

HIV Peer Case Management in Timor-Leste



*A handbook to assist with
supporting people living with HIV*

December 2021

V 1.0

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INTRODUCTION

This Handbook is designed to be a simple guide to identifying and supporting PLHIV in Timor-Leste.

It has a strong focus on counselling, supporting PLHIV to manage their own health, and minimising the HIV-related stigma and discrimination that limit the effectiveness of healthcare services.

This Handbook is not a clinical guideline. It does not address the management of clinical problems (e.g., opportunistic infections or medication side effects). Where such problems arise, the recommendation is that they are brought to the attention of the ART Centre team.

The development of this Handbook was prompted by a request from HIV peer counsellors for guidance to support their work.

Topics were chosen according to a priority needs assessment involving a range of personnel including Ministry of Health counsellors, HIV peer counsellors, ART Centre healthcare workers, and laboratory technicians.

The Handbook's development was informed by two key documents - the HIV Stigma Index Report Timor-Leste 2017, and the Report on Loss to Follow Up in Timor-Leste 2021 – as well as WHO guidelines and global evidence from HIV research.

Some sections are relevant to all healthcare personnel, such as HIV basics, creating a friendly healthcare environment, and preventing HIV transmission (Sections 1, 3, and 8).

For example, CHC healthcare workers may wish to refresh their knowledge on providing support at the time of diagnosis, and successfully linking the client to ongoing care (Sections 6 and 7).

Midwives will have a particular interest in how to approach HIV testing, and HIV in pregnancy (Sections 5 and 9).

Counsellors will find recommendations for Peer Case Management (Section 4) as well as information on counselling to support PLHIV in a range of situations - also highly relevant for all ART Centre workers (Section 10).

As the quality-of-care increases throughout the country, more and more PLHIV will be supported to stay on long-term treatment, to remain healthy, and to be non-infectious to others.

Together, let us work towards zero deaths from HIV, and no further HIV transmission in Timor-Leste.

KEY TERMS AND ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome	VL	Viral load
ANC	Antenatal care	VCCT	Voluntary, Confidential Counselling and Testing
ARV	Antiretroviral		
ART	Antiretroviral therapy		
CD4	Immune system cell		
EMTCT	Elimination of mother-to-child transmission		
HIV	Human Immunodeficiency Virus		
LTFU	Lost to follow up		
OI	Opportunistic infection		
PEP	Post-exposure prophylaxis		
PrEP	Pre-exposure prophylaxis		
PITC	Provider Initiated Testing and Counselling		
PLHIV	People living with HIV		
PMTCT	Prevention of mother-to-child transmission		
STI	Sexually transmitted infection		
TB	Tuberculosis		
TLD	Tenofovir, lamivudine and dolutegravir		
TLE	Tenofovir, lamivudine and efavirenz		



Section 1

HIV Basics

WHAT IS HIV?

HIV stands for **Human Immunodeficiency Virus**.

HIV attacks the body's immune system.

By slowly damaging the immune system HIV makes the body more and more vulnerable to other illnesses.

The damage usually cannot be seen or felt in the early stages.

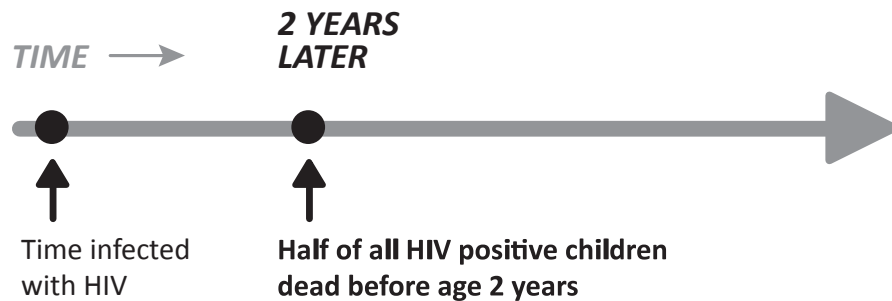
In adults, HIV often progresses slowly.

It could take 10 years before an adult with HIV shows symptoms:



In children HIV often progresses more quickly, compared with adults.

If not treated, most children with HIV will die within the first few years:

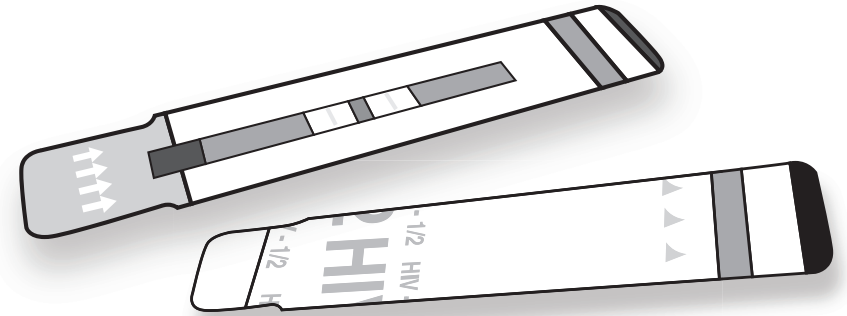


Many people have HIV in their body for years without realising it.

People who are HIV positive can feel healthy, and not know that the virus is slowly attacking their immune system.

You cannot tell if someone has HIV just by looking at them.

To detect HIV, you need to do a specific blood test (**called the HIV Determine Test**).



If the Determine Test is positive, it must be followed up with confirmatory tests (see Section 6 Support at the time of Diagnosis).

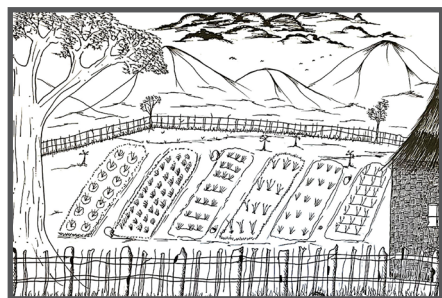
Most HIV positive people in Timor-Leste do not know that they have HIV. This is because they have not had an HIV test yet.

In Timor-Leste it is common for people to be diagnosed late (e.g., 10 years after acquiring HIV) with HIV when the immune system has already been severely damaged.

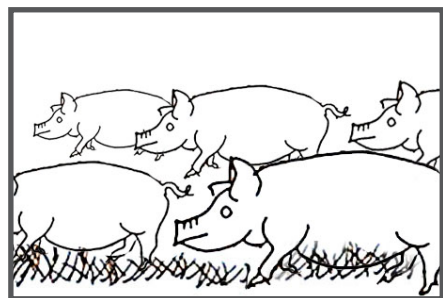
HIV damages the CD4 cells, which make up an important part of the immune system. Without treatment, the number (count) of CD4 cells gets lower and lower over time.

A damaged immune system leaves people vulnerable to **opportunistic infections (OI's)**.

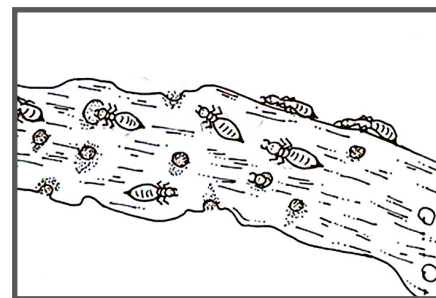
This analogy showing the relationship between the immune system, HIV, opportunistic infections, and ART may help understanding.



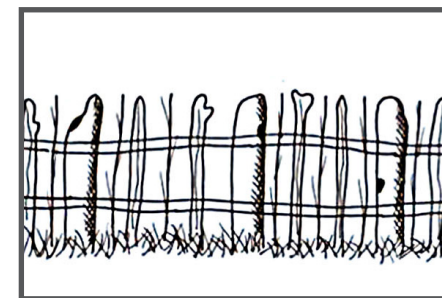
Imagine a thriving garden.
The garden represents you/your body



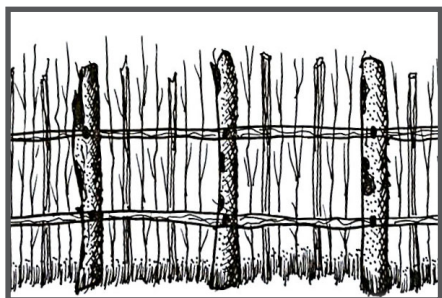
Imagine there is a family of wild pigs living near here, who want to get into the garden and eat everything/make a big mess.
The pigs are like the illnesses (opportunistic infections) that are all around us.



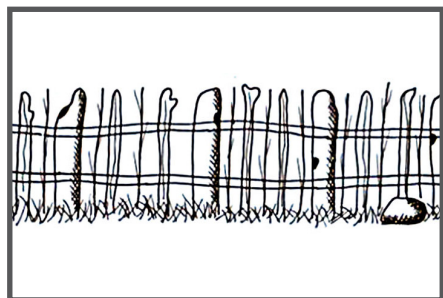
Now, imagine that wood-eating ants appear, and they start eating at the wood that the fence is made of. **The ants are like HIV eating at the immune system.**



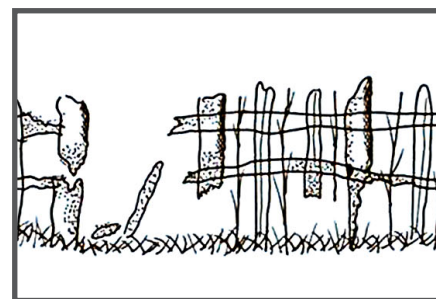
In the beginning, it seems like the fence is fine, but already there is damage to the wood inside.
This is like the early stage of HIV, when there are no major symptoms yet.



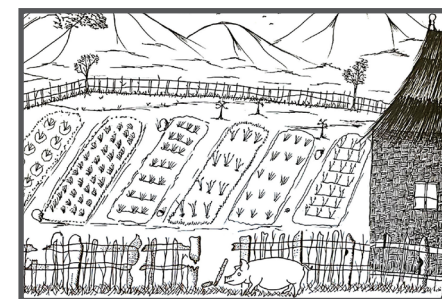
Imagine there is a good strong fence that protects the garden.
It is like the immune system protecting the body from infection/illness



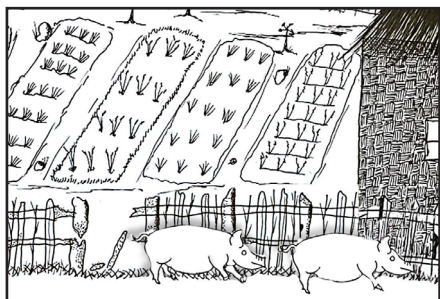
All the pieces of wood are joined together to make a strong fence.
This is like the CD4 cells joining together to make a strong immune system.



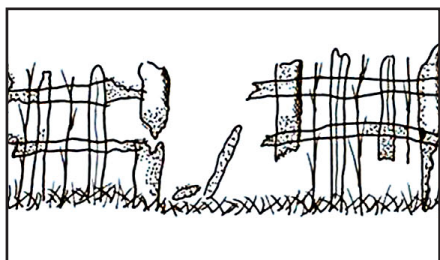
The ants keep on eating the wood, and after some time the fence falls down completely. This is like the late stage of HIV, when the immune system is badly damaged.



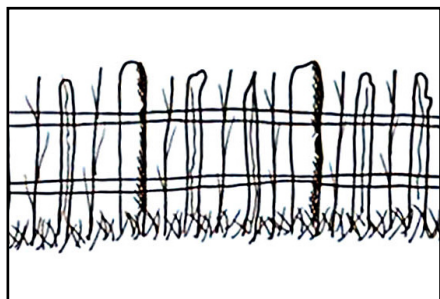
Now the pigs can get inside the garden and trample everything and make a big mess. **This is like AIDS, when opportunistic infections damage the body (for example TB or pneumonia).**



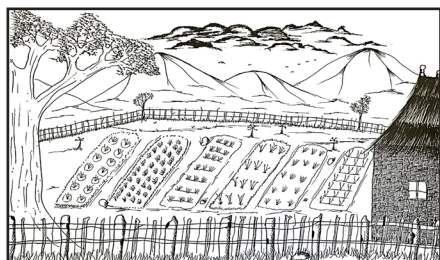
The first priority is to chase all the pigs out of the garden.
That is like giving treatment for the opportunistic infections



Imagine the gardener stops bothering with the special dye.
In that case, the ants will come back and multiply, and the same damage will happen again.
That is like what happens if someone quits taking their ART.



The next priority is to build the fence again and stop the ants from causing more damage. Special dye is painted on the wood which suppresses the ants and protects the fence.
The protective dye is like HIV treatment (ART). Rebuilding the fence is like rebuilding the immune system.



With the fence rebuilt and the dye painted on regularly to keep the ants under control, the garden is safe from the pigs and can flourish and grow.
In the same way, someone living with HIV can keep their immune system strong with ART, so they can live a long and healthy happy life.

HOW DOES HIV TREATMENT WORK?

HIV treatment is called **ART (Anti-Retroviral Therapy)**.

On effective ART, HIV is suppressed so that the **immune system can become strong again**.

ART tablets contain a combination of powerful medications that act together to suppress the HIV.

There are different kinds of ART, often combined into one tablet.

ART does not cure HIV. The tablets only work if the individual continues to take them every day.

ART should be taken **life-long**.

Regularly taking ART helps to keep the amount of virus in the body very small.

If ART tablets are taken in an on/off manner, HIV can multiply and change itself so that it is no longer affected by the medication. We call this **developing drug resistance**, which means those ART medications will not work properly anymore.

Taking ART every day without missing doses means that the ART will continue to effectively control the virus. This is called taking ART with **good adherence**.



When the amount of HIV virus is so small that we cannot detect it on the **Viral Load Test**, we say it is **Undetectable**.

If a PLHIV's viral load becomes *undetectable*, they **cannot transmit HIV** to another person.

This is known as:

Undetectable = Untransmissible,
or **U = U.**

The goal of ART is to control the **HIV virus** so that it cannot do any further damage to the body and the immune system can become strong again.

We can check the strength of the immune system by **measuring the CD4 count**.



From the time of acquiring HIV, the CD4 count decreases (immune system weakening)

OPPORTUNISTIC INFECTION PROPHYLAXIS AND TREATMENT

The process of re-strengthening the immune system with ART takes time – often several years.

When the immune system is still weak, it is easier for other infections to use this opportunity to enter and make the body sick.

These special or **opportunistic infections (OIs)** can include TB and pneumonia.

While waiting for the immune system to recover, PLHIV may be advised to take **prophylaxis** medicine to protect against opportunistic infections:

- **Co-trim** gives protection against pneumonia and other infections. It is usually the first medication that is started for newly diagnosed PLHIV.
- **Isoniazid** or Rifapentin (TB preventive therapy) give protection against TB.

TB is the most common OI affecting PLHIV in Timor-Leste.

Opportunistic infections may already be present if someone's HIV is **diagnosed late**. These infections must be **identified and treated urgently**.

As a peer case manager, you can help your clients minimise illness from opportunistic infections by:

- Encouraging them to talk to their ART Centre team about any symptoms they have that might indicate an opportunistic infection is present
- Checking they understand the importance of adherence to their prophylactic medication
- Supporting ART adherence to help your clients achieve viral suppression and immune system recovery.

Did You Know...?

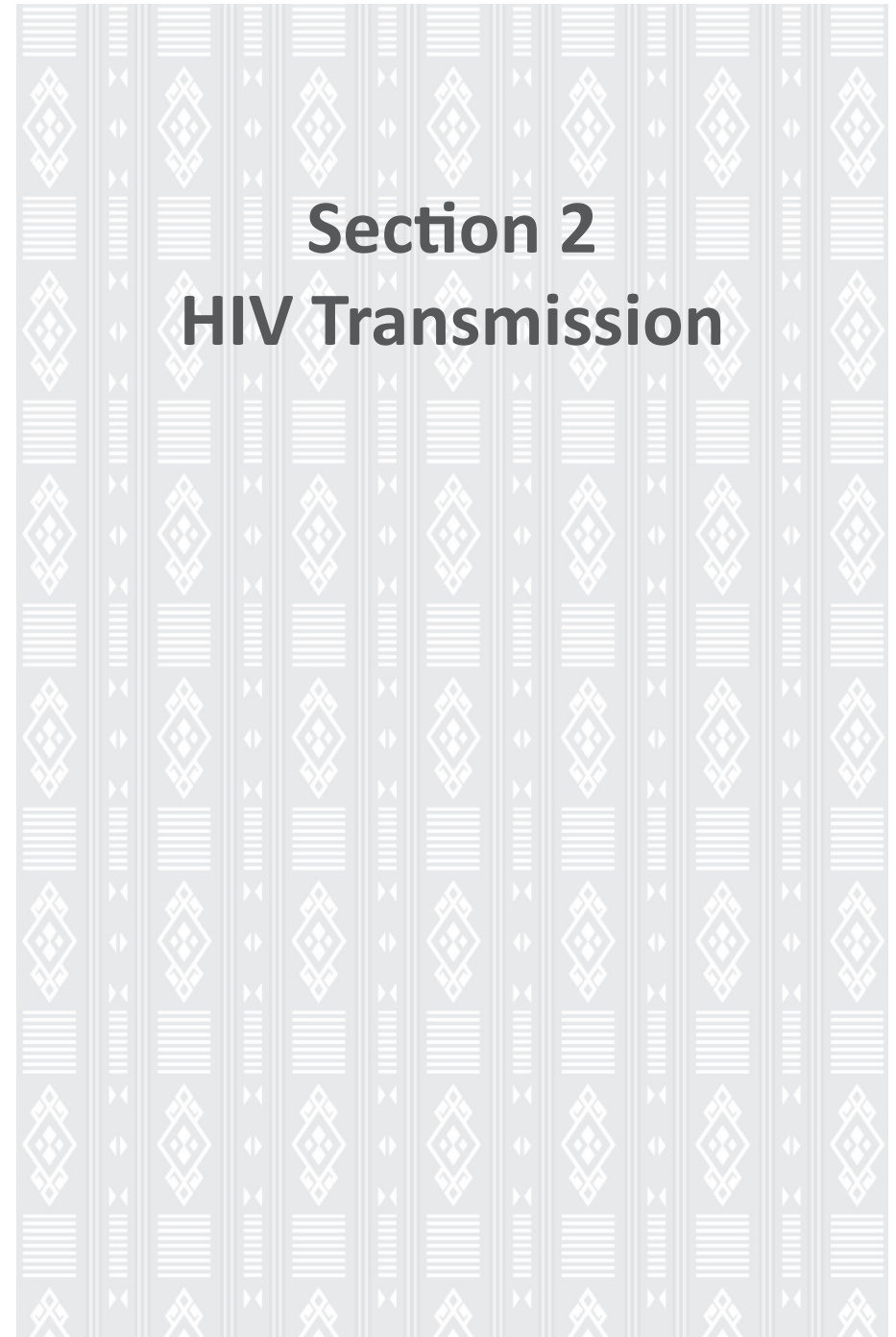
AIDS stands for Acquired Immune Deficiency Syndrome. AIDS occurs when the immune system is badly damaged and serious opportunistic infections occur.

AIDS can be reversed. On effective ART the immune system can recover.

If someone with HIV starts effective treatment early, the immune system stays healthy, and they will never develop AIDS.

