

HIV EDUCATION COUNSELLING GUIDE

HIV Education and Adherence Counselling

Note: for children/adolescents, the script below should be modified towards the caregiver

Section 1: Introductions, climate setting, and review of objectives for the session

- Ensure privacy and confidentiality
- Introductions of all participants
- Present the key message for each section using simple terms that the patient will understand, using analogies as appropriate
- Use IEC material when available
- Ask the patient if they have any questions at the end of each section, and then ask them to explain the main points back to you to confirm understanding
- If this is a follow-up session, review what they remember from previous sessions and adapt the session to address their needs

Section 2: HIV

- What is HIV
 - HIV stands for "Human Immunodeficiency Virus"
 - HIV is a virus that attacks the body's immune system. The immune system protects the body from infections
- How is HIV transmitted
 - Sexual contact
 - Needles
 - Exchange of blood and bodily fluids
 - Mother-to-child transmission
- Why should family members be tested for HIV
 - Sexual partners are at risk for already having HIV
 - All children born to HIV positive mothers are at risk for already having HIV
 - Encouraging partners/children to test for HIV now is the best way to identify HIV early, so they can also get into treatment
 - Starting treatment early will help them live long and productive lives
 - Whether they test positive or negative, they can be an important source of support for your own treatment



Section 3: Viral load

- **What is viral load**
 - Viral load is the amount of HIV in your body
 - When your viral load is high it means you have a lot of HIV in your body; this causes damage to your body
 - Viral load is measured by a blood test
- **How often is viral load measured**
 - Viral load is measured after being on treatment for 3 months
 - After 3 months of treatment, we expect the amount of virus in your body to be undetectable; if your VL is detectable then we have to discuss the reasons
 - Having an "undetectable" VL means the test cannot measure the virus in your blood because your ART is working, but it does not mean you are no longer infected with HIV
 - Repeat viral load tests are done depending on how you are doing; if you are doing well on treatment then the viral load is measured again every 6 months (for children/adolescents and pregnant/breastfeeding) or annually
 - For HEI with positive PCR, we also measure viral load at the start of treatment
- **What do viral load measurements mean**
 - After being on treatment for 3 or more months, your viral load should be undetectable
 - If your viral load is undetectable, it means your treatment is working well and you should continue taking it the same; the virus is not damaging your body any more
 - If your viral load is detectable, it means your treatment is not working properly, usually because you have been missing some of your pills; the virus is damaging your body and you and the clinic team will need to work together to figure out how to fix the problem

Section 4: CD4 cells

- **What are CD4 cells**
 - CD4 cells are the immune cells that protect the body from infections
 - CD4 cells are measured through a blood test, called CD4 count. For adults a normal CD4 count is above 500
- **How are CD4 cells affected by HIV**
 - HIV attacks and destroys CD4 cells
 - After years of constant attack from HIV, the CD4 count falls
- **What happens when CD4 cells decrease**
 - When the CD4 count falls too low (usually below 200), diseases called "opportunistic infections" are able to infect the body because the body cannot defend itself
 - Common opportunistic infections include: tuberculosis, pneumonia, skin problems, white spots in the mouth, and chronic diarrhoea
- **How often is CD4 count measured**
 - CD4 count is measured for all patients at the beginning of treatment, to see if you are likely to get any opportunistic infections
 - Once you start treatment for HIV, we do not need to check CD4 count frequently, but we will use the VL test to monitor your response to anti-retroviral treatment

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Section 5: Antiretroviral therapy (ART)

