side-to-side at the end of a feed with a white pressure line across the tip.
- **Breast abscess:** Painful swelling in the breast that feels full of fluid. There may be discoloration of the skin at the point of the swelling.

If you experience any of these problems, you must see your healthcare provider right away.

Introducing complementary foods

Age (months)	Type of food	Frequency	Amount of food an average child will usually eat at each meal
0–6	Exclusive breastfeeding		
6–9	Continue breastfeeding and introduce other foods alongside it Start with thick porridge, and well mashed foods. Continue with mashed family foods	2–3 meals per day Depending on the child's appetite, 1–2 snacks may be offered	Start with 2–3 tablespoons per feed, increasing gradually to 1/2 of a 250 ml cup
9–12	Continue breastfeeding and introduce more solid foods Finely chopped or mashed foods, and foods that the baby can pick up	3–4 meals per day Depending on the child's appetite, 1–2 snacks may be offered	1/2 of a 250 ml cup/bowl
12–24	You may wish to continue breastfeeding during this period Family foods, chopped or mashed if necessary	3–4 meals per day Depending on the child's appetite, 1–2 snacks may be offered	3/4 to full 250 ml cup/bowl

Feeding recommendations

For mothers living with HIV in low-income settings:

- **Breastfeed exclusively until 6 months** if there is little access to clean water, sanitation and health services or it is difficult to safely prepare bottles 6–8 times each day.
- **Continue breastfeeding after 6 months, while introducing complementary foods.**
- **After 12 months, decide if you want to stop breastfeeding or continue.** If you are taking your ARVs every day and are well, then you can continue breastfeeding up to 24 months or longer.