AIDS is a term which is not commonly used now, and some people find it stigmatising.

It is more useful to talk about whether HIV is **advanced** (badly damaged immune system), on treatment, or **well controlled** (viral load low and immune system healthy).



HOW IS HIV TRANSMITTED?

In Timor-Leste the two main ways HIV is transmitted are:

1. Sex without a condom (vaginal or anal sex)
2. Vertical transmission (from mother to child during pregnancy, delivery, or breastfeeding).

Other, less common ways that HIV can be transmitted are:

3. Blood transfusion
4. Sharing needles during drug use
5. Accidental needlestick injury in healthcare settings

There are many myths (wrong information) about HIV transmission in Timor-Leste. HIV is **not transmitted** through:

- Touching
- Kissing
- Toilet seats
- Sharing food, cups, plates, clothes, or bedding
- Mosquitoes
- The air

Many cases of HIV-related stigma and discrimination are related to limited information about HIV transmission.

Lack of accurate knowledge can result in fear, which can lead people to act in stigmatising ways (e.g., avoiding physical touch with PLHIV).

As a healthcare worker, you can improve the quality of services you provide by staying up to date with your HIV-related knowledge



Table 1.
Factors associated with increased risk of HIV transmission

SEXUAL transmission of HIV is more likely:

- If the HIV positive person has a high HIV Viral Load
- If condoms are not used correctly and consistently
- If either person has an active STI (e.g., syphilis)
- With sex that causes bleeding (e.g., sexual assault)
- With condom-less anal sex (compared with vaginal sex)
- If the number of sexual partners is higher
- If the HIV negative person is uncircumcised

VERTICAL (mother-to-child) transmission of HIV is more likely:

- If the mother has a high HIV Viral Load, especially during delivery and breastfeeding
- If the baby's anti-viral prophylaxis is given late (>4 hours after delivery)
- If the baby's anti-viral prophylaxis is not correct (wrong drug or wrong dose)
- If instrumentation (e.g., forceps or vacuum delivery) is used during labour
- If an episiotomy is performed

To fully understand HIV transmission, it is necessary to understand some of the forces which shape the way people behave.



Abelina is HIV negative
Manuel is HIV positive
(but does not know it yet)

Abelina and Manuel do not use condoms when they have sex


Abelina becomes HIV positive

Sex without a condom is the **direct cause** of Abelina acquiring HIV.

Looking at Table 2 you can see some of the deeper reasons why Abelina is now HIV positive.

Table 2. Some root (underlying) factors that promote HIV transmission in the community

Direct cause	Root cause
<i>Manuel does not know he is HIV positive because he hasn't had a test.</i>	▶ Low knowledge of HIV in the population and perception of own risk is low
<i>He thinks about getting tested but worries the healthcare workers may say something judgemental</i>	▶ Fear of stigma as barrier to attending healthcare
<i>Abelina thinks about using condoms but doesn't know how to get a supply them.</i>	▶ Lack of condom availability and awareness
<i>She thinks healthcare workers only provide them for married women.</i>	▶ Lack of comprehensive sexuality education
<i>Manuel doesn't like the idea of using condoms and is the one who makes the decisions in the relationship.</i>	▶ Gender power imbalance impacting capacity to negotiate self-protection
<i>Manuel hits Abelina sometimes, and thinks he has a right to sex from her.</i>	▶ Women in violent relationships are at higher risk for acquiring HIV
<i>Abelina has no job or money of her own and doesn't know how she could support herself without Manuel.</i>	▶ Poverty and economic dependence increase vulnerability to acquiring HIV

 **Did You Know...?**

The amount of virus in the body is at its highest during the first few weeks after acquiring HIV.

This explains why someone with early HIV infection is at high risk of transmitting the virus to others.

Some people experience a flu-like illness during this early phase, called **HIV seroconversion illness**.

A flu-like illness after recent unprotected sex indicates the need for immediate HIV testing.



Section 3

Creating a Friendly Healthcare Environment

Encouraging people to attend your health centre and then remain engaged in care depends to a very great degree on creating a **friendly and welcoming environment**.

High rates of drop out from a healthcare centre can be an indication that PLHIV are not feeling **safe** or **comfortable**.

The options outlined below are simple and inexpensive, but they can show PLHIV:

- We care about you, and
- we want you to feel welcome here.

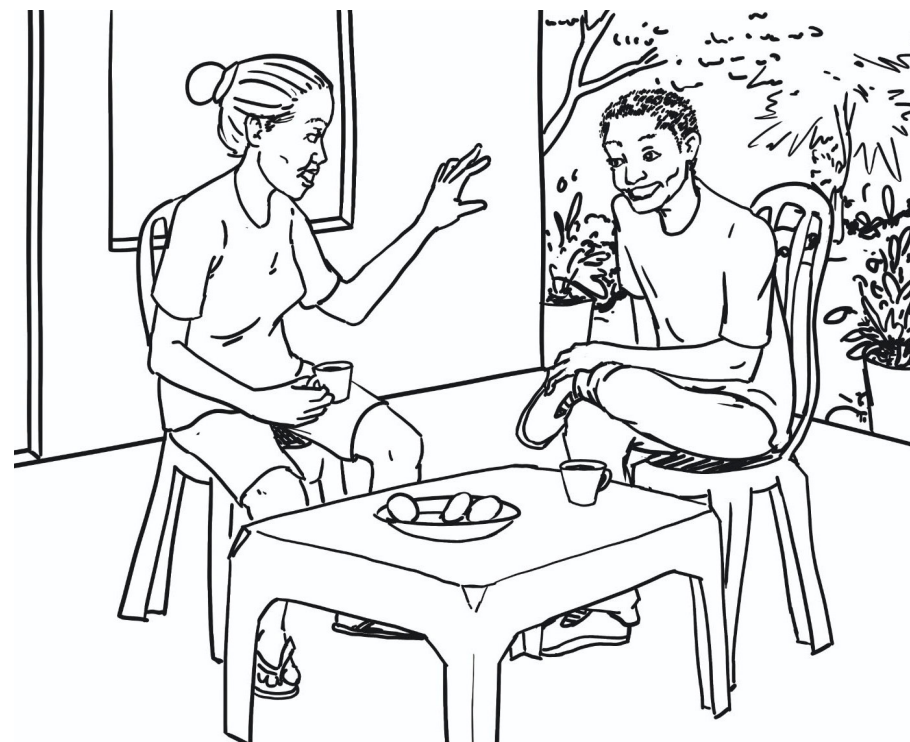
Welcoming a client to the clinic is like welcoming a visitor to your home.

When clients feel comfortable, they are more likely to continue attending appointments with **good engagement**.

A welcoming environment is made up of both the physical aspects of the space and the actions of the team.

THINK ABOUT:

- When welcoming visitors to your home, how do you make them feel comfortable and respected?
- What are the ways you like to be welcomed when visiting others?
- Are there any parts of this that could apply to the clinic setting?



PHYSICAL ASPECTS OF THE HIV CLINIC

Think about how you can optimise your clinic environment to preserve client confidentiality.

- Choose a private waiting area where clients do not feel exposed to the view of other patients waiting or people walking past
- Avoid signs announcing “HIV centre”
- A side entrance where clients can enter the clinic discreetly is ideal
- Post a sign inside the clinic containing a message assuring clients that everything discussed will remain confidential

Make the **waiting area as nice as you can**. A private, shady outdoor space where people do not feel overcrowded is ideal (and makes it easier to follow COVID-19 physical distancing rules).

Place a written sign at the front of the clinic with a short **message of welcome**

Display some **colourful artwork** on your walls that has been made by local artists

Avoid placing a desk directly in between you and your client (the desk can act as a psychological barrier)

Rather than sitting behind a desk, place your chair and the client’s chair at approximately 45-degree angles to each other (to promote the feeling you are having a friendly discussion as equals)



ACTIONS AND POLICIES FOR THE HIV TEAM

Ensure anyone who spends time in your centre, including cleaners, security guards and students on rotation, understands the vital importance of always maintaining total client confidentiality.

Regular staff training can be backed up by:

- Requiring all staff/students to sign a client confidentiality form (see Annex 1).
- Discuss with your manager what the consequences will be for any staff member who breaks client confidentiality (including possible termination of the staff member's contract).

Let your PLHIV know you are truly happy to see them.

Smile when they attend for their appointment and take a little bit of time to chat like you would with any friend or neighbor.

“I like the way the counsellor (health care worker) talks to me nicely and respects my privacy and makes me feel comfortable, but I don't like the way the doctor communicates to me with a look like I am so disgusting to him”.

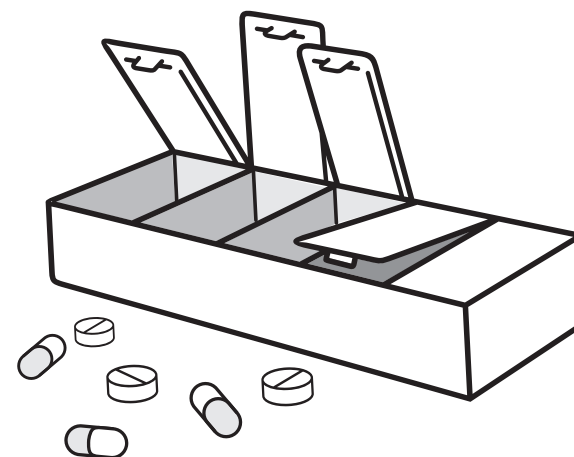
A PLHIV who is disengaged from HIV treatment and care.

Report on Loss to Follow Up in Timor-Leste, 2021

Review your models of care, looking for ways to **make things easier** for your PLHIV.

Examples with strong supporting evidence from research include:

- Multi month dispensing of ART
- Door-to-door delivery of medications
- Text message reminders about appointments
- Use of dosette boxes to help clients cope with complicated medication regimens



“Counsellors have to open up to PLHIV so they don't feel alone. Always ask about the PLHIV's news or condition, treat them like a friend”

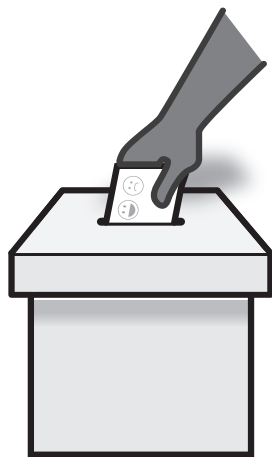
HIV Peer Educator, Dili 2021

- **Schedule appointment times** (see below) carefully, to minimise waiting times and avoid crowding in the waiting area (this is also good for Infection Prevention and Control reasons).
- **Make small friendly gestures** like offering a glass of water. If someone in your team brought in some snacks that day, share some with your client.
- **Invite your clients to offer feedback** and suggestions on your healthcare centre's service (see Annex 1 for a sample client satisfaction questionnaire). Use this feedback to guide improvements you make to your service.

Place a box at the front of the clinic where clients can post their responses anonymously.

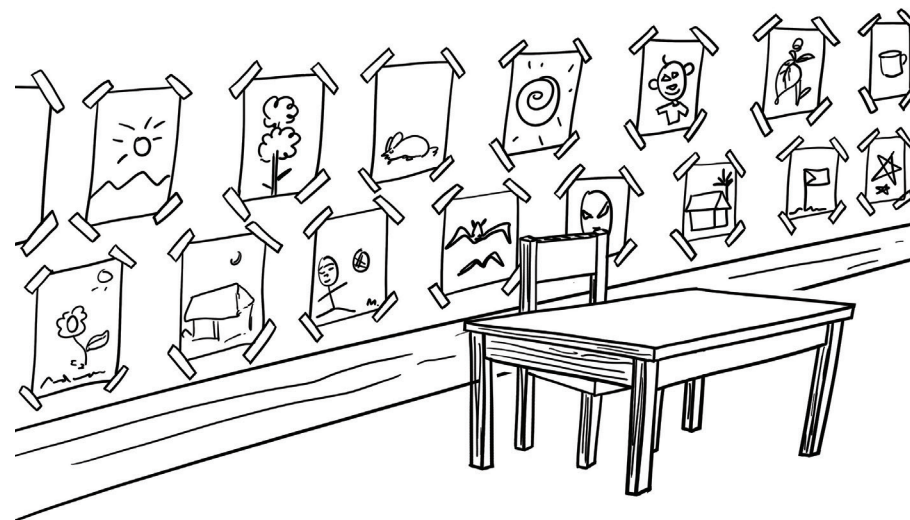
So PLHIV feel comfortable to use it, put the feedback box in a place where staff aren't looking at it all the time.

This will help show PLHIV that you care about their opinions, and that you want to do your best to continually build the quality of your service.



- Allow your centre to be used for a relaxed afternoon coffee session (e.g. for women living with HIV to chat together).

- Clinics can be frightening places for young children. Encourage children attending your service to do some crayon drawings. Tape these up on the wall to make the environment less appear threatening.
- Promote a **strong culture of inclusion** in your clinic, where diversity is celebrated. Reflect on your colleagues' level of understanding about LGBT issues and consider whether a training workshop would be a good idea. Ensure nobody uses homophobic or stigmatising language in your centre.



 **ACTIVITY:**

Block out a full afternoon where no appointments are scheduled, and your team has no other duties.

Discuss which **strategies you would like to try** to make the experience of attending clinic as positive as possible for your PLHIV.

It would be a great idea to collect suggestions from your PLHIV about this.

You may find it interesting to collect client feedback before and after you make these changes.

TIPS FOR MANAGING APPOINTMENTS

It can be helpful to use a **wall calendar** and **reminder cards** to help manage return visits to the clinic.

The **benefits** to the **HIV team** include:

- Improved time management and client flow (not too many clients in one day)
- Minimizing crowding is good for infection control reasons
- Can plan time for other activities, such as training or reporting
- Can follow up early with those who miss their regular visit – this helps minimise drop out from care

The **benefits** to the **client** include:

- Reduced waiting time
- Can plan their time better, and feel their time is respected
- Can mentally prepare for a visit that may include some feelings of anxiety
- Don't have to return multiple times if a consultation is not possible the first time
- Improved satisfaction and engagement with the service

An **appointment calendar** can be downloaded, printed, and placed where it will be easy to write new appointments.

Dec 2021							Feb 2022						
S	M	T	W	T	F	S	S	M	T	W	T	F	S
			1	2	3	4	6	7	8	9	10	11	12
5	6	7	8	9	10	11	13	14	15	16	17	18	19
12	13	14	15	16	17	18	20	21	22	23	24	25	26
19	20	21	22	23	24	25	27	28					
26	27	28	29	30	31								

JANEIRU 2022

DOMINGU	SEGUNDA	TERSA	KUARTA	KINTA	SESTA	SABDU
26	27	28	29	30	31	1
2	3	4	5	6	7	8
9	10	11	12	13	14	15
16	17	18	19	20	21	22

Only use **PID codes** on the calendar, **not names**

Other tips which can help your clinic run smoothly include:

- Give clients a reminder card to take home with them, so they know what date and time to return for their next appointment

Tif: (000) 000 - 0000
Apontamentu _____
Data: _____
Oras: _____
Karik ita la bele tuir ita nia apontamentu, favor ida bele telefone ba ami obrigada

- Sending clients **reminder SMS messages** the day before their appointment can reduce the number of missed appointments and reduce your need to make follow up phone calls later
- Limit the number of appointments every day, so you have enough time for each client



WHAT IS PEER CASE MANAGEMENT?

Peer case management involves PLHIV providing practical, emotional, and social support to other PLHIV with the goal of promoting behaviours that improve health and wellbeing.

Peers are people who share similar characteristics (e.g., HIV status, gender, cultural background etc). Sometimes PLHIV may feel more comfortable talking openly to a peer who has shared similar experiences, than to a health professional.

HIV peer supporters share their expertise in coping with the physical, mental, and social aspects of HIV.



By engaging with HIV peer supporters, people who are newly diagnosed with HIV can see with their own eyes how PLHIV can live long, healthy, and fulfilling lives on treatment.

Peer case management is **not** the same as clinical (or medical) case management.

Clinical case management is the responsibility of ART Centre healthcare professionals.

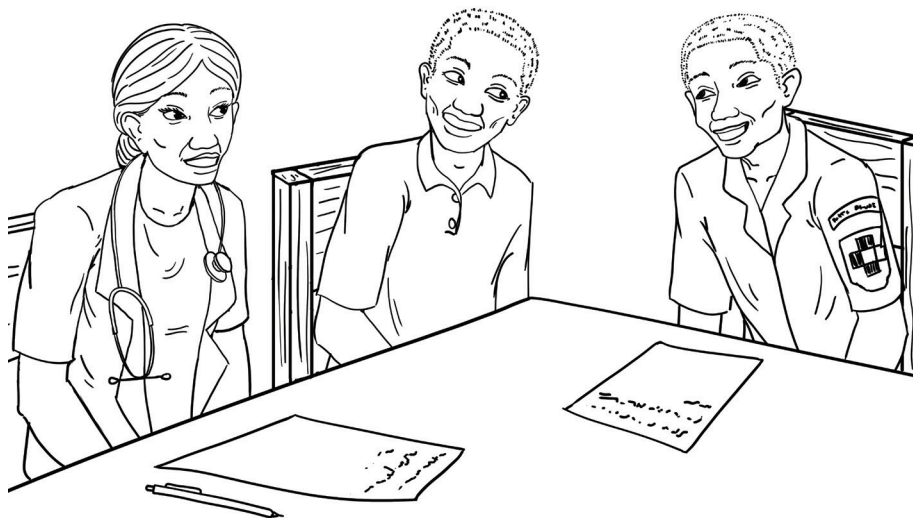
It includes some of the same elements outlined here (e.g., counselling and phone follow up) as well as clinical aspects of HIV care (e.g., diagnosis and management of illnesses, blood test monitoring etc).

There are many ways in which the **peer case manager** and the **ART Centre team** can work together to support the clients. For example:

- The peer case manager may realise their client is having some mental health problems. If the client gives permission, then the peer case manager can update the ART Centre team about the issue.
- If the ART Centre team sees that a client's viral load is high, then they may collaborate with the peer case manager to focus on adherence counselling with the client.
- The ART Centre team may contact the peer case manager to see if they can help arrange transport for a client.

The activities of the ART Centre team and the peer case manager complement each other.

Regular communication between the ART Centre team and the peer case managers is vital.



WHAT ARE THE BENEFITS OF HIV PEER CASE MANAGEMENT?

Research has shown that the potential benefits of peer case management for PLHIV include:

- Increased accessibility of needed services for PLHIV
- Reduced drop-out from care
- Optimised treatment adherence
- Improved viral suppression and CD4 cell recovery
- Reduced feelings of isolation
- Improved client self-sufficiency
- Improved quality of life
- Reduced transmission of HIV in the community

Note that the benefits of peer case management are not limited to the client alone.

Improved quality of life for peer case managers can arise from helping others and having an important purpose in life.