- What is ART:
 - ART is a combination of 3 or more different medicines
 - ART fights HIV, lowering the amount of virus in the body allowing the body to protect itself against opportunistic infections
 - When the virus level is low then the CD4 count can increase
 - Increased CD4 count means the body is able to protect itself against opportunistic infections
- What are the benefits of ART:
 - After a few weeks of taking ART, you will begin to regain appetite and weight (if it has been affected)
 - Many people report an increase in their energy levels and general sense of well being
 - People can often return to work or school or care for their families
 - With ART, people with HIV can live a long and healthy life if they take it properly
- When is ART started:
 - Everybody with HIV should start ART
 - Even if your CD4 count is high, the virus is doing damage inside of you and needs to be controlled
 - ART should be started as soon as you are ready, preferably within 2 weeks
 - The longer you wait to start ART, the more time the virus can damage your body, increasing your chances of getting sick or even dying
 - Sometimes ART is started a few weeks later if you have certain infections, or if you do not think you are ready to take them properly
- Does ART cure HIV:
 - ART does not cure HIV
 - ART lowers the amount of virus in your body so your body can protect itself from infections
 - It does not remove the virus completely
- Can you still give HIV to others while taking ART:
 - Transmission of HIV is very unlikely once your viral load is undetectable
 - You should practice safer sex to reduce the risk for other infections as well, including disclosure of HIV status to sexual partners and consistent and correct condom use
- How long is ART taken for:
 - ART is a life-long treatment
 - Once you start ART, you need to take it every day for the rest of your life (either once a day, or twice a day, depending on which drugs you are on)
 - You must take the ART as prescribed and never miss a dose otherwise the treatment might fail and the drugs stop working against the virus



Section 6: Treatment failure

- **What happens if you stop taking ART:**
 - When you stop taking ART the virus begins to increase in your body very quickly
 - The virus goes back to the same high level it was at before you started ART
- **What happens if you do not take ART regularly:**
 - The virus begins to increase to high levels again
- **What happens if the viral load increases:**
 - When the virus is allowed to increase again, it will also affect your immunity and reduce your CD4 count putting you at risk of opportunistic infections
 - When the virus is allowed to increase again, it can change and get stronger, and becomes resistance to the ART
 - When the virus becomes resistant, the ART does not work against the virus anymore
 - The risk of resistance increases by not taking the ART correctly and by starting and stopping the medications several times
 - When resistance occurs, this is called treatment failure
- **What happens in treatment failure:**
 - The ART no longer works because the virus has become resistant to it
 - If treatment fails, it is necessary to use stronger, more expensive ART, but it still may not work as well
 - With the stronger ART you may need to take more pills every day, and you may have more side effects
 - If you become resistant to the new ART as well, then there may not be any drugs that can work for you, and the virus will increase quickly and your CD4 count will go down
 - It is essential that you take your ART every day as prescribed so that you do not develop treatment failure, and can live a long and healthy life

Section 7: ART side effects

- **What are the side-effects of ART:**
 - Sometimes people can get side effects from taking ART
 - Side effects vary from person to person
 - Some people have none while other experience mild effects which are unpleasant but often manageable
 - Most side effects occur within the first few weeks of starting ART and then improve after a few weeks or months
 - Some common side effects include:
 - Headache
 - Loss of appetite
 - Skin rash
 - Fatigue
 - Nausea, vomiting, diarrhoea
 - Muscle pains
- **What do you do if you notice any side effects:**
 - If you develop any side effects, you should continue taking your ART as prescribed, without missing any doses, until you discuss with the clinician
 - If the side effects are mild then you can continue taking your ART without missing any doses, and then discuss the side effects with the clinician at your next appointment
 - If the side effects are bothering you too much then return to the clinic immediately, even if you do not have a scheduled appointment, to discuss what to do next; you can also call the clinic if you are not able to make it yourself immediately
 - Severe side effects include rash all over your body, or rash in your mouth or eyes, constant vomiting, inability to eat or retain food, or anything else that makes you think you should stop the ART. If this occurs then contact the clinic immediately
 - The clinician will help you manage the side effects, and occasionally the ART may need to be changed