CORE PRINCIPLES OF PEER CASE MANAGEMENT

Core principles of peer case management include:

- 1. Confidentiality** - The client must be confident that the case manager will always respect their confidentiality. Remember that while the peer case manager is bound by confidentiality rules, the client does not have the same formal workplace rules. The case manager should be mindful of this when it comes to sharing personal information with the client.
- 2. Trust** - Case management depends on a special relationship between the client and the peer case manager which is trusting and positive.
- 3. Goal Oriented** - In general, the goals will relate to the health and wellbeing of the client. Specific, client-focussed goals will be worked out between the client and their peer case manager.
- 4. Client self-management** - This is encouraged by the peer case manager. The attitude is not “I will do it for you”, but rather “together we can do it”. Eventually, the goal is for the client to have the confidence and skills to take care of their own health.
- 5. Voluntary** - Working with a peer case manager is voluntary for all PLHIV. PLHIV should understand they are free to accept working with a peer case manager, and free to stop.
- 6. Adaptable** - An experienced peer case manager will be able to adapt to the changing needs of their clients, e.g., intensifying efforts during periods of increased risk.

PEER CASE MANAGEMENT ACTIVITIES

There are many ways in which peer case managers can support their PLHIV clients.

Key services provided by peer case managers include:

- 1. Linkage Assistance**
- 2. Connecting with Other Services**
- 3. Counselling**
- 4. Phone Follow-Up**
- 5. Medication Support**
- 6. Re-engaging with Lost To Follow Up PLHIV**
- 7. Peer Support Groups**

Each of these activities are described in more detail below.

1. Linkage Assistance is when a peer case manager helps a newly diagnosed client link to the ART Centre of the client’s choice (*see Section 7: Successful Linkage of PLHIV to Care*).

The peer case manager plays a vital role in ensuring that PLHIV are supported at this critical point and are successfully linked to long-term care. This may involve:

- Meeting the client at the site where the client has tested positive for HIV (e.g., following an urgent phone call from the healthcare worker at the CHC)

- Helping the client know what to expect at the ART Centre
- Helping the client choose which ART Centre they would prefer to attend
- Escorting the client to their ART Centre appointment
- Joining the client for the first appointment, if the client wishes



2. Connecting with Other Services. In addition to helping the client access care at the ART centre the peer case manager will also facilitate other connections as needed. For example:

- If the client is pregnant the case manager will ensure they can attend regular antenatal appointments
- If the client is eligible for financial support from the Ministry of Social Solidarity, then the case manager can help them access this

- When the client feels ready, the peer case manager may introduce them to one of the HIV peer support organisations (e.g., Estrela Plus, Esperansa, CODIVA)


Lista Apoiu Xave

 **Estrela+**
Lina Belun Konfiansa
7522 0561 / 7403 0902 / 8001 099

 **Alfela Dili**
7743 2103

 **PRADET**
Fatin Hakmatek Dili
332 1562 / 7752 4597

Uma Mahon iha Dili
FOKUPERS Dili
331 1534 / 7847 2598
FOKUPERS Uma Entrada - 7847 2598
Casa Vida Dili - 7735 2345
FFCJ Dili - 7796 9826

 **Ministériu Solidariedade**
Sosiál no Inkluziun
Pontu Fokal ba Violensia
Bazeia ba Jeneru (VBJ)
7725 7439
Ofisial Protesaun Labarik (OPL)
7731 6975 / 7705 0970

 **PNTL-VPU**
Unidade Ema Vulneravel Dili
7734 1607

Hotline Saúde Mental
Liga ba 12 123 Gratuita
Atende hosi tuku 08:00 - 17:30
Loron Segunda to'o Sesta

Asistensia Mediku COVID-19
Liga ba 119
COVID-19 Helpline via WhatsApp
+670 7556 0000

Atensaun Mediku Urjente
Liga ba Ambulansia iha 110
Numeru HNGV
3310 541 / 3311 008



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'hamahon.tl' atu hetan
numerus importantes
ba assistensia. Bele mos
asesu direktamente iha
<https://hamahon.tl>

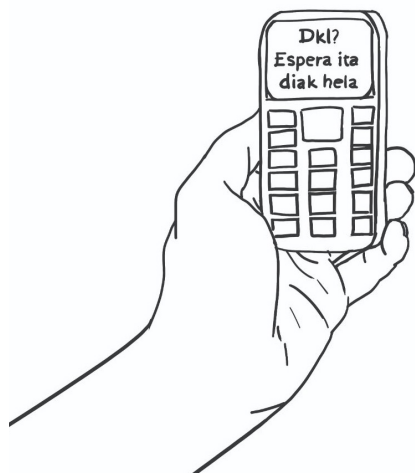
3. Counselling is a core part of peer case management. Section 10 outlines key counselling skills and techniques. Peer case managers offer counselling across a range of situations, including:

- At the time of HIV diagnosis
- To support HIV disclosure to partners/family
- To identify PLHIV at higher risk of poor adherence or dropping out from care
- To support starting ART and ART adherence
- To support healthy behaviour change (e.g., stopping smoking, safer sex)
- During times of high psychological stress (e.g., losing job, relationship breakdown)

- To address self-stigma and mental health issues
- When client is pregnant or planning a pregnancy
- In palliative care situations

Three one-on-one counselling sessions for someone newly diagnosed with HIV is likely to be the minimum required. For some PLHIV this may be enough, while others will need more frequent, ongoing counselling.

4. Phone Follow-Up (talking or messaging) complements the face-to-face counselling sessions and allows the peer case manager to monitor the client's progress. It is also a good way to keep the client engaged and to continue to show support during limitations imposed by the coronavirus pandemic.



5. Medication Support may involve a combination of activities, including:

- adherence counselling
- encouraging the client to discuss medication concerns with the ART team
- practical help like collecting and dropping off medication if the client has transport difficulties

6. Re-engaging with Lost To Follow Up PLHIV is indicated when strategies to prevent Loss To Follow Up have not been successful. It can be helpful for the peer case manager and

members of the ART Centre team to collaborate on attempts to find and re-engage with LTFU clients.

Re-engaging LTFU clients can be very challenging and is often unsuccessful, emphasising why strategies to prevent drop-out from occurring in the first place are of utmost importance (see Section X: Creating a Friendly Environment).

7. Peer Support Groups are one of the most helpful ways of supporting PLHIV.

It is common for PLHIV to be fearful about risk of unintended HIV disclosure, and this may stop them from wanting to engage with HIV-related group activities.

If the client can first become comfortable with the peer case manager during their one-on-one sessions, then later they may become open to the idea of attending a group event.

Peer case managers may facilitate formal group discussions (e.g., an update on recent HIV-related research) or informal group gatherings of PLHIV (e.g., a coffee morning to meet and chat) – both are highly beneficial.



RIGHTS AND RESPONSIBILITIES FOR PEER CASE MANAGERS

It is important that peer case managers have access to:

- Ongoing **training** in the core competencies required for effective HIV case management. Ideally this will be a mix of:
 - Classroom-style teaching; and
 - On-the-job training/mentoring (e.g., at an ART Centre)
- Use of **materials** to help them perform their role (e.g., a directory with names/contacts for all key health and other services that PLHIV may need to access)
- Ongoing **supervision and mentoring** to help the peer case managers develop their skills
- **Logistical support** to enable their work (e.g., fuel to enable transporting clients to appointments when needed, phone credit to enable phone follow-up)
- **Opportunities to debrief** about emotionally challenging situations

Peer case managers must have a **clear awareness of their limits**. The supervisor should help peer case managers recognise which situations will require referral or asking for help (e.g., contacting the ART Centre team if a client has a physical illness or serious mental health issue).



Setting boundaries with clients is very important for peer case managers. *Being available to clients 24 hours a day is not sustainable.*

Clients should know when and in what situations it is okay to contact their case manager.

Peer case managers should be wary of taking on too many clients at one time. It may be difficult to say ‘No’ when many PLHIV need help, but there is a danger of burn-out if peer case managers take on too much.

The client-case manager relationship is a professional relationship. Sexual or intimate relationships are not appropriate.



Section 5 HIV Testing

PRINCIPLES OF HIV TESTING

There are two situations when HIV testing takes place in Timor-Leste:

- 1. Voluntary Confidential Counselling and Testing (VCCT)** is when the client asks for the HIV test (“opt in” testing)
- 2. Provider Initiated Testing and Counselling (PITC)** is when the healthcare worker recommends the HIV test, and the test goes ahead unless the client declines (“opt out” testing)

In both situation, HIV testing must follow these three key principles:

Consent, Counselling, and Confidentiality

1. Consent

Remember that HIV testing must always be **voluntary**.

Give the individual the **option of saying no** (i.e. choice of an “opt out”) – otherwise, testing is not voluntary.

Mandatory testing or testing without consent is a violation of the individual’s rights.

If someone is reluctant to have an HIV test you might be tempted to push hard, to insist the individual agrees to the test – avoid this, even though it is frustrating.

“When I had the test I didn’t know or did not get pre- and post- test counselling. After the test I heard that I was affected with HIV and first I was amazed because I didn’t know the doctors had tested me for HIV.”

HIV Stigma Index Report Timor-Leste, 2017

Pressuring someone into having an HIV test, or testing without their knowledge, can lead to:

- Negative feelings related to loss of autonomy that can be long-lasting
- Reduced ability to adjust well to a positive HIV diagnosis
- Increased risk of disengagement from ongoing care (including a loss of trust for the health system)

What if someone cannot give consent for an HIV test?

Occasionally the situation will arise when an HIV test is medically indicated but the individual cannot give their consent (e.g. when someone is confused or has a reduced conscious state).

In this case, **do not** ask consent from the family since this can lead to big problems in the future related to confidentiality.

The healthcare worker involved takes the decision to do the HIV test, and the result is conveyed to the individual later once they can understand.

ACTIVITY:

With your colleagues, discuss a time in your life when somebody else made a decision on your behalf, leaving you out of the decision-making process. The decision may or may not have been 'for your own good'.

How did this loss of autonomy make you feel?

2. Information and Counselling

Pre-Test information is designed to help people make an informed decision about having the HIV test.

Giving pre-test information **does** need to include some essential elements but **does not** need to be long or complicated.

Lengthy pre-test information sessions can be a barrier to having the HIV test.

Giving **brief pre-test information** is only okay if you combine it with **comprehensive Post-Test Counselling**.

Box 1. What is good about having an HIV test?

The HIV Determine test is:

- Free
- Quick (20 minutes)
- Easy (1 drop of blood)
- Confidential
- Your choice
- The key step for connecting with good care to keep you healthy if the result is positive

If someone is uncertain about whether to have the HIV test or not, ask if you can talk to them about some of reasons the HIV test could be a good idea for them (see Box 1).

If they don't feel ready to take the HIV test yet, check if they would like to make an appointment to come back later after some time to think.

Essential information before testing

The **four essential elements** your client must understand when giving **HIV pre-test information** are:

1. The **name** of the test that is being done (i.e., “HIV test” or “test for HIV”)
- vague comments about ‘testing for problems in your blood’ are not okay
2. A basic understanding of what HIV is, including the fact that **good treatment is available**
3. An understanding that the test result **will not be shared** with other people
4. An understanding that they **can say no** to the test if they want to

Box 2 below shows the essentials of HIV pre-test counselling in three sentences – something even very busy healthcare workers can do.

Box 2. Minimum requirements for Pre-Test information

Sentence 1	<i>“We would like to do a test for HIV, which is an illness that is a problem if it is not treated, but good treatments are available now”</i>	Includes the name of the test Brief mention of what HIV is , and that treatment exists
Sentence 2	<i>“The test result will be just between you and me - I won’t tell anyone else without your permission”</i>	Reassurance about confidentiality
Sentence 3	<i>“Would you be happy to have the HIV test and wait for the result, Mana/Maun?”</i>	Option to decline (seeking consent) Includes request to wait for result

Include additional information depending on your assessment of the client’s needs, and any questions they may ask.

ACTIVITY:

Imagine you are talking with a midwife working in a busy antenatal clinic.

Maybe she just writes 'HIV test' on the form for antenatal serology and sends her clients off to the lab without discussion. She might feel like she doesn't have time to do any special counselling for the HIV test.

How would you explain the importance of **Consent**, **Counselling** and **Confidentiality** related to HIV testing?

How would you encourage her to improve on her usual practice?

See the **Did You Know** box for five key points that may be useful when you are talking with people who have limited knowledge about HIV.

Did You Know...?

1. People with HIV can live long and healthy lives on the right treatment
2. Taking the right treatment every day means that PLHIV will not transmit HIV to other people
3. There is no cure yet for HIV, but we do have excellent treatments that are available for free
4. HIV is something that can happen to anyone – old and young, married and single, men and women, gay and straight
5. HIV is a medical issue, not a moral issue

3. Confidentiality

Many people in Timor-Leste feel afraid about the idea of having an HIV test.

A key reason for this fear is the possibility of **broken confidentiality** related to HIV status.

People who do not trust that their HIV result will be kept confidential will often avoid testing for that reason.

In a key study, **40%** of interviewed PLHIV reported that a **healthcare worker had told other people about their HIV status without their consent** (HIV Stigma Index Report Timor-Leste, 2017).

“Without my consent, the health workers told my family of my HIV+ status before I could tell them and so I was subjected to stigma and discrimination from my family ... some members of my family do not want to be near me and they separate my things, clothes and plate and cups.”

HIV Stigma Index Report Timor-Leste, 2017

PRACTICAL TIPS FOR HIV TESTING

Maintaining Supply of HIV Determine Tests

Communicate with your Supplies Manager so that they can order an adequate supply of Determine tests. Ensure the severe consequences of test stock-out are well understood.

It is very important that healthcare workers do not feel they need to ration or limit themselves when requesting HIV testing.

Planning for Post-Test Counselling

After you facilitate an HIV test for someone, you have an urgent duty to inform that person of the result.

At all costs, avoid the disaster of being left with a positive test result and no way to notify that person.

Giving a positive result back quickly is important.

A healthcare worker who allows this situation to occur has failed in their responsibility to their client, and lives are likely to be lost because of this failure.

The best strategy to avoid this disaster is to:

- Ask the client to **wait for the results** of their test.

The Determine HIV test only takes 20 minutes to perform.

If it is unavoidable that the client leaves your centre before hearing their result, then:

- Make a **specific appointment** for them to return for the result (ideally the following day)
- Ensure you document their **contact phone number** (at least one, preferably two) and **address**
- Check your client **understands clearly** about the importance of returning for their result



APPROACH TO A NEGATIVE HIV TEST RESULT

What does a negative HIV Determine result mean?

A negative result on the HIV Determine test can indicate:

1. The client does not have HIV (true negative); OR
2. The client does have HIV and the test is a false negative

A **false negative HIV test** result can occur when you perform the test too early after exposure.

This is because it takes some time for the body to produce the HIV antibodies that are measured by the HIV test.

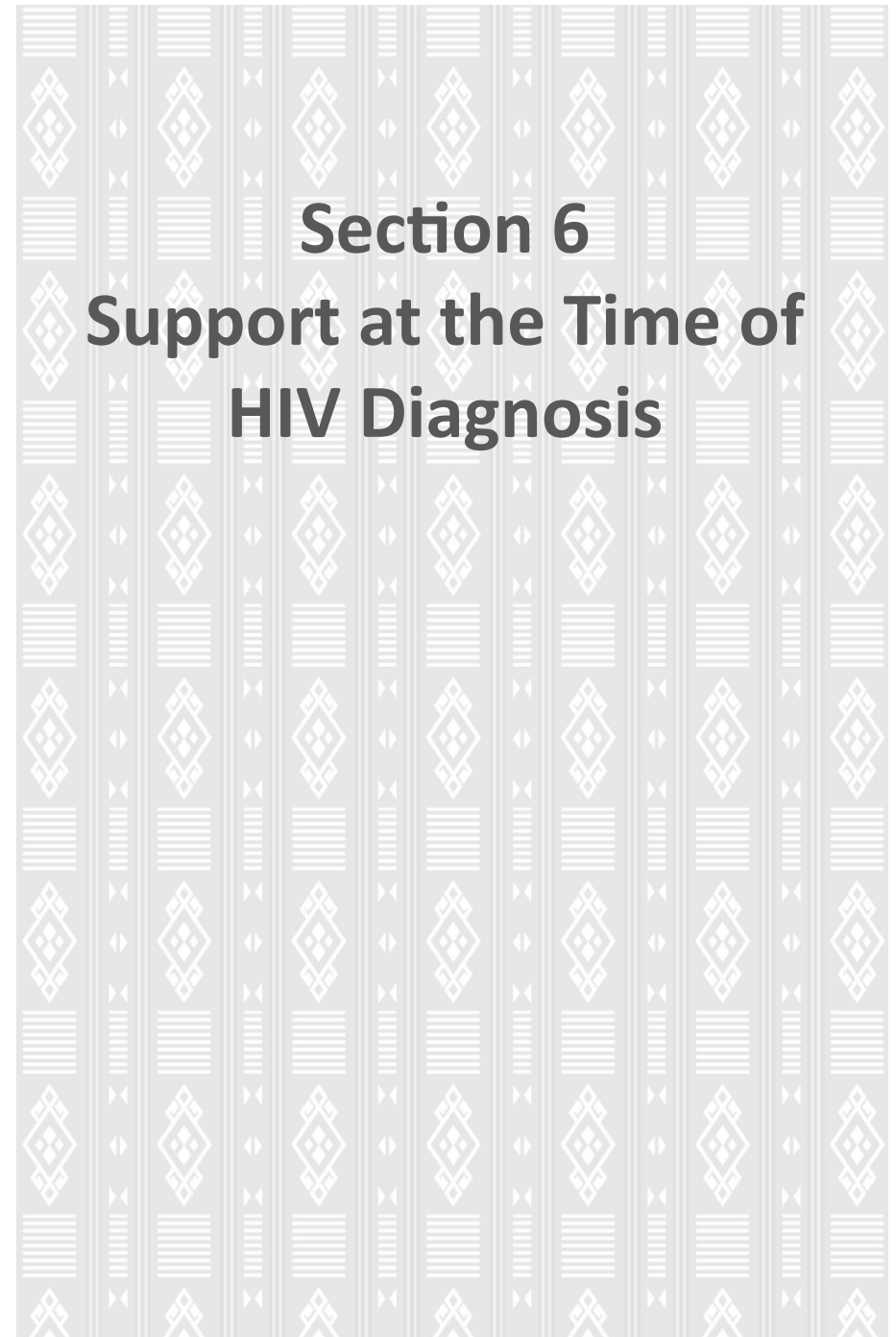
There is a period of time **after infection** with the virus but **before antibodies have been produced** when the HIV test will be falsely negative. This period is known as the '**window period**'.

If someone is at risk of HIV infection (e.g. recent sex without a condom) and their current HIV test is negative, then recommend that they return for another test in 3 months' time.

Explain the importance of using condoms consistently during this 3 month wait.

A negative test result gives you a great opportunity to encourage healthy behaviours (like consistent use of condoms) to help that person remain HIV negative.

Do not perform HIV Determine testing on people who are already known to be HIV positive and are on ART, since false negative results may occur in this situation as well.



Section 6

Support at the Time of HIV Diagnosis

WHAT DOES A POSITIVE HIV DETERMINE RESULT MEAN?

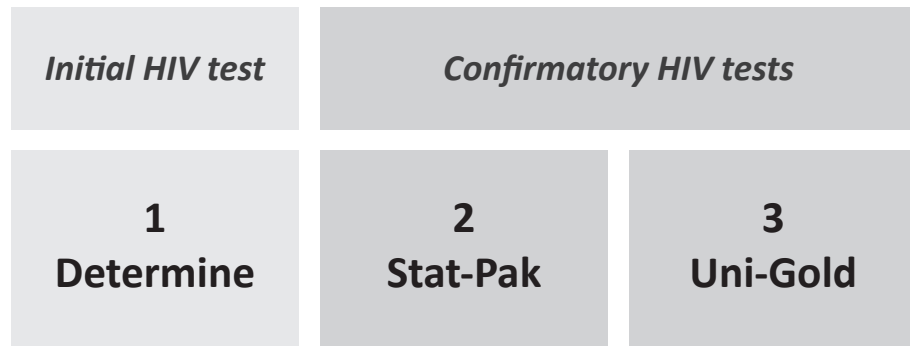
A positive HIV Determine result can indicate:

1. The client does have HIV (true positive); OR
2. The client does not have HIV and the test result is a false positive

It is most likely that a positive result is a true positive but remember that no test is 100% accurate.

It is because of the possibility of **false positive** results with Determine HIV testing that **two more HIV serology tests** are needed before a diagnosis of HIV can be **confirmed**.

Note that this process is for adult HIV testing - a different testing process is used for infants.



POST-TEST COUNSELLING WITH A POSITIVE RESULT

Understand that your client's experience of receiving this result will have a **long-term impact on their life and health**.

Individuals are more likely to disengage from long-term care if they have a traumatic initial experience related to their HIV test (e.g., HIV test done without informed consent, broken confidentiality, or a judgemental attitude from healthcare workers).

It is understandable to feel nervous about telling someone their HIV result is positive, especially if you don't yet have much experience doing this.

If you follow these simple steps, then you will be able to do a great job.

What to Do?

In this situation, people will often forget the details of what you say but **they will always remember how you make them feel.**

Ideally, pre-test counselling and post-test counselling will be done by the same person.

Ask an HIV-experienced colleague for tips before you talk with your client, if you feel you would benefit from this support.

Find a **private place** away from other people.

Family members should not accompany your client at this point – give the result to your client and **your client alone.**

X Do not leave the door open

X Do not tell anyone else, including the clients family

X Do not have a table between you and the client



Make sure you **will not be interrupted.** Turn your phone onto silent and ask colleagues not to disturb you.

Sit down with your client and use **open body language.** Avoid sitting with a desk or table directly between you and your client.

Talk in a calm, friendly way that is not too fast.

Address your client by their first name, and make sure they know your name.



✓ *Do keep the door closed*

✓ *Do tell colleagues to not interrupt you*

✓ *Do sit near your client and use open body language*

✓ *Do use the client's name and share yours with them*

✓ *Do show emotional support and listen*

Show emotional support through touch e.g. a hand on the client's shoulder, if they seem comfortable with this.



The issue of physical touch has been made more challenging by coronavirus and physical distancing rules.

However, you may need to touch the client anyway (e.g. for checking vital signs or performing a physical examination).

Follow your healthcare centre's Infection Prevention and Control rules. When you wash hands or clean surfaces, make sure your **client understands it is a routine coronavirus precaution and nothing to do with their HIV status.**

Other **caring gestures** can also convey emotional support, for example offering a drink of water or a box of tissues.

Use your voice and your body language to convey the messages of “this is going to be okay” and “together we will work this out”, and “this is a **not** disaster!”

Provide written information for your client to read later (i.e. basic information leaflet about HIV – see Annex 2).

After your interaction together, you want your client to feel **warmly accepted, reassured, supported, and empowered.**



“this is going to be okay”

“together we will work this out”



WHAT TO SAY?

Keep what you say simple.

Your client may be feeling shocked and will not be able to absorb a lot of complex information at this time.

Remember that there will be more chances later to provide full information – there is no need to cram everything into the first counselling session.

The **essential elements** your client must understand during **HIV post-test counselling** are:

1. That their HIV test is **positive**
2. That **confirmatory HIV testing** will be necessary
3. That their **confidentiality** will be respected
4. That nothing will happen without their **consent**
5. That they will **not be left to cope alone** – there are caring people who will take care of them
6. That people with HIV who are on treatment can **live long and healthy lives**.

Below are some simple phrases you can use when conveying a positive HIV test result to someone.

“Are you feeling ready for us to talk about your HIV test result?”

“Your HIV test is positive”

“This result indicates that you have HIV, but we will need to do another blood test to confirm that this is a true result”

“I won’t tell anyone else about this result unless you say it is okay”

“When you are ready, we can talk together about what the options are, and I can help you decide about next steps”

“You won’t have to deal with this alone – later I will take you to meet the HIV team who do a great job looking after many people who have HIV”

“People with HIV can live long and healthy lives. The only difference is they need to take a tablet every day to stay healthy”

“The day I came to health centre to collect my result, there was so many people around the counselling room. The counsellor walked with me away from the crowd.

Holding my hand, he told me that there was a bad news and a good news.

The bad news was I had HIV, but the good news was that I shouldn't be worried as treatment was available.

He added that I would be fine if medicines were taken regularly as per the physician's prescription. I cried and was surprised to have the support from the counsellor and my husband. I decided to start treatment and still on ART for XX years.”

Report on Loss to Follow Up in Timor-Leste, 2021

After hearing their positive HIV result, different people can react in different ways. Your client may cry, go quiet, deny the result, or get angry.

These are all normal reactions – give your client time to express how they feel.

Listen carefully and respond to what your client says to you.

What to Avoid?

Do not say anything that is not the truth. Saying anything that is not the truth may destroy someone's trust – not just in you, but in the entire healthcare system.

Avoid vague statements that are half-truth (e.g. “we need to take another blood test because there was a problem with the first one”).

If you are not sure about something, **do not pretend that you are.** Say “I'm not sure about that, but I can find out”.

Try not to let your client feel rushed. Give your client enough time to think and to reach decisions.

Emotionally challenging discussions (e.g., partner disclosure) do not have to take place at the moment of HIV diagnosis. They cannot be forgotten, but they can wait until you have established a trusting relationship with the client.

Avoid going into details on how, why, or when the client acquired HIV at this stage, unless the client specifically asks you.

Avoid morally charged messages e.g., about sexual behaviours.

Understand that lecturing a client is likely to make them feel stigmatised and unlikely to lead to behaviour change.

Don't let your own religious beliefs interfere with providing counselling for your clients.

Overall, avoid any comment or behaviour that could make your client feel rejected, judged, ashamed, or alone.

 **ACTIVITY:**

Imagine that you have just been told you are HIV positive.

Try to picture it realistically – in your mind, see yourself sitting in the consulting room with a healthcare worker talking to you.

What thoughts and emotions could you experience?

What would be your priorities in this situation?

Trust in HIV Test Results

A common reason for PLHIV to disengage from care is **lack of belief in a positive HIV test result**.

There is a higher risk of disbelief if someone was not properly prepared to receive the result (i.e., **lack of pre-test counselling**).

Sometimes, if a healthcare worker is not confident in providing a positive result, there may be a temptation to tell a client their HIV test result is negative when the result was actually positive. **This is a disastrous situation.**

The consequences of this situation can be catastrophic since it becomes extremely difficult for the client to accept the true result later.

The client's trust in the healthcare system tends to remain low after this kind of experience.

When people feel well (no symptoms) it can be difficult for them to believe a test result telling them that there is an issue with their health.

Careful counselling will be needed about the way HIV damages the body and how symptoms take time to appear.

Ways to encourage belief in the HIV test result include:

- Pre-test information including the **4 essential elements**
- Show the piece of paper with the test result from the laboratory to the client (not just saying it verbally)
- Show the HIV Determine test strip itself to the client. You can point out the two lines indicating that their test is positive, alongside a negative test with only one line. It can be helpful for people to see the difference with their own eyes.
- Allow clients to repeat their HIV test if they wish – this may help them to eventually believe the result.

“I don’t feel that I am having HIV because they never show me the test result and just communicate verbally to me that you are HIV positive, and your viral load is high which makes me not to trust what was told to me.”

Report on Loss to Follow Up in Timor-Leste, 2021

Avoid arguing with the client about the test result or trying to insist that they must believe you.

Understand that for many people it will be a struggle to accept their diagnosis. This can be especially true for PLHIV experiencing **self-stigma** (see Section 10).

WHAT NEXT?

See the next section for how to successfully link your client to ongoing HIV care.



Section 7

Successful Linkage to Ongoing HIV Care

WHY AND HOW TO LINK PLHIV TO SUPPORT

The moment of HIV diagnosis is one of the highest danger points on the journey taken by PLHIV. Fear and confusion are high at this point, while HIV-related knowledge is generally low.

Many PLHIV are lost out of the healthcare system at the point of diagnosis if they not strongly supported, sometimes forever.

Linkage refers to the key step for PLHIV, from knowing they are HIV positive to accessing ongoing HIV care. It is generally defined as the client attending their first ART Centre appointment within 1 month of their positive HIV test result.

Unsuccessful linkage is associated with high HIV-related mortality and expansion of the epidemic.

With successful linkage to care, PLHIV can access the emotional support and accurate information which they urgently need at that time.

PLHIV can then be supported to **start treatment** without delay, which protects health and reduces onward HIV transmission.

Factors associated with improved linkage to care are outlined below and have been incorporated into the **Linkage SOP** (see page 91).

While the act of sending a referral letter is a one-way process (who knows if the client attended or not?) successful linkage involves **collaboration**.

A successful linkage process requires collaboration between:

- The Client
- The Referring Person (e.g., CHC HIV Responsible Person/Counsellor)
- The ART Centre Team
- The Peer Case Manager



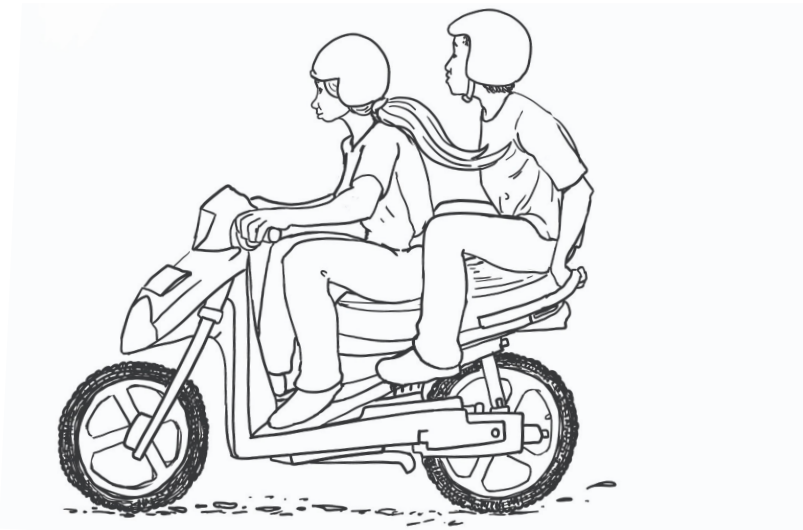
Sending the client to the ART Centre with a letter is an example of **passive referral** which has a low success rate (i.e., linkage to care is unlikely to occur).

Active referral processes have much higher success rates.

*The key element of active referral is to **accompany the client from the testing site to the ART Centre.***

The Linkage SOP indicates accompanying the client as the Preferred Plan, but also includes an Alternate Plan if nobody has capacity to accompany the client on that day.

Early linkage is crucial. Aim for the client to have a **same-day review** at the ART Centre if it can possibly be arranged, otherwise within the next couple of days (e.g., if positive test is late on a Friday afternoon).



If linkage does not occur within a week of the positive test, it is unlikely to occur at all.

Utilising **peer counsellors** in a **case management** role has been shown to significantly increase rates of successful linkage to care for PLHIV (See Section 4 on Peer Case Management).

The Linkage SOP indicates that Peer Counsellors be involved with newly diagnosed PLHIV unless the client opts out.

In keeping with a rights-based approach, the Linkage SOP supports PLHIV **autonomy**. E.g., the client has the right to choose their preferred ART Centre.

A **friendly, welcoming environment** at the ART Centre is crucial, not only for linkage of PLHIV, but for ongoing retention in care.

Documentation is essential for streamlining the linkage process, but it is understood that excessive bureaucracy is unhelpful.

The Linkage SOP contains 3 documentation items:

- The **Standardised HIV Referral Form**
- The **Positive HIV Results Register**; and
- The **Expected Clients Register**

The Referring Person has responsibility for the first two documentation items, and the ART Centre Team has responsibility for the third item.

Accurate documentation is vital to enable monitoring of how well the HIV linkage systems are working.

Good documentation also helps to clarify who has responsibility for which tasks and to ensure accountability.

In the Linkage SOP the responsibilities of the Referring Person (from the HIV testing site) are shaded in blue, while the responsibilities of the ART Centre Team are shaded in green.

If the client does not attend their ART Centre appointment, then this problem becomes everyone's responsibility, and this section is shaded in yellow.

The Linkage SOP below outlines the responsibilities of the Referring Person (from the HIV testing site), the responsibilities of the ART Centre team and where the Peer Case Manager can support.

If the client does not attend their ART Centre appointment, then this becomes everyone's responsibility.

STANDARD OPERATING PROCEDURES (SOP) FOR SUCCESSFUL REFERRAL AND LINKAGE

Actions at the Site of HIV Testing
(e.g., CHC or private clinic)



Referring Person

STEP 1 - Laboratory staff (or whoever performs the HIV test) **notify the HIV Responsible Person / Counsellor** (the Referring Person) of the positive HIV test result

STEP 2 - Referring Person **notifies the client of positive HIV test result** (see *Post Test Counselling on page 73*)

STEP 3 - Referring Person **asks the client to choose their preferred ART Centre** from among the available options. Input from a peer counsellor may be especially helpful for this step.

STEP 4 - Referring Person **completes Standardised HIV Referral Form** and gives to the client

PREFERRED PLAN FOR LINKAGE

STEP 5 - Referring Person **contacts an ART Centre Team Member** and **notifies them to expect the new client** on that same day

ALTERNATE PLAN FOR LINKAGE

(If accompanying client to the ART Centre is not possible)

STEP 5 - Referring Person **contacts an ART Centre Team Member**, notifies them about the new client, then **makes an appointment date/time** – it must be **within 1 week (sooner is better)**

Step 6 - Referring Person documents the following in the **Positive HIV Results Register**:

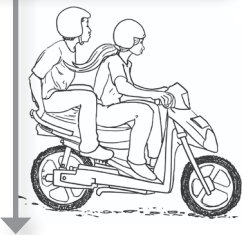
- Today's date, and the name, date of birth, address, and phone number of the client
- If the client does or **does not give permission for confidential follow up in the future via home visit**, if necessary
- Name of the ART Centre and details of Team Member contacted

Step 7 - Client is accompanied to the ART Centre in one of these three ways:

1. **Referring Person** accompanies the client; OR
2. Referring Person arranges for **ART Centre Team Member** to come and collect the client; OR
3. Referring Person arranges for a **Peer Counsellor** to come and collect the client

****This is the most important step in the linkage process***

If none of these 3 options for accompanying the client to the ART centre is possible then follow the Alternate Plan for Linkage



Step 6 - Referring Person documents the following in the **Positive HIV Results Register**:

- Today's date, and the name, date of birth, address, and phone number of the client
- If the client does or **does not give permission for confidential follow up in the future via home visit**, if necessary
- Name of the ART Centre and details of Team Member contacted

Step 7 - Referring Person notifies client of the **appointment date/time** and **writes this down for them**

Step 8 - Referring Person gives the client the **name of the ART Centre Team Member** they will meet (if possible, put the client on the phone to chat with them for a few minutes)

Step 9 - Referring Person gives **clear directions** on where to find the ART Centre

Step 10 - Referring Person checks that the **client understands** the importance of attending the appointment and that the ART Centre Team will be expecting them

Step 11 - Referring Person provides **Information Pamphlet** (What to Expect At Your First ART Centre Visit) to the client, and points out the phone number for client's chosen ART Centre

Step 12 - Referring Person connects the client with a **Peer Counsellor**.

Depending on the client's preference this can be done by:

1. Giving the client's phone number to the Peer Counsellor; OR
2. Giving the Peer Counsellor's phone number to the client;

Referring Person or client notifies **Peer Counsellor** of client's **appointment date** so they can help remind/follow up

Step 13 - Referring Person encourages client to choose a **Treatment Supporter** (trusted friend or family member) to bring with them to their ART Centre appointment (this is not mandatory)

↓
Actions at the ART Centre
 (e.g., HNGV, Maloa, BPC, or Referral Hospital)



ART Centre Team

↓

Step 8 - When the Referring Person calls, the ART Centre Team Member **immediately documents** the **client** details and the **Referring Person** details in the **Expected Clients Register**

↓

Step 9 - Referring Person **introduces the client to the ART Centre Team Member** and client is welcomed

↓

Step 10 - ART Centre Team Member **takes the Standardised HIV Referral Form** from the client

↓

Step 11 - ART Centre Team Member **registers the client** in the patient register

↓

Step 14 - When the Referring Person calls, the ART Centre Team Member **immediately documents** the **client** details and the **Referring Person** details in the **Expected Clients Register** and the appointment calendar (see page 43)

↓

Step 15 - ART Centre Team Member **sends an SMS reminder** to the client the day before their appointment

↓

Step 16 - **Client attends** for their appointment and is welcomed by the team

↓

Step 17 - ART Centre Team Member **takes the Standardised HIV Referral Form** from the client

↓

Step 12 - During the first visit, the ART Centre Team Member **connects the client with a Peer Counsellor** (if not already done by the Referring Person) **unless the client opts out.**

Depending on the client's preference this can be done by:

1. Giving the client's phone number to the Peer Counsellor; OR
2. Giving the Peer Counsellor's phone number to the client; OR
3. Arranging for the Peer Counsellor to come to the ART Centre to meet the client

↓

Step 13 - ART Centre Team Member **encourages client to choose a Treatment Supporter** (trusted friend or family member) to bring with them to the second appointment (this is not mandatory)

↓

Step 14 - ART Centre Team Member notifies the Referring Person that the client has been successfully linked to care

↓

Step 18 - ART Centre Team Member **registers the client** in the patient register

↓

Step 19 - ART Centre Team Member **notifies the Referring Person** that **the client has been successfully linked to care**



ART Centre Team

↓
Follow-up from the Site of HIV Testing



Referring Person

↓

Step 15 - Referring Person documents the successful linkage against the client's entry in the Positive HIV Results Register

Step 20 - Referring Person documents the successful linkage against the client's entry in the Positive HIV Results Register

↓

Step 21 - HOWEVER: If they have not been contacted within 1 week, then the Referring Person will contact the ART Centre to follow up what happened

HIV Peer Counselor

ART Centre Team



Referring Person

If the client does not attend their appointment at the ART Centre:

STEP 1 - ART Centre Team Member tries to **contact the client by phone** to encourage them to attend

↓

STEP 2 - If client does not answer or does not attend within **1 week** of the missed appointment, then **ART Centre Team Member will contact: the Referring Person AND Peer Counsellor**