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Section 8: Adherence

- What is adherence
 - Following a care plan as agreed with the healthcare team
 - Attending clinic appointments as scheduled
 - Picking up medicines and taking them as prescribed
 - Getting lab tests according to the recommended schedule
 - Following nutritional recommendations
- How should ART be taken
 - You must take the correct dosage. If you take less than the dose prescribed the treatment will not be effective and will result in resistance and treatment failure. Never share your ART with someone else
 - For children, the dosage keeps changing as they grow and gain weight
 - You must take ART the correct time of day:
 - If your ART is supposed to be taken once per day, then pick a time when it will usually be convenient for you to remember, e.g., with breakfast every day.
 - If your ART is supposed to be taken twice per day, then you should set a convenient time to take your drugs approximately 12 hours apart (e.g., 8.00 am and 8.00 pm every day). It does not have to be exactly 12 hours apart if your schedule does not allow; the most important thing is to take them twice per day every day (e.g., you can take it at 6.00 am and 8.00 pm every day)
 - If you miss a dose of ART then take your dose as soon as you remember, as long as it is not within a couple of hours of your next dose, and then return to your regular schedule. Do not take a double-dose of ART to make up for a missed dose
 - You must take ART according to dietary restrictions. Some ART should be taken with food, for some it does not matter, and a few require that you have an empty stomach. These dietary restrictions will be explained to you once your ART regimen is selected
 - It is essential to take ART as prescribed and not miss any doses
 - Some medications (prescription, non-prescription, and herbal) interact with ART and make them ineffective. Be sure to tell your clinician and pharmacist the names of all the medications (including traditional/herbal) that you are taking, and any time you are given new medications. Avoid use of alcohol
- What usually interferes with good adherence (can apply to the patient or to the caregiver)
 - Stigma: it is hard to take ART correctly if you need to hide it because you are worried about people finding out you have HIV
 - Disclosure: it is hard to take ART correctly if the people closest to you, particularly family members and close friends, do not know you have HIV
 - Change in routine: if your daily routine suddenly changes it may be difficult to remember to take your ART at the usual time
 - Travel: frequent travel, or unexpected travel (such as for a funeral) may interfere with taking ART, particularly if you do not have enough drugs with you for the entire trip
 - Alcohol and drug use: it is hard to remember to take ART when under the influence of alcohol or other drugs
 - Caregiver changes: every time a child has a new caregiver, that person needs to learn about how and why ART is taken
 - Side effects: when people get side effects from ART they sometimes stop or reduce the amount of ART they are taking, hoping it will reduce the side effects
 - Pill burden/palatability: sometime the number of pills (or taste of syrups for children) makes it difficult to take ART correctly



- Distance: choosing an HIV clinic that is far away from your home can make it difficult to come to appointments and pick drugs regularly
- HIV knowledge: when people do not understand what HIV is, and why ART is important, they may not take their drugs properly. This also applies to children and adolescents, if they have not been told they have HIV and taught what it means
- Mental health disorders: depression and other mental illnesses can make it difficult to take ART correctly
- Religious beliefs: some people stop taking ART after faith-healing, although there has never been a case of someone being cured of HIV this way
- What might make it difficult for you individually to take your ART as prescribed
 - Ask the patient: *"Based on what you have learned so far, what challenges do you think you will have taken ART correctly, every day, for the rest of your life?"*
 - Discuss strategies to manage any expected barriers to adherence
- What can help you take ART as prescribed
 - Disclosure: It is easier to take your ART properly when the people close to you know your HIV status, so you do not have to try and hide your ART or miss doses to avoid being seen. Family and friends can also provide additional support once they are aware you have HIV and understand more about it. We can help you disclose your HIV status to important family members or friends when you are ready
 - Treatment supporter: Having a "treatment buddy" can help you take your ART correctly; ask a friend, partner, or family member to remind you to take your ART. If possible, invite that person with you to some of your clinic appointments and counselling sessions so they can learn about ART, the importance of good adherence, side effects, etc.
 - SMS reminder system (if SMS reminder system in place at the facility): Receiving a regular SMS, e.g., every week, can help you take your ART correctly. We enroll all our patients into this service for SMS reminders at our clinic, unless you do not want to receive them. The messages simply ask how you are doing, and do not mention HIV, ART, the clinic, or anything else that may reveal your HIV status to others
 - Support group: Joining a support group will help you learn from other people how they overcome challenges in living with HIV and taking ART correctly. Some support groups also have economic activities to help increase your income. We have support groups based at the health facility, and there are also support groups in the community
 - Other reminders:
 - Set a specific time of day to take your ART
 - Associate your ART with a specific event/s in your daily schedule (e.g., when you eat breakfast and dinner)
 - Set an alarm on your phone or watch
- What happens if you miss an appointment?
 - The healthcare team will be concerned about you, and will try to contact you by phone
 - Confirm patient phone number and consent to call if misses an appointment or any urgent lab results
 - If we cannot contact you by phone, we will try to call your treatment buddy
 - Confirm treatment buddy name and phone number, and consent to call if needed
 - If we cannot reach you or your treatment buddy, we may try and visit you at home, if we have your permission
 - Confirm locator information and consent to perform home visits if needed
 - Once you are back in care, we will work with you to figure out what caused you to miss an appointment and how it can be prevented in the future
- You will not be punished for missing an appointment