↓

STEP 3 - ART Centre Team, Referring Person, and Peer Counsellor **discuss together** how best to reach client, with options including:

- Home visit providing that client gave permission for this during initial meeting with Referring Person
- Further attempts to reach by phone calls/messaging

↓

STEP 4 - HIV Counsellors to **discuss client at Quarterly Meeting to check if client may have registered at another ART Centre**

↓

STEP 5 - If client has not attended the ART Centre within **3 months** of positive HIV test, then Referring Person and ART Centre will document **failed linkage**



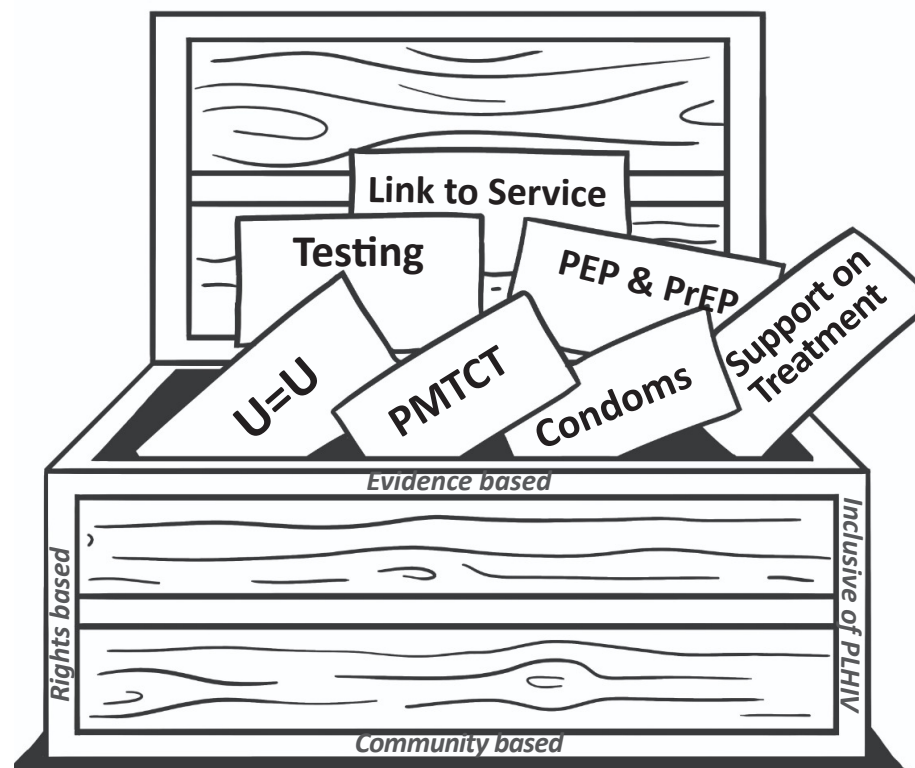
Section 8

Preventing HIV Transmission

We have multiple tools available in our **HIV prevention toolbox**.

This means that people can **make choices** about the HIV prevention tool that works best for themselves and their situation.

Having a range of **evidence-based tools** in our prevention toolbox provides benefits for communities at higher risk of HIV, people living with HIV and the whole community.



HIV Prevention Toolbox

WHAT ARE THE PRINCIPLES OF THE HIV PREVENTION TOOLBOX?

The strategies of an effective HIV Prevention Toolbox are based on the following key principles:

1. Rights Based

Human rights are rights that everyone has, due to existing as a human.

Examples of how HIV approaches relate to human rights include:

- HIV negative & positive people treated equally
Right to Non-Discrimination
- Results are kept confidential
Right to Privacy
- PLHIV can have children and marry if they wish
Right to Marriage and Family
- All people can make prevention & treatment choices
Right to Benefit from Science

2. Evidence Based

Evidence-based strategies have had their effectiveness proven through high quality research. Annex 5 outlines key evidence-based HIV prevention strategies for individuals and for healthcare workers.

3. Community Based

Tackling the HIV epidemic requires a joint response by government in partnership with the community.

This includes involving communities in decisions about the HIV prevention approaches used, the type of HIV services that are available, and the design of those services.

4. Inclusive of PLHIV

PLHIV should have the central voice in decision-making about any HIV-related strategy. This is the principle of “Nothing About Us Without Us”.

THE HIV PREVENTION TOOLBOX EXPLAINED

As counsellors and healthcare workers, it is our job to provide people with options, and **help them make the best choice for their situation**. Clients know their own lives and situations best.

The following section provides an overview of evidence-based HIV prevention strategies that are relevant for Timor-Leste.

Testing

HIV testing is a crucial element of a comprehensive HIV prevention strategy.

Getting a test to **know their HIV status** provides people with the power to make choices, whether the result is positive or negative.

The goal is to diagnose all individuals with HIV as early as possible after infection before symptoms develop and before the virus can be passed to others.

Linkage to HIV Services

After a positive HIV test, it is essential that successful linkage to ongoing care at the ART Centre happens as soon as possible.



Support on Treatment

The primary benefit of HIV treatment is that it keeps PLHIV in good health.

An added benefit of effective treatment is that it minimises the amount of HIV in the body, which reduces the chance of transmitting the virus to others.

This concept is referred to as **Treatment as Prevention**.

If someone's viral load remains undetectable on ART they cannot transmit HIV to others.

This is known as **U = U**, or

Undetectable = Untransmissible.

PEP and PrEP

PEP (Post-Exposure Prophylaxis) can be offered to HIV negative people who have had a specific high-risk HIV exposure within the last 72 hours (including sexual assault).

PrEP (Pre-Exposure Prophylaxis) is taken every day by HIV negative people who have a higher risk of being exposed to HIV, like the pill to prevent pregnancy.

It is an extra tool for those who are HIV negative to protect themselves, including sex workers who are struggling to negotiate condom use.

Discuss with an HIV team trained in PEP and PrEP if you think your client might be interested in these prevention strategies.

Prevention of Mother to Child Transmission of HIV

See Section 9: HIV and Pregnancy for information on Prevention of Mother to Child Transmission of HIV.

Condoms with Counselling

There is strong research evidence that consistent and correct use of condoms is a highly effective strategy for preventing HIV transmission.

Offer condoms to clients at each visit to the healthcare facility.

Making condoms available somewhere that people can collect them confidentially and without hassle (e.g., no need to give their name) is a good idea.

Counselling at the same time as offering condoms can allow you to:

1. Explain the correct way to use a condom (emphasising the importance of lubricant)
2. Empower clients with negotiation skills for condom use
3. Dispel negative beliefs about condoms

Check that everyone on your team understands that condoms are a health choice, not a moral choice.

Phrases you can use to **promote condom use** to your clients include:

“Having sex without a condom is risky - a sexually transmitted infection can occur (some STI’s are curable, and some are not). Pregnancy is another possible consequence”

“Using condoms every time you have sex greatly reduces your risk of acquiring infections such as HIV”

“Safe sex is good sex - calm your mind and use a condom”

“There are many reasons to use a condom. If you are single, in a serious relationship or are married, it doesn’t matter - anyone can use a condom!”

“Using condoms is a way of respecting yourself and your partner”

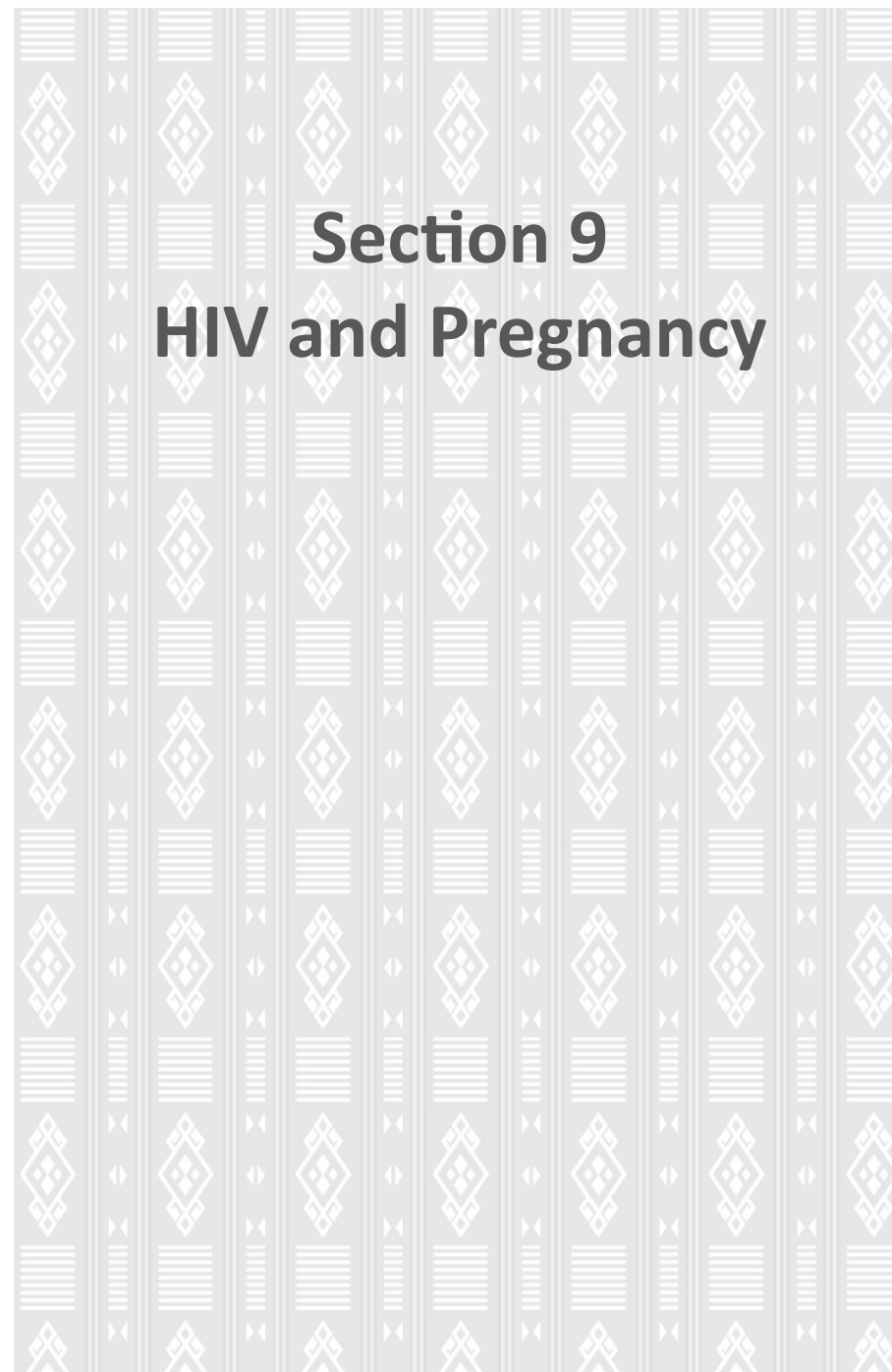
“There is no problem using condoms and other types of contraception at the same time”

Using Condoms Correctly

Basic Steps	Important Details
<p>1 Before using a condom, ensure there is consent between partners</p>	<p>Open and effective communication between those involved</p> <p>Ensure that you and your partner agree together to have sex, to use a condom, and decide together</p>
<p>2 Use a new condom for each sex act and check the date</p>	<p>Wash your hands before using the condom</p> <p>Check the packet. Don’t use if damaged or open.</p> <p>Don’t use a condom that’s past it’s expiry date</p> <p>Be careful that you don’t break it by opening it with your teeth or nails</p>
<p>3 Put the condom on an erect penis before sex. Then start to roll it down.</p>	<p>Put the condom on before contact with the genital or anal area</p> <p>Putting a little bit of lube on the head of the penis before putting on the condom can increase sensation</p>

<p>4 Roll the condom down to the base of the penis</p>	<p>Hold the tip of the condom to remove air and gently roll it down</p> <p>If the condom is difficult to roll down, it might be on the wrong way. Throw it away and start again.</p> <p>Using more water-based lubricant can increase pleasure and reduce risk of breakage</p>
<p>5 Immediately after ejaculation, hold the base of the condom to remove while the penis is still erect</p>	<p>When sex is finished, remove the penis carefully while still erect, holding the condom carefully at the base to prevent semen spilling</p> <p>Use a new condom if continuing sex or starting another sexual act</p>
<p>6 Dispose of the used condom in a safe place</p>	<p>Wrap the used condom in a tissue or it's wrapper and throw it in the bin or dig a hole to bury it. Make sure children won't be able to find it. Don't throw it in the toilet. Wash your hands when finished</p>

Adapted, with thanks, from Marie Stopes Timor-Leste



Section 9 HIV and Pregnancy

This section is written as a guide for how to support women living with HIV, particularly regarding pregnancy and contraception. It is aimed at HIV peer case managers and would also be of special interest to midwives.

WHAT IS PMTCT HIV?

PMTCT HIV means Prevention of Mother to Child Transmission of HIV. You may also see this described as EMTCT, which refers to Elimination rather than Prevention.

Mother to child transmission of HIV is a serious problem in Timor-Leste.

Many steps can be taken to reduce the risk of children acquiring and dying from HIV. As a peer case manager, you can work closely with your client to help them follow the recommendations from their ART Centre team.

Did You Know...?

If all the recommendations can be followed, then the risk of mother to child transmission of HIV can be reduced to less than 5%.

If none of the recommendations are followed, then the risk of mother to child transmission of HIV is approximately 45%.

Below, you will see the key points at which you can step in to support women living with HIV and to help meet the goal of eliminating mother-to-child transmission of HIV in Timor-Leste.

Supporting PLHIV who are Planning a Pregnancy

It is a great idea to plan a pregnancy, rather than to let a pregnancy happen by accident.

For men and women living with HIV, it is recommended to always use condoms for sex while waiting for the viral load to become **undetectable**. This generally takes around six months (sometimes more, sometimes less, depending on the situation).

As the peer case manager, you can support your clients to maintain optimum treatment adherence to ART so that viral suppression can be achieved quickly and sustained.

PLHIV wanting to get pregnant can start having sex without using condoms once they have a stable undetectable viral load (see Section 1 for more information on Undetectable = Untransmissible).

If your client is a woman living with HIV who wants to have a baby, support her to become as healthy as possible before becoming pregnant. Work with her and with her ART team, aiming for:

- Any opportunistic infections or other illnesses to be identified and treated
- Eating a good, well-balanced diet
- A healthy weight
- Good mental health
- Good adherence with all medication from the ART Centre as well as any recommended pre-pregnancy supplements (e.g., folate and iron).

Supporting PLHIV who are Currently Pregnant

Ideally, women living with HIV will already be stable on ART, with an undetectable viral load, before becoming pregnant.

However, it is common for women to only find out about their HIV during pregnancy, as part of their antenatal screening.

A pregnant woman who has just been diagnosed with HIV needs all the same supports as any other client with a new HIV diagnosis (See Section 3: Support at the Time of HIV Diagnosis and Successful Linkage of PLHIV to Ongoing Care).

If you become aware of a woman who has been newly diagnosed with HIV while pregnant, do everything in your power to ensure she is reviewed by the ART team **urgently** (same day as the test result).

You can work with the ART Centre team to help your client become mentally ready to start ART without loss of time.



Sometimes pregnant women will feel anxious about taking medication when they are pregnant. Ensure your client understands that the **number one best thing she can do** to protect her baby is to start effective ART as soon as possible, and to continue taking it with good adherence.

The best way to protect the baby from acquiring HIV is to help the mother get her viral load undetectable, and to keep it undetectable all through the pregnancy and breastfeeding period.

Fortunately, the current first-line ART regimen in Timor-Leste has the capacity to drop viral loads quickly.

Support your client in practical ways through her pregnancy, as needed. For example, she may need help with transport to make sure she can attend all her scheduled ART Centre and Antenatal Care visits.

She may benefit from you joining her for her ANC appointments, especially if she is afraid of encountering stigma and discrimination in the antenatal clinic. This is unfortunately a common experience for women living with HIV in Timor-Leste.



If it happens to your client, you can ask if she would like you to advocate on her behalf (e.g., bringing the problem to the attention of the head of the healthcare centre, or to the National AIDS Program).

Support During Labour and Delivery

If your client asks what to expect regarding labour and delivery you can reassure her that everything should be the same for her as it is for HIV negative women. The midwives should be wearing the usual gloves/gown as always (nothing extra required).

The only difference is that for HIV positive women in labour it is preferable to avoid procedures that may cause bleeding (e.g., episiotomy, forceps delivery etc), if possible.

Support for PLHIV Caring for an Infant / Other Children

If you can be on-site with your client directly after delivery, then see if you can offer support in these areas:

Remember to say “parabens!”. Unfortunately, this important step is sometimes omitted for HIV positive women.

Support the mother to start **breastfeeding** as soon as possible. Encourage her to breastfeed exclusively (**not mixed with formula**) for a minimum of 6 months. Explain that breastmilk protects the baby in many important ways.



The risk of HIV transmission to the baby through the breastmilk is minimised by keeping the mother’s viral load suppressed with daily ART.

Liaise with the ANC team and the ART Centre team to facilitate starting **antiviral prophylaxis** for the baby **within 4 hours of delivery and no later**. If the anti-viral prophylaxis is not available on the labour ward, then you may be able to help by fetching it from the ART Centre (even if it is after-hours – this cannot wait until the following day).

The ART Centre team and the midwives can help the parents learn how to give the medicine to the baby before leaving the hospital.



The mother and baby will need to attend an important ART Centre appointment when the baby reaches **age 1 month**.

Make sure the mother does not forget this appointment, and make sure she has transport available.

At this point, the baby will have its **first HIV test** (a different test is used compared with the HIV test for adults). This is not the last HIV test, which cannot be done until after breastfeeding is completed.

During the 1-month appointment the ART Centre team will check on how the parents are going giving the **antiviral prophylaxis** to the baby.

Age 1 month is also the time the baby will need to start **cotrim prophylaxis** which will continue until the final HIV test is proved to be negative.

It is worthwhile offering **intensified counselling and support** to the mother during the post-delivery period. Mothers are at risk of adherence problems after delivery (e.g., lack of sleep due to the newborn means they might not be thinking clearly).

Remind the mother that the virus can pass to the baby through the breastmilk if she misses doses. Missing doses gives the virus in the body a chance to multiply. Find ways to help her miss zero doses of her own or the baby's medication.

When meeting any woman living with HIV it is vital to check to **see if she already has other children**. If she does, liaise with the ART Centre team to arrange HIV tests for them urgently.

In many cases it will be too late (i.e., the child already died before the mother's HIV was identified).

It is **extremely important** to ask, because sometimes living older children with HIV can be identified and successfully treated.

Avoiding Unintended Pregnancy

Avoiding unintended pregnancies is an important part of PMTCT HIV.

There are fewer children born with HIV when women living with HIV are supported to help them plan when they do, or do not, have children.

The full range of effective contraceptive methods should be accessible to all women and girls, so that they can plan or avoid pregnancy as they desire. This is true for all women and girls, regardless of HIV status.