Section 9: Other medications

- What other medications will you take, in addition to ART:
 - CPT: all PLHIV should take cotrimoxazole preventive therapy once per day, in order to reduce the chance of getting other infections such as pneumonia, malaria, and diarrhoea
 - TPT: all PLHIV should receive 6 months of isoniazid preventive therapy (or another approved TPT regimen), unless they have active TB disease, in order to prevent development of TB
- Other medications may be recommended for specific conditions

Section 10: Nutrition

- Why is nutrition important:
 - When the viral load is high, your body uses a lot of energy trying to fight the virus
 - If your nutrition is poor, you have more chance of getting other infections as well
 - You need to eat well so your body has everything it needs to fight HIV, and look healthy
- What can you do to improve your nutrition?
 - Eat a balanced diet from a variety of foods.
 - Try not to eat a lot of sugar, red meat, or fatty/fried foods
 - Try to eat plenty of whole grains, vegetables, fruit, beans, and fish
 - Drink plenty of clean safe water
 - Physical activity and exercise is encouraged.

Section 11: Follow-up

- How often will you need to come to the clinic
 - Before starting ART: you should come to the clinic at least every week in order to get you prepared for ART so you can start as soon as possible
 - Soon after starting ART: after you start ART you should come to the clinic in 2 weeks in order to see if you have had any trouble taking your pills or have developed any side effects; then you can be seen after another two weeks for the same; then every month until your first viral load test
 - Once you have been on ART for a while: if your first viral load (after 3 months) is undetectable then you can be seen every 1-6 months depending on other factors that will be discussed with the clinician
 - Unscheduled visits: if you ever have any concerns, feel unwell, or need to speak with any of the clinic team then you can call or come to the clinic, even if you do not have an appointment scheduled for that day
- What will we be checking for during your clinic visits
 - At each visit you will be asked if you have had any illnesses since the last visit, if you have had any trouble taking your ART, and if you are experiencing any side effects. You may need a physical exam or blood tests at some visits

Section 12: ART readiness assessment

- Are you ready to start ART today?
 - Complete the ART Readiness Assessment (Table 5.4) for each patient to see if they should start ART today, and if not, to identify what issues need to be addressed before starting ART



Section 13: Management plan

- Which investigations will you have today
 - See Table 3.2 and Table 3.5 for recommended baseline and follow-up investigations respectively
- Which medications will you start today
 - May include: ART; CPT; TPT; other
- What else is required as you start or as you prepare to start ART
 - May include: assisted disclosure; support group referral; engagement of a treatment buddy; drug and alcohol counselling; depression management; referrals; other
 - For patients not starting ART today, management plan should include specific strategies to address any issues preventing/delaying ART initiation
- When should you return to the clinic
 - Book appointment date for next visit, preferably with the same healthcare worker