Ideally, all contraceptive methods and reproductive health counselling should be available for women living with HIV to access at their ART Centre. If not, and your client agrees, then facilitate referral to a site where they are available (e.g., health facility or Marie Stopes Timor-Leste clinic).

There is the potential for some (not all) ART drugs to interact with some types of hormonal contraception.

However, this is generally less of an issue than ensuring women and girls can **choose the contraceptive method that suits them best**, following proper counselling.

Women and girls on ART are eligible to use all methods of hormonal contraception.

Ability to choose from a range of contraceptive methods is associated with more effective contraceptive use.

Hormonal contraceptive methods (e.g, pill, implant, injectables, and LNG-IUS) can be effectively combined with condom use, increasing protection against unintended pregnancy, HIV transmission, and other sexually transmitted infections.

In Timor-Leste, women with living with HIV are sometimes forced into using contraceptive methods which they do not want.

This represents an abuse of human rights.

If this happens then it should be brought to the attention of the head of the healthcare centre, or to the National AIDS Program.

“I had a problem with stigma and discrimination when I was pregnant and had a caesarean but doctors from [hospital] would not receive me to have a caesarean operation because of my HIV status.”

Report on Loss to Follow Up in Timor-Leste, 2021



Section 10

Counselling to Support PLHIV

WHAT IS COUNSELLING?

Counselling means using talking therapy with the aim of helping people to **reach their goals** and to **make positive changes** in their lives, within the context of a trusting professional relationship.

Counselling involves setting time aside for the client and the counsellor to talk about challenges the client is facing.

The counsellor uses specific techniques to help their client to see things more clearly and to **develop their own strategies** to cope effectively with challenges.

‘Counsellor’ in this context means an HIV peer counsellor or a healthcare worker who has had some training in counselling skills.

Counselling is not:

- Giving advice
- Solving the client’s problems for them
- Being judgemental or moralising
- Pressuring clients to make a ‘good’ decision
- Expecting the client to have the same values as the counsellor

Characteristics of Effective Counsellors

These are some of the **characteristics of an effective HIV counsellor**:

- **Accepting** – counsellor accepts the client without criticism or prejudice and avoids any preaching about correct or ‘moral’ behaviour.
- **Warm** – shows warmth or positive regard towards clients regardless of who they are or what they do.
- **Empathetic** – able to understand what the client is feeling, or to “walk in the client’s shoes”.
- **Adaptable** – able to change style and focus to adapt to different clients and different situations.
- **Observant** – able to read body language and ‘hear’ what is not said out loud to gain insight into the client.
- **Self-Aware** – aware of their limitations and with the confidence to seek help in situations beyond their scope

An **effective HIV counselling interaction** will be:

- **Private and confidential**
- Tailored towards that individual client (**client-centred**)
- On an **equal level** (counsellor does not have higher power/status compared with client)
- **Interactive** (not just counsellor telling, with client passively listening)

What are the Benefits of Effective Counselling?

There are many benefits arising from effective counselling for PLHIV.

Some of the **key benefits** include:

- Enabling PLHIV to have an **optimistic view** towards their life
- Helping PLHIV to **feel supported and not alone**
- Empowering PLHIV to **change behaviour** in positive ways
- Enhancing PLHIV's **decision-making skills**
- Restoring the **social wellbeing** of PLHIV
- Developing PLHIV's **confidence to speak openly** about what bothers them

Taken all together, these benefits of counselling can help PLHIV to **remain engaged in care** and to **promote the complete wellbeing** of PLHIV

*“What helped me the most was counselling. What I can advise to others is that every person need to go for counselling because it helps a lot; it **soothes the soul** and makes you able **to accept the status you have.**”*

A PLHIV who is engaged in care on ART , report on Loss to Follow Up in Timor-Leste, 2021

To perform effectively, **key tools needed by HIV counsellors include:**

1. **Good communication skills**, including:
 - Knowledge of **body language** and **non-verbal communication**
 - How to use **active listening**
2. An understanding of the **counselling process**
3. Accurate basic **knowledge about HIV**

COUNSELLING STEPS

The **basic approach to the HIV counselling process** is outlined below.

This is general outline including some steps and techniques which are common to many counselling techniques.

You can adapt this basic structure to carry out counselling in a specific style (e.g., Strengths Based Counselling), or towards a specific goal (e.g., improving adherence).

This is not a rigid format and depending on the situation the steps may merge together or be taken in a different order.

As you follow the **counselling steps** with your clients, you can begin developing the **counselling skills** described here.

STEP 1 – Begin to Build a Trusting Relationship

Remember that the quality of the client-provider relationship is a key factor determining the outcome for PLHIV.

Relationship-building is a process which develops over time, and many factors contribute towards quality of this relationship.

Key principles for building a trusting relationship with PLHIV include:

- **Always maintain client confidentiality**
- Cultivate feelings of **hope**
- Show **warmth and welcome**, and avoid acting in an angry, judgemental, or dominating way towards clients

STEP 2 - Listen to the Client's Story

Using **open questions** is a good way to start conversations. Open questions cannot be answered with Yes or No – instead, they encourage your client to talk. For example:

“Could you tell me about what is on your mind?”

“How did you feel when...”

Listen carefully to your client, without interrupting.

You can encourage your client to keep talking by:

- Using phrases like “mm hmm”, and “can you tell me a little more about that?”, with a calm tone of voice
- Keeping a **friendly facial expression** (your client is likely to stop talking if you frown or look shocked)
- **Resisting the impulse to interrupt**
- **Resisting the impulse to ‘fill the silence’** – wait a moment longer before speaking

Then **summarise back** something the client said to you, using your own words.

Check – *“did I understand that correctly?”*

Show your client that you are listening carefully, and you want to understand their emotions. E.g., you could say:

“It seems like what your mum said made you feel angry, is that right?”

Reassure your client that the feelings they are expressing are natural and understandable. E.g., you could say:

“It makes sense that you would feel that way”.

Avoid the opposite situation, where the client's feels their words have been judged or ignored.

STEP 3 - Ask Questions Carefully

It is important not to let your client feel as though they are being ‘questioned’, like a police officer might question a suspect.

The way you phrase your questions is important.

Questions which start with “Why?” can sound critical and make people feel defensive e.g. *“Why aren't you taking your medicines?”*

Instead, you might try:

“Can you tell me a bit about how it's going with taking your medicines?”

Give your client time to answer one question before you ask the next question (i.e., avoid asking two questions at once).

Remember that your **tone of voice** often matters more than the content of what you say.

“Tell me what happened?” in a gentle, questioning voice will get a very different response compared with “Tell me what happened!” in a loud, demanding voice.

STEP 4 - Ask Before Providing Information

Asking before providing the client with information is a good way to show respect to your clients. It helps them realise they have some control in this conversation and are not 'being lectured'.

This step is especially useful as a way to prepare patients before giving them difficult information e.g., a positive HIV test result.

For example,

"I have your test results here – would you like for us to go through them now?"

"I could tell you a bit about... if you like?"

"Would you like to hear about...?"

Be brief when providing information, especially if your client is feeling stressed or upset. Limit the information to just the most essential points.

Use simple language without complicated medical words (doctors especially need to be careful about this).

Check understanding. Avoid asking "Did you understand?" since this can feel like pressure on the client. (The client might think "If I didn't understand, will they think I am stupid...?").

Alternative questions could be:

"How did I go with explaining that?"

"Would you like me to clarify that a little more?"

Encourage your clients to **ask questions**. Often, your clients will only ask questions after they have become very comfortable with you, especially if the question is about something sensitive.

STEP 5 - Identify Key Challenges and Strengths Together

Now that you have listened to the client's story and clarified details, you and your client will have an idea about the key problems the client is facing.

There may be many, in which case you and your client may wish to choose just one or two priority areas to focus on at the beginning.

A Strengths-Based approach to counselling can work well in this step, alongside consideration of problems.

STEP 6 - Identify Strategies for Moving Forward

Once you and the client have identified a particular challenge or a goal, you could ask:

"What are your choices?"

"How will you make that happen?"

"What is one thing you could do to take a step in the right direction with this?"

The client might think or say "but you are the expert! Don't you know what I should do?!"

Encourage the mindset of **there being two experts in the room**. You are an expert in your role as counsellor or healthcare worker, but the client is the expert in their own life, body, and mind.

A client is more likely to successfully follow a strategy they have identified for themselves, compared with someone else's plan.

STEP 7 – Follow Up

Make an appointment for when you and your client will next meet.

At your next review, ask your client about their progress in a positive way.

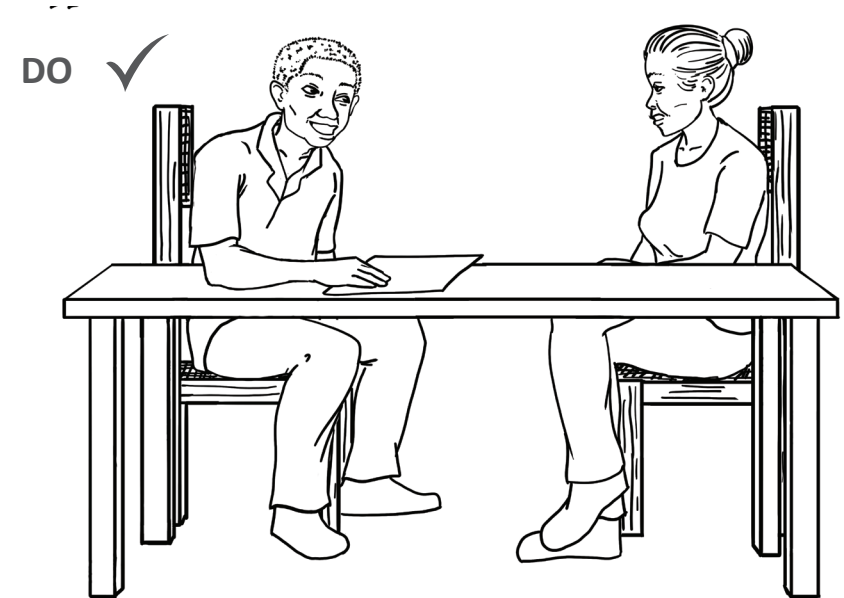
They are unlikely to have fully reached their goal at the first attempt. Help them to realise that this is normal and congratulate them on any small steps they have achieved.

For example, for your client who wants to quit smoking: they may not have quit yet, but they may have started to think about it more.

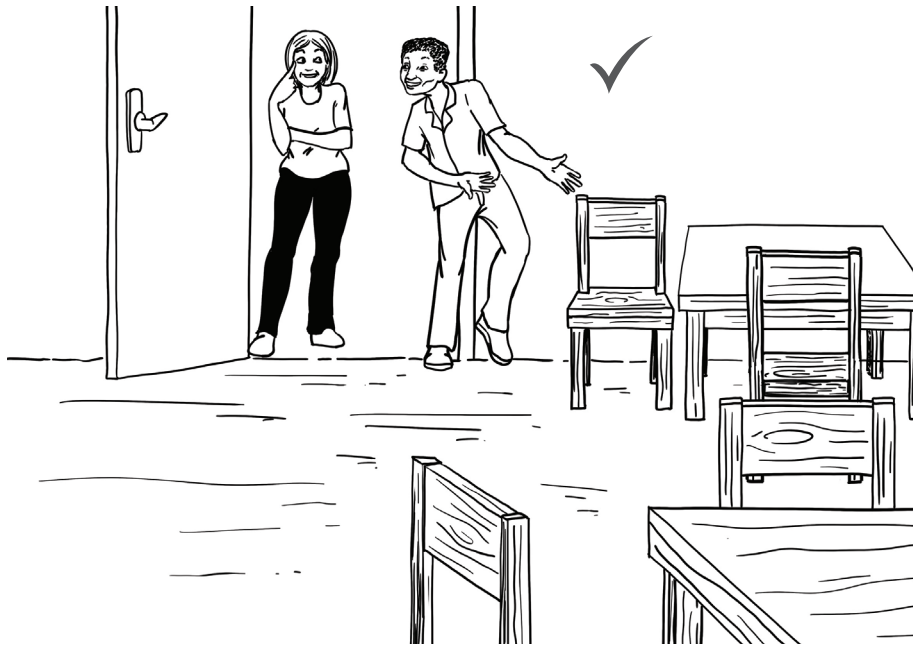
BODY LANGUAGE

Below are some suggestions on how your body language can impact on your relationship with your client.

Remember that clients may not be consciously thinking about your body language, but the subconscious impact can be strong.



- ✓ Place yourself at the same level as your client
- ✓ Have your chair and body slightly angled towards your client
- ✓ Keep a comfortable distance apart
- ✓ If you need the desk for writing, arrange it so it is slightly off to the side
- ✓ Leaning slightly forward indicates you are open to listening to your client



- ✓ Ask the client where they would like to sit
- ✓ Have a chair near the door available
- ✓ Use a friendly smile or a neutral expression, depending on the situation
- ✓ The right amount of eye contact helps demonstrate that you care about what your client is saying

AVOID X



X Avoid standing over the client, especially if the client is lying down, since this can feel threatening

X Be careful your body is not turned away from your client, since this can seem like you are uninterested



X Being directly opposite and too close can seem confrontational

X Avoid having the client sit in the inner corner of the room – this can feel like being trapped.



X Avoid placing a desk directly in between you and the client, since this can act as a psychological barrier

X Leaning backwards, or crossing your arms over your chest, can suggest that you are disapproving or closed off to what your client is saying.



X Avoid facial expressions that appear disapproving, angry, or shocked.

X Too little eye contact can seem like you are not interested. Too much eye contact can seem confrontational.

DOCUMENTATION

A busy counsellor cannot remember every specific detail about each client.

Developing a practice of documenting client interactions (using the PID only) can help you to improve the quality of your counselling.

During your next client encounter you can refer to your notes to refresh your memory about what was discussed previously.

Sometimes, writing notes about the client interaction that just took place can lead you to have more insight into their emotional state.

You may find it helpful to be able to refer to your notes and say “last time we met you were thinking about ... how did you go with that”?

Avoid writing too many notes while talking with your client. If your eyes are on your notes, then you are not making good eye contact.

Be extremely careful about safeguarding your documentation.

Use PID numbers rather than names, and never leave documentation where any unauthorized person could have access to it.

A STRENGTHS-BASED APPROACH TO COUNSELLING

Focussing too much on problems can blind people from recognising their own strengths and capacity to find good solutions.

Using a strengths-based approach means focussing on your client’s strengths, not their problems.

Strengths can be both **internal** (e.g., a sense of humour, creativity) and **external** (e.g., a supportive spouse, a satisfying job).

Everyone has strengths, and everyone has the capacity to adapt to life’s challenges.

Hard times are a part of life for everyone, but by adapting to challenges people can become even stronger.

The strengths-based approach recognises that **what we focus on shapes our reality.**

Using a strengths-based approach, you will still be aware of problems and challenges – these are not ignored, but they are not the focus.

Encourage your client to focus on positive and healthy goals that are in line with what is truly important to them.

You can give confidence to PLHIV to reach their goals by helping them to recognise and develop their strengths.

Using a strengths-based approach means **you do not solve the client’s problems** for them.

Encouraging your client to take the lead in their own care process may feel a bit strange initially. Clients and healthcare

workers may be more used to the idea of “doing what the doctor says”.

You can provide your clients with hope and the confidence to take control of things themselves.

Box 1 compares a strengths-based approach with the problems-based approach that is typical of many healthcare interactions.

<i>Strengths-Based Approach</i>	<i>Problems-Based Approach</i>
<i>What are the client’s strengths?</i>	What are the client’s problems?
<i>Client determines the goals for themselves</i>	Expert decides the goals for the client
<i>Feels like provider and client are equal colleagues collaborating</i>	Feels like the provider has more power
<i>The client is the expert in their body and their health</i>	The provider is the expert and knows best
<i>Support the client to work through options and strategies</i>	Fix the problem for the client
<i>Flexible, provider tries to work around the client’s priorities</i>	Rigid, client must follow provider’s priorities
<i>Empower the client</i>	Control the client
<i>Celebrates client successes</i>	Get angry about client failures
<i>Understand the whole picture</i>	Diagnose the problems
<i>Enhance wellbeing</i>	Minimise illness

How to incorporate strengths-based principles into your own approach

You can incorporate a strengths-based approach to any type of interaction with your clients – it is not limited to a ‘special’ type of counselling.

You are following a strengths-based approach anytime you:

- Celebrate your client’s achievements, big and small (e.g., the first undetectable viral load, went for a run instead of staying in bed, took medicine for 3 days in a row without missing a dose).
- Encourage your client to decide the priorities to discuss during the clinic visit, rather than you decide.
- Ask your client questions like:

“Which aspects of your life do you feel are going well for you currently?”

“When you have a good day, what do you think it was that make it a good day?”

“When you have faced this kind of challenge in the past, what did you try that worked well?”

“Who are the important people in your life – the people you care about and who care about you?”

COUNSELLING FOR BEHAVIOUR CHANGE – SUPPORTING ADHERENCE

Much of what we do as HIV counsellors and healthcare workers involves encouraging PLHIV to adopt healthy behaviours.

For example:

- Starting ART (and other medications) and maintaining good treatment adherence
- Regular exercise
- Using condoms for sex
- Not smoking
- Minimising alcohol use

If you have ever tried to make a long-term change to your own behaviour, then you know it is not easy.

This section focuses on encouraging behaviour change related to ART adherence, but these **principles of behaviour** change can be used to encourage many types of healthy behaviour.

Providing Information and the “Know-Do Gap”

Providing accurate information is an important element of promoting behaviour change, but it is not enough on its own.

The **Know-Do Gap** illustrates that just knowing you should do something does not mean you will do it.

You **know** that you should exercise regularly... but **do** you?

If you don't, it probably isn't because you don't know the benefits of regular exercise.

The reasons people behave the way they do are complex.

Some of the key principles that influence behaviour change are discussed below.

Barriers and Strengths

Behaviour is influenced by **internal** and **external** factors.

Some factors can be built (e.g., self-confidence). Other factors are realities of life (e.g., lives far from the clinic) which can't be eliminated but can be addressed (e.g., providing financial support for transport).

Some factors promote good adherence (**strengths**), and some factors get in the way of good adherence (**barriers**).

It is important to understand that PLHIV who stop taking their ART or are struggling with adherence are not being 'bad' or 'naughty'.

In general, it means that the barriers to adherence (from the client's perspective) are stronger or more numerous than their

strengths at that time.

Be careful of the language you use – avoid stigmatizing terms like “defaulter” or “treatment refuser”.

Counselling to support adherence aims to empower your client to **change their own behaviour** regarding their medication.

“Musts” and “Don’ts” Don’t Work

As humans, we value our autonomy to make our own decisions.

If you feel pressured to go one way, it typically makes you feel like actually you want to go the opposite way.

If a counsellor tries to persuade the client to make a certain choice, the client may **make the opposite choice** to assert their sense of autonomy.

When this happens, it is generally an accident on the part of the counsellor and an unconscious reaction on the part of the client.

Key Point:

*People do what they want to do and telling them to do something risks making them **want to do the opposite***

Picture these two scenarios of a PLHIV who is considering starting ART.

Scenario 1.

PLHIV: <i>(thinking to themselves)</i>	<i>“I wonder if this HIV treatment could be a good choice for me...?”</i>
Counsellor:	<i>“You must start ART! You have no choice – you will die if you don’t start treatment!”</i>
PLHIV: <i>(thinking to themselves)</i>	<i>“I don’t know about this... I’m not sure those tablets are a good idea...”</i>
Counsellor: <i>(Later)</i>	<i>“What, you didn’t start treatment yet? Why didn’t you start?! You have to start; the treatment is so important for you!”</i>
PLHIV: <i>(thinking to themselves)</i>	<i>“I don’t have to do anything! I don’t want that stupid treatment!”</i>

In this scenario, the counsellor has inadvertently triggered the opposite reaction than the one she wanted.

Scenario 2.

PLHIV:
(thinking to themselves)

"I wonder if this HIV treatment could be a good choice for me...?"

Counsellor:

"Would you like me to tell you a bit about the ART tablets?"

PLHIV:

"Thanks, that would be good".

Counsellor:

*"Well, taking the tablets helps the immune system get strong again. With this type of ART side effects are rare..." [briefly explains ART]
"Did I explain that okay? Can you think of any questions for me?"*

PLHIV:

"Yes, thanks. Would I have to start the tablets today?"

Counsellor:

"No, you can take some time to think it over. How about you let me know what you're thinking about the idea at your appointment next week. We can see if you're feeling ready. You can choose the date to start."

PLHIV:

"Okay, I'll think about it. It sounds like it will be a good idea to start soon".

In the second scenario, the counsellor avoids triggering the negative psychological response by giving as much control back to the client as possible.

You may have noticed that this handbook talks about 'adherence' not 'compliance'.

We are on the same level as our clients when we **support them to adhere** to treatment. **Telling them to comply** with treatment suggests we have more power than our clients.

ACTIVITY:

Ask 2 of your team members to role play Scenario 1 and Scenario 2, with the rest of your team as the audience.

Afterwards, ask the audience to comment on why they think the Scenario 2 approach was more effective.

THE READINESS TO CHANGE MODEL

Making a significant change to your behaviour is not easy, and it generally does not happen overnight.

PLHIV often need time to adjust to their diagnosis, and to get used to the idea of taking lifelong medication.

The **Readiness to Change** model highlights that behaviour change is a process, not a single step.

This model has been used to facilitate many types of behaviour change, like stopping smoking and doing regular exercise.

The model can guide which counselling strategies to use at what time, depending on where the client is in their psychological level of readiness to change their behaviour.

 **Key Point:**

People Need to believe that the advantages of new behaviour will outweigh the disadvantages, before they will fully adopt it

Some people move through the stages within a few days, and for other people it may take longer.

Note that **psychological readiness** for HIV treatment is not the same as **medical readiness**, which includes being sure any opportunistic infections have been addressed etc before starting ART.

Below is an example of how the Readiness to Change model could be used to support a PLHIV who has stopped taking their ART.

Stage 1. Not ready yet

“I don’t need to take that stuff, I feel fine”

PLHIV can be in Stage 1 following initial HIV diagnosis, or in the setting of Lost To Follow Up.

Your client may be in Stage 1 because of:

- Not understanding the relevant information yet (e.g., HIV does damage to the body that you can’t feel)
- Not trusting that they truly have HIV
- Placing hope elsewhere (e.g., traditional healer or God will cure my HIV)
- Feeling demotivated about ‘failing’ when unsuccessful adhering to ART previously

Strategies for Stage 1:

- Ask your client if it is okay for you to provide some information about ART
- Start **strengths-based counselling** and **building resilience**
- Beware of triggering the **opposite emotional reaction** – avoid trying to pressure or persuade your client

Stage 2. Thinking about it

“Okay, I understand about the viral load, but I’m scared my brother will ask questions if he sees me take the tablets, and I’m worried about side effects”

Your client may be in Stage 2 because of:

- Now **feeling conflicted** (or “in two minds”)
- Aware of the advantages of starting ART/improving adherence, but also aware of the perceived disadvantages. Common disadvantages described by PLHIV in this context include:
 - Being seen taking tablets leading to unintended status disclosure
 - Fear of side effects (e.g., if side effects happened in the past)
 - Getting to the clinic every month is hard

Clients can get ‘stuck’ in this stage. They may decide on one day that they will start ART and then change their mind the next day.

Strategies for Stage 2:

- See if your client is willing to talk about the advantages and disadvantages of making the change. Then, encourage them to say what they think are the advantages and disadvantages of not changing.
- Continue strengths-based counselling and building resilience
- Continue to avoid triggering the opposite emotional reaction – be very careful not to persuade or argue during this stage

Stage 3. Ready

“I want to start the tablets again, and take them every day”

Your client may have reached Stage 3 because of:

- They now have enough knowledge to fully understand the benefits of treatment and the importance of good adherence
- They now have more confidence in their own strengths and capacity to make this change
- Client feels supported and resilience is now higher
- Client feels their autonomy is preserved. Nobody has triggered the opposite emotional reaction and accidentally pushed the client backwards to Stage 1

Key Point:

Evidence from research indicates that PLHIV are less likely to follow solutions which have been imposed on them, compared with solutions they have chosen themselves

Strategies for Stage 3:

- Assist the client working out what steps they want to take towards the goal, including strategies to address anticipated challenges (e.g., “if my brother asks about my tablets, I’ll tell him they are vitamins”).
- Many PLHIV will need to start Cotrim before they start ART – encourage your client to take their Cotrim with good adherence as “practice” before starting ART.
- You can suggest the practice with Cotrim strategy when the client is in Stage 2 or Stage 3
- **Start ART** with big smiles and encouragement from the ART Centre team – make this moment feel as bright and positive as possible

Stage 4. Action

“I’ve been taking the tablets every day, except I didn’t last Thursday when I stayed the night at my friend’s house”

Your client may have reached Stage 4 because of:

- All the strengths (including those you helped with) have combined to be stronger than the barriers

Strategies for Stage 4:

- Celebrate your client’s success! Congratulate them on their achievement and affirm that you understand that this was not easy
- You might suggest a cake or a small party for your client and their supporters when a major milestone is reached, such as the first suppressed Viral Load
- See if you can help to build your client’s support systems (do they feel ready to join a PLHIV support group now?)
- Assist with problem solving as needed (e.g., keeping a few doses of ART in a plastic packet inside her handbag, in case she unexpectedly spends a night away from home again).

Stage 5. Sustaining

“I always take my tablets; it just feels like part of normal life now”

Your client may be in Stage 5 because of:

- The same reasons as per Stage 4 continue to hold strong
- Risk of “going backwards” is always possible - often associated with periods of extra stress in the client’s life (e.g., relationship breakdown)

Strategies for Stage 5:

- Continue to celebrate your client’s successes.
- Continue strengths-based counselling and building resilience to protect against future breakdowns in adherence.
- Ask your client if they would be interested in becoming a role model or support person for other PLHIV. Note that the act of **volunteering** can be an important source of strength for many PLHIV.

Strategies in case of setbacks

- Reassure your client that many people don’t reach perfect treatment adherence the first time they try
- Avoid anything (verbal or body language) that could be perceived as being angry, disapproving, or giving up e.g., scolding, raising your voice, frowning, pointing your finger, crossing your arms, or walking away. These kinds of behaviours may lead your client to disengage from care entirely
- If your client drops back to an earlier stage (1 – 4), restart your counselling and support efforts from whichever stage they ended up at
- Make it clear that it is the current behaviour (poor adherence) that is a problem, but the person is not the problem. Showing warmth and positive regard for your client is very important at this point.

HIV, ART, and Adherence

5 Key Pieces of Information for PLHIV to Know

1. If you as a person living with HIV wants to climb a mountain, have children, study at university, or do any kind of job that you want, HIV shouldn't stop you
2. You can **live a long and healthy life** with HIV. The only difference is you have to take a tablet every day to stay healthy
3. Getting and keeping an **undetectable viral load** is the best thing you can do to stay healthy
4. If your viral load is consistently undetectable, you will not transmit HIV to someone else through sex (**Undetectable = Untransmissible**)
5. HIV treatment only works properly when you take it every day

Adherence and Traditional Medicine

Imagine one person says, *"I can cure your HIV!"* and another person says, *"you have to take treatment for the rest of your life"*. Who would you prefer to believe?

Then imagine that the first person has spent a lot of time talking and listening to you, and the second person only spent 3 minutes with you at the end of a busy clinic.

On top of that, there is often pressure from family to take traditional medicine.

You can see how PLHIV might prefer to choose the traditional healer.

Remember that even though **you** know that your client needs ART, it is **what your client believes** that matters.

Don't make your client feel like they must choose between traditional medicine or staying on ART, since they are likely to choose in the opposite direction than the one you want.

If your client wants to take both ART and traditional medicine then that is okay.

Adherence and Religion

Religion can act as an adherence **strength** for some PLHIV and as an adherence **barrier** for others.

Many PLHIV describe attending church and private prayer as sources peace and hope which support their treatment adherence.

On the other hand, two beliefs have been observed in Timor-Leste which can be major barriers to treatment adherence:

1. Belief that HIV is a punishment from God. This belief can be tied up with strong feelings of guilt and shame and may connect with other complex emotional issues like sexual identity.
2. Belief that God will cure their HIV. Clients may believe that the HIV is a test of their faith, and that God will cure them if, for example, they pray enough or conduct a ritual of some kind.

These situations can be very challenging for counsellors and others who work with PLHIV.

Screening for possible depression is very important.

Recruiting support from a church leader can be helpful in this situation but only if the client gives permission, and the church leader has an attitude of warmth and acceptance towards PLHIV.

HIV-RELATED STIGMA

Stigma refers to irrational and negative attitudes towards people sharing a particular feature, like the colour of their skin or being HIV positive.

Stigma is a powerful social process that is influenced by factors such as culture, religion, and level of education.

HIV-related stigma is generally related to:

- **Lack of accurate knowledge** about HIV
- **Fear** of acquiring HIV due to ignorance about HIV transmission
- **False beliefs** e.g., that only specific groups of people are affected by HIV
- **Negative value judgements** about PLHIV (thinking it is a moral issue rather than a health issue)

“At that time after the diagnosis I felt I didn’t believe [it], depression, felt ashamed and scared and wanted to kill myself.

Before I revealed my HIV status, some of my friends knew my HIV status and they also started to make stigma, [saying I] cannot be with them and this friend told my other friends and their partners to not be near or around me”

- HIV Stigma Index Report Timor-Leste, 2017

External HIV-related stigma can be **experienced** (events which occur to PLHIV in real life) and anticipated (worrying about the possibility that stigma might happen).

Discrimination refers to actions taken due to stigmatising beliefs i.e., treating HIV positive people differently from HIV negative people.

Examples of external HIV-related stigma and discrimination which occur in Timor-Leste include:

- Gossiping about PLHIV
- Separating PLHIV from partners and children
- Pressuring PLHIV to live in a separate building or sleep in a separate room
- Refusing to share plates, cups, bedding etc with PLHIV
- Exclusion of PLHIV from social events
- Healthcare workers breaking client confidentiality about HIV status
- Healthcare workers refusing to physically touch PLHIV, or wearing double gloves or unnecessary PPE due to fear of acquiring HIV
- Pressuring or forcing women to not have children due to their HIV status
- Firing people from their jobs due to HIV status
- Violence against PLHIV

These are obvious examples, but people can stigmatise PLHIV in less obvious ways – e.g., by small comments, tone of voice, how they look at PLHIV – that can be equally damaging.

Stigma may be especially difficult for PLHIV to cope with when it comes from people who are close to them (family or friends), or when their relationships with people are changed as a result.

Some PLHIV are vulnerable to **added stigma** due to belonging to a marginalised group (e.g., sex workers, transgender people) or having a co-morbidity which is also stigmatised (e.g., mental health issues).

These experiences of being rejected or labelled as immoral have an immense negative impact on mental health for many PLHIV.

PLHIV may start to believe the negative attitudes of others, and this can lead to profound feelings of shame and sadness.

This is referred to as **internal** or **self-stigma**, and it can have a devastating impact on the way PLHIV see themselves.

Self-stigma can lead to:

- Reduced engagement with healthcare services
- Reduced motivation of PLHIV to look after themselves and take treatment
- Social isolation
- Depression and other serious mental health disorders
- Severely reduced quality of life

“When I tested for HIV I felt very sad because I did not expect to have the virus inside my body.

I was worried that some day my family members might know my status.

I am feeling shy and no self-confidence to interact with community and family members. Often I’m very depressed”

- A PLHIV who is disengaged from HIV treatment and care. Report on Loss to Follow Up in Timor-Leste, 2021

SUPPORTING HIV DISCLOSURE

When someone chooses to tell another person about their positive HIV status this is referred to as HIV disclosure.

Voluntary disclosure of HIV status has significant impacts on both the client and their partner(s) / family.

It can be a challenging situation, and unfortunately, bad experiences involving stigma and discrimination are common in this context.

Often people who are newly diagnosed with HIV are very scared about the idea of telling anybody about their status.

A trained and empathetic counsellor can do a lot to minimise the chance of a bad outcome following HIV disclosure.

Much of this section is focussed on disclosing HIV status to a sexual partner. However, many of the principles also apply to disclosing HIV status to others (e.g., family members or friends).

ACTIVITY:

With your colleagues, discuss what a client might feel when you bring up the issue of disclosing their HIV status to their partner.

See if you can imagine what your client might be feeling while thinking about disclosing their HIV status to their partner.

Some of the emotions that are common in this context are listed below in Box 1.

Box 1. Common emotions among PLHIV when considering disclosure

- Fear that the healthcare worker or counsellor will take the decision out their hands (i.e., might tell the partner or others without permission)
- Fear that their partner will accuse them of being unfaithful
- Anger that their partner could have passed HIV to them
- Anger that their partner could have been unfaithful
- Fear that they could have passed HIV to their partner
- Fear that the partner could be very angry, e.g., throw them out of the house or act violently
- Shame related to long-ago sexual relations that might come to light, including possible sexual abuse as a child

Disclosure of HIV status is to be encouraged, but make sure your client takes time to think carefully about the benefits and risks first (see Table 1 below).

HIV disclosure is often a slow process, with people choosing to disclose to more people over time. In the beginning, your client may wish to identify just one key person who they trust – a partner or a family member.

Disclosing to this one person can be described as **“selective disclosure”** or **“shared confidentiality”**.

It is vitally important that the partner/family member who is chosen understands the concept of shared confidentiality.

The chosen person is not free to share the client’s HIV status to a third person without direct permission from the client.



Table 1. Benefits and risks associated with HIV disclosure

BENEFITS	RISKS
Increased access to support from family	Risk of rejection e.g., forced divorce
Improved medication adherence, no need to hide tablets	Risk of intimate partner violence
Reduced stress from no longer having to keep the secret and cope alone	Risk of family taking control of decision-making, especially if client is female
Partner can be treated for HIV if positive, or protected from acquiring HIV if negative	Risk of status being disclosed to others without consent (broken confidentiality)

Reluctance to Disclose

It is common for the client to show reluctance the first time that disclosure is suggested. This is very understandable in Timor-Leste’s current context of high HIV-related stigma.

This can be a challenging situation for counsellors and healthcare workers because it brings two important values into conflict.

On one hand, you are worried about the partner/children. You want them to have an HIV test so that if they are positive, you can look after them too.

On the other hand, your client is your first priority, and you understand that confidentiality cannot be broken.

If you push too hard on the issue of talking to/testing the partner/children, there is a serious risk your patient will get scared and disengage (run away).

Tips for this situation include:

- Remember your client being able to trust you is the most important thing. Often, establishing trust will take time. Your client may need a few appointments with you before they are ready to talk about disclosure.
- Reassure your client that you will not tell anyone about their HIV status without their permission. This gives control back into the client’s hands which can help to reduce anxiety.
- Point out to your client that partner disclosure is not only for the benefit of the partner (so they can have a test), it is also for their own benefit (see Table 1).

There is a danger in this situation that healthcare workers or counsellors may believe they “know better” than their client. There is a higher risk of people thinking this way if the client is uneducated and a woman.

In situations when intimate partner violence is identified as a risk then HIV disclosure may be contraindicated.

Offer further support for your client in this situation (e.g., connecting them to Estrela + Hotline, phone number 7522 0561/ 7403 0902/ 8001 099 or 7522 0561 / 7403 0902 / 8001 099 or Uma Mahon in Dili: FOKUPERS Dili 331 1534 / 7847 2598, FOKUPERS Uma Entrada - 7847 2598, Casa Vida Dili - 7735 2345, FFCJ Dili - 7796 9826, ka PNTL-VPU Unidade Ema Vulneravel Dili 7734 1607, or MSSSI Focal Point for Gender Based Violence (GBV) 7725 7439).



Urgent Situations

There are two situations when there is higher urgency around encouraging your client to disclose their status:

1. If the client’s partner is pregnant. This is because if the pregnant woman turns out to be HIV positive then there is a limited period time to achieve viral suppression in order to protect the baby from acquiring HIV (See Section 9: HIV and Pregnancy).
2. If your client’s partner or child is sick. In this case it is possible that the partner or child has advanced HIV and may need urgent treatment of a serious opportunistic infection.

What To Say

Sometimes counsellors and healthcare workers are not sure of the best words to use when talking to their clients about HIV disclosure.

Below are some phrases that you may find helpful:

“Maybe your partner could also have HIV, but not know it yet – what do you think?”

“If they do have HIV, they can start on treatment, same as you. If they don’t, we can talk about how to protect them from getting HIV”.

“We have other clients who found this difficult to do as well. It is very understandable to be feeling this way”.

“Would you like me to help talk to your partner about having the HIV test? Together we can help explain everything clearly”.

How To Say It

Remember that **what** you say is often less important than **how** you say it.

Use your friendliest manner with your client so they understand you are not judging them.

Be mindful of your body language.

Express empathy, showing that you understand the disclosure process is difficult.

In some cases, it may be helpful to adopt a Strengths-Based counselling approach to help your client take this step.

A “Menu” of Strategies for HIV Disclosure

Choosing their preferred option from the menu can help your client feel that they have some control over a scary situation, which tends to reduce anxiety.

“Menu” of Strategies for HIV Disclosure

Option 1: Client Alone

Client discloses to partner(s) alone. Client ensures that the partner(s) understand need for HIV testing.

Option 2: Support If Needed

The counsellor/healthcare worker accompanies the client when the client discloses their status to their partner(s) and provides support if needed. HIV testing offered to the partner(s).

Option 3: Do It Together

The counsellor/healthcare worker and the client disclose the client’s status to the client’s partner(s) together. HIV testing offered to the partner(s).

Option 4: On Client’s Behalf

With permission from the client, the counsellor/healthcare worker confidentially contacts the client’s partner(s) directly and offers HIV testing.

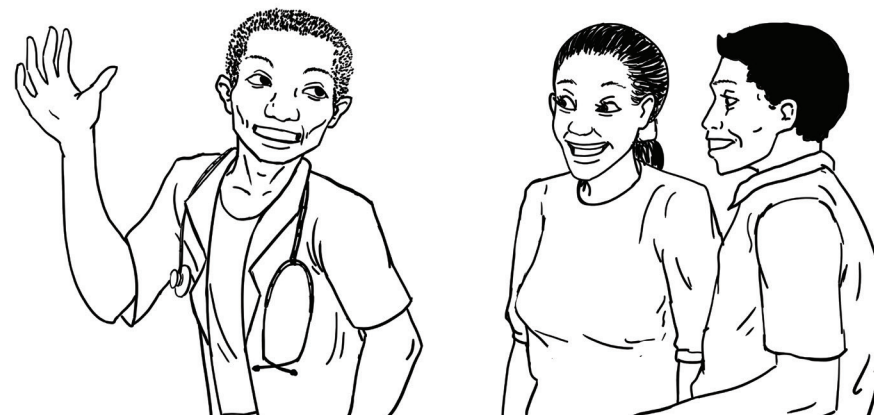
Option 5: Joint Agreement

The client agrees to bring their partner(s) for an HIV test within a specified timeframe.

Otherwise, the counsellor/healthcare worker contacts the partner(s) directly and offers HIV testing.

When the client’s partner tests HIV positive

- Explain that both partners could have had HIV for many years without knowing it.
- Try to deflect anger by explaining that HIV transmission was not on purpose. HIV transmission can just happen when people don’t know their HIV status and don’t know about using condoms.
- The priority should not be focussing on what happened in the past. The priorities should be how they can support each other now, and planning for a healthy and happy future.
- After the disclosure discussion, make sure that both partners have an opportunity to express how they are feeling.



Box 2.

In Timor-Leste it is common for the woman to be diagnosed with HIV first (as part of testing during pregnancy), then her partner is diagnosed with HIV second (as part of contact tracing).

It is easy for people to become confused and to think that the **order of testing** for HIV is the same as the **order of acquiring** HIV.

In other words, the man may think that the woman passed HIV to him, whereas it is often the other way around. This can be suggested by seeing that the man's CD4 count is much lower than the woman's CD4 count, indicating he has probably carried the virus for longer than she has.

It is generally not helpful to focus on who passed the virus to who first. However, it is worth being mindful of this issue if the man gets angry with the woman and threatens to divorce her.

When the client's partner is HIV negative

- For now, they should always use condoms for sex (provide condoms).
- If they want to have children in the future, they can – but wait until the HIV positive partner is stable on ART with an undetectable viral load before trying.
- Encourage the HIV negative partner to support the HIV positive partner (e.g., remind about tablets).
- Make a plan for the HIV negative partner to have another HIV test in 3 months' time.
- Sometimes, PEP and PrEP can play a role in this context.

COPING STRATEGIES

People cope with HIV, and with life generally, in different ways.

Negative coping to change refers to approaches that reduce people's stress in the short term, but which lead to poor outcomes in the long term.

For example:

- **Using alcohol or other drugs:** people feel better temporarily and can stop thinking about their problems for a while, but alcohol dependence may become another problem.
- **Avoidance:** is when people pretend to themselves that there is no problem. People may turn to alcohol or overwork to help them avoid thinking about the problem.

Approaches which help people adapt well to change and which lead to positive health outcomes are known as **adaptive coping strategies**.

One of the most valuable things you can do as a counsellor is to **help someone learn how to cope with life's challenges in a more positive way**.

Some adaptive coping strategies for PLHIV are described in the next section. They are written with a view to being read by PLHIV, so you as an HIV counsellor or healthcare worker may choose to:

- Select one which you think may be particularly relevant to your client, and work through it together; and/or
- Print the coping strategies for your clients to read about at home.

By helping your client learn a combination of adaptive strategies you are helping to **build their resilience**. Resilience refers to someone's capacity to bounce back from the tough situations in life.

ACTIVITY:

Working as an HIV peer counsellor or healthcare worker can be emotionally demanding, and it is extremely important that you take care of your own mental health. You are encouraged to use the information and strategies in this section to help build up your own resilience.

1 - Develop Your Problem-Solving Skills

Everyone has to deal with problems in life. Fortunately, everyone can strengthen their problem-solving skills.

Sometimes people waste a lot of energy trying to change things which can't be changed (like a positive HIV status).

For other problems, **changing the situation** may be the best choice (like quitting a stressful, unsatisfying job)..

Here are some simple steps to follow that can help you solve problems:

1. **Check** to see if the problem is one you can change (like a stressful job), not one that can't be changed (like a positive HIV status)
2. **List** all the possible actions you could take (e.g., quit your job, or try to resolve conflicts with your boss, or ask if you can work from home instead of at the office). You may need to find out extra information to know what all the options are.
3. **Compare** the advantages and disadvantages of each choice. It can be helpful to do this on paper.
4. **Choose** which strategy seems the best to you after weighing the advantages and disadvantages of each.
5. **Act** by carrying out the problem-solving strategy you chose.
6. **Review** how it went. If your chosen strategy worked out well, great! If it didn't work well, try one of your other options from step 2.

Other problem-solving tips:

- **Talk through your options** with a trusted person – you may get some new perspectives.
- As humans, we don't always make decisions just based on logic: we are influenced by our emotions. Try not to let fear stop you from choosing the problem-solving strategy that would serve you best.
- Remind yourself that **you have power to solve problems**. If you don't really feel like you do, see if you can work with your counsellor to build up your confidence.
- It is rare for problems to be solved by passively waiting. Most problems are better solved by making a plan (as outlined above) and taking **direct action**.
- Choose a **small problem** to practice your new skills on first.

2 - Strengthen Emotional Support Systems

Finding and maintaining strong social support systems is an important part of thriving as a person living with HIV. Don't let yourself become isolated.

- 1. Spend time with friends and family** who are emotionally supportive. This provides protection against the negative impact of stigma and other stress
- 2. Selectively disclose your HIV status** to someone you trust (HIV counsellors and healthcare workers can assist with this step)
- 3. Talk about how you feel** with people you trust. This can reduce your stress and improve your mental health. If you don't feel ready to talk about HIV-related issues with friends or family, reach out to:
 - An HIV peer counsellor
 - An HIV healthcare worker
 - The Estrela+ Belun Konfiansa Hotline
[7522 0561/ 7403 0902/ 8001 099]
4. Join an **HIV peer support group** to hear about what living with HIV like and to share experiences
5. Join other groups or volunteer organisations that you think would be a good fit for you

3 - Educate Yourself about HIV and Positive Living

Knowing up to date, relevant information is a vital coping strategy for PLHIV.

Beware of deciding anything about your health without being clear on the true facts about HIV.

It is easy to be misled by incorrect information on the internet, or by what a misinformed person tells you.

Ask your peer support counsellor to tell you everything they wish they had known when they were first diagnosed with HIV.

Ask your HIV healthcare worker to tell you what they believe are the top 5 pieces of information that PLHIV need to know.

Positive Living refers to the idea that there is no need for PLHIV to limit themselves to just hoping not to be sick.

Being well is not just the absence of illness. It includes physical, mental, and social wellbeing.

Your counsellor and HIV care team can help you find ways to be as healthy, happy, and fulfilled in your life as possible.

Living with HIV is about more than surviving, it is about **thriving**.

4 - Optimise Your Physical Health

Having good physical health is an important part of good mental health.

Many PLHIV find that their physical health improves after their HIV diagnosis, because they start to pay more attention to taking good care of themselves and making healthy choices.

Important ways you can keep yourself physically fit and healthy include:

- 1. Keep your viral load undetectable** on ART, and maintain good contact with your HIV Care team
- 2. Exercise** has a major effect on both physical health and mental health. Many people find exercise is very good for stress relief.
Aim for 30 minutes of moderate exercise 5x per week. Try different types of exercise to find out what you like best.
Exercise that you can do while enjoying the natural environment (like a walk on the beach) will have extra benefits for your mental health.
- 3. Get enough sleep.** There is research evidence to show that people who do not get enough sleep are at higher risk from cancer and other illnesses.
Adults generally need around 8 hours of quality sleep per night.
- 4. Avoid smoking** (any amount of smoking is harmful – quitting is important) and limit your intake of alcohol.

5. Eat a healthy balanced diet, which means:

- Eating lots of vegetables and fruit
- Eating enough protein foods (e.g., beans, tofu, eggs, milk, fish, and meat)
- Minimising sugary drinks and processed food (e.g., breakfast cereals, cakes, biscuits, deep fried food)

Traditional foods of Timor-Leste such as red rice, moringa, and purple sweet potato are excellent nutritional choices.

5 - Change Your Thoughts to Change Your Mood

The way you think affects your mood.

When you change your thoughts, you can change the way you feel.

Many PLHIV focus on negative thoughts, sometimes because of internalised stigma. (E.g., “I’m not worth anything to my family” or “I deserve to have HIV”)

Focussing on negative thoughts commonly leads to low mental health.

Sometimes negative thoughts are not rational, but it can be easy to automatically believe them and keep thinking that way.

With practice, you can learn to change your negative thoughts about a situation into more positive thoughts, using the steps in this **simple technique**:

1. Identify a negative thought that seems to be commonly in your mind.
2. Ask yourself: Is this thought really the truth? Is there actual evidence for this thought?

3. Consider whether the situation could be less extreme than you think.
4. Are there other ways to think about this situation that could be more positive and more realistic?
5. Repeat the process anytime the negative thought appears in your mind.

By practicing catching your negative thoughts and changing them to more positive ones you can improve your emotional wellbeing.

This process of changing your thoughts can seem hard to begin with but like with anything it gets easier with practice.

6 - Change Your Behaviour to Change Your Mood

The way you behave affects your mood.

When you feel depressed, you tend to become less active. Staying at home and not doing anything can then make you feel more depressed.

Scheduling positive activities is a helpful technique to use in this situation.

Scheduling the activity (i.e., setting a date and time) can help overcome the low energy and low motivation that can happen with depression.

The steps for this technique are:

1. Choose some activities that you would normally find fun or enjoyable, and/or some activities that will give you a sense of achievement when you complete them.

2. Delete any activities that are not in line with your goals and values. For example, you might think eating an entire pizza would be enjoyable, but it is not in line with your goal of getting healthy.
3. Delete any activities that are not realistic for your current level of energy or motivation (e.g., “clean the whole house”).
4. Do your chosen activity at the scheduled time (even if you don’t feel like doing it).
5. Don’t stop after just one or two activities. Keep going, and you will find that your mood starts to improve.
6. You can re-schedule the activities that work best for you on a daily or weekly basis. Try new activities to replace the ones that don’t work so well.

Activities which connect you with other people will have extra benefits for your mental health.

If you are having trouble thinking of activities, see the list below for some ideas:

- Go out for a walk with a friend
- Bake something to share with friends/family
- Climb up Cristo Rei
- Plant some flower seeds
- Practise playing guitar
- Write a short poem
- Volunteer with the Church or an NGO

- Clean the bathroom
- Make a pot of coffee to drink while watching the sunrise
- Visit a grandparent
- Play football with some kids
- Lift weights

7 - Work Towards Acceptance

Some PLHIV struggle to accept their diagnosis of HIV, especially when:

- Pre-test counselling was not performed adequately
- They feel well (“I have no symptoms, so how could I have this virus ...?”)
- They do not believe themselves at risk for HIV (“But I don’t visit sex workers, how can this be?!”)

These PLHIV are in danger of dropping out of HIV care, or never starting treatment at all.

People can waste a lot of energy worrying about something that can’t be changed, leaving less energy to address things that can be changed.

If you are HIV positive, then accepting your status as a fact of life is a great step on your journey to living the life you want to live.

It is understood that this is not an easy step, and that some people will need more time than others to reach acceptance.

Talk to your HIV care team if you think that repeating your HIV test or seeing the test result with your own eyes might be helpful for you.

HIV AND MENTAL HEALTH

Good mental health means more than just the absence of mental illness.

It includes the ability to maintain positive relationships, be part of a community, complete tasks needed for daily life, cope with stress, and feel like life has a purpose.

Helping PLHIV maintain good mental health is equally as important as helping them maintain good physical health.

Mental health issues range from temporary distress related to an event or situation, to serious mental health disorders such as depression.

PLHIV experience higher rates of mental health disorders compared with the general population.

HIV affects key population groups who are often marginalized in society (e.g., men who have sex with men, transgender people). These groups are also among the most vulnerable to mental health issues.

When PLHIV experience mental health issues it can impact on:

- **Engagement** with ongoing HIV care
- **Adherence** to HIV treatment
- **Physical health**
- **Quality of life**

Mental health disorders suffered by PLHIV are often not recognised or adequately treated.

PLHIV may be reluctant to openly share their mental health concerns for fear of stigma. Unfortunately, there is a high level of stigma surrounding mental health issues in Timor-Leste.

There are different treatment options for mental health issues, including counselling (described in this handbook); and medication (beyond the scope of this handbook).

Providing support for PLHIV with mental health issues can improve quality of life, treatment adherence, and viral suppression.

Issues related to HIV, physical health, and mental health cannot be separated. So, it is a good idea to combine mental health support and HIV support together.

“I am unemployed, so my challenge is to cover my transport cost for ART refilling. Family supports sometimes, but I am reluctant to ask them as I am not a child anymore. To add further to my problems, this [COVID-19] pandemic is giving more hard time in accessing any job vacancies”.

- Report on Loss to Follow Up in Timor-Leste, 2021

What factors can contribute to mental health issues for PLHIV?

Mental health problems can arise when the people experience stress that is severe and prolonged.

Common sources of stress for PLHIV include:

- **Stigma**, including self-stigma
- **Interpersonal relationship challenges** (also influenced by stigma), especially within the family
- Living with a **chronic medical condition**
- **Medication side effects**, especially when people then feel conflicted about whether to keep taking the medication or not
- **Physical health problems**
- **Fear of early death**
- **Poverty** is a source of severe stress for many PLHIV. Poor physical or mental health can impact on earning capacity, making PLHIV especially vulnerable to poverty
- **The Coronavirus pandemic** causes stress in many ways e.g., fear of infection, death of family members, reduced ability to access healthcare due to lockdowns, and reduced ability to earn income

MENTAL HEALTH DISORDERS AND HIV

Depression

Depression means more than just feeling sad. It is a serious disorder that affects both mental and physical health. PLHIV are more likely to experience depression compared with HIV negative people.

A depressed person may describe feelings of sadness, emptiness, hopelessness, worthlessness, shame, or guilt. For PLHIV, some of these feelings may develop as a reflection of internalized or **self-stigma**.

They may no longer enjoy doing things they used to like doing in the past.

You should consider the possibility that someone is depressed if:

- Their low mood/sad feelings **persist** (longer than 2 weeks)
- They have **other symptoms**, including any of:
 - Loss of appetite
 - Sleeping badly
 - Getting angry or irritated easily
 - Low energy levels
 - Trouble concentrating/thinking clearly
- These symptoms represent a **change from what is usual** for that person

When someone is depressed, they may struggle to get through their usual day-to-day activities, and they may feel as if life isn't worth living.

You may notice that they stop going out and **withdraw from family and friends**.

Sometimes depression can happen for no clear reason.

Sometimes depression can be triggered by circumstances in someone's life, for example facing stigma from family, or feelings arising from self-stigma related to their HIV status.

Depression impacts strongly on the ability of PLHIV to **adhere to ART**. It is very difficult for people to feel motivated to attend the clinic and take medication every day if they are feeling sad, helpless, and demotivated.

If you believe someone might be depressed, then it is vital to talk to them about **thoughts of suicide**.

Box 1 – shows some simple questions you can use when asking your client about suicide

Questions to check if suicidal thoughts are present or not:

“Sometimes when people are feeling low, or going through a tough time, they can start to feel like they don't want to be alive anymore. Does it ever feel like that for you?”

“Does your mood ever get so low that it makes you think about killing yourself?”

If they answer ‘yes’ to any of these, follow up to clarify if an active plan is present or not:

“Did you think about how you would do it?”

“Could you tell me about what specific plan you thought about, when you were having these thoughts?”

Talking about suicide

If you think someone may be struggling with their mental health, then it is important that you ask them about thoughts of suicide.

Do not worry that asking about suicide will “give them the idea”.

Asking about thoughts of suicide, in a respectful way, will not cause problems. It is **not** asking about suicide that can be a problem. If someone has an active plan for suicide, with a clear method in mind, that signals high danger for that person.

Urgently discuss the situation with your client’s HIV care team.

If possible, stay with your client until help can be arranged, or recruit a family member to stay with them.

Remove obvious hazards (e.g., if your client has mentioned thoughts of stabbing himself then remove knives from the house).

ACTIVITY:

It is likely to feel strange the first time you talk openly about suicide with a client. The only way to become comfortable with this is to practice.

Have one team member play the role of a client who is depressed and having suicidal thoughts. Other team members practice talking to the client using the questions like those outlined in Box 1.

Anxiety Disorder

Anxiety is a feeling of worry that something bad is going to happen.

Anxiety is a natural response to a stressful event – for example, you might feel anxious before an important job interview.

An **anxiety disorder** may be present if anxiety symptoms are severe, persistent (e.g., > 6 months), and impair ability to perform usual daily activities.

HIV positive people experience anxiety more commonly than HIV negative people.

The **psychological symptoms** of anxiety include:

- Constantly worrying about bad things might could happen
- Feeling ‘edgy’ and unable to relax

The **physical symptoms** of anxiety include:

- Feeling heart beating rapidly
- Sweating
- Headaches
- Dizziness
- Choking feeling in the throat
- Feeling like it is difficult to breathe properly

It is very important that the HIV doctor considers and rules out the possibility of a medical cause of such symptoms, before attributing them to anxiety.

Acute, severe symptoms of anxiety are experienced during a **panic attack**.

For some people, anxiety is triggered by a specific situation (like attending the HIV clinic or being in a crowded place). For other people, anxiety can just happen, without any specific trigger.

It is common for anxiety to co-exist with depression, but it can also happen by itself.

Some people may turn to alcohol or cigarettes to try to reduce their anxiety symptoms. This may seem to help in the short term but usually worsens the problem over the long term.



ACTIVITY:

Imagine a time in your life where you felt anxious. For example, before an important exam at university, or if you just realized that you made a mistake at work.

Think about how it felt – maybe you felt very worried, maybe your mouth went dry, and your heart was racing.

Imagine if you felt that way all the time. How do you think it would impact on your quality of life?

What would you do to try to cope with such a situation?

Psychosis

Psychosis is an uncommon, severe form of mental health problem. Typical symptoms of psychosis include:

- **Hallucinations**, which can be visual (seeing things that are not there) or auditory (hearing things that are not there)
- **Delusions**, which means strongly believing things which are not true (e.g., someone may believe their family member is trying to poison them)

When psychosis occurs in PLHIV it can be due to **direct damage by the virus to the brain**. This occurs more commonly in PLHIV who have been off treatment for a long time and who have advanced HIV infection.

This condition can be improved by HIV treatment.

Other symptoms of this condition include personality changes and memory loss.

Culture may influence the way that people perceive a mental health problem like psychosis. In Timor-Leste people may believe an angry spirit is responsible and so seek the help of a traditional healer.

If you think your client is showing symptoms of psychosis, then you should urgently contact the HIV clinical team to arrange a medical review.

Medical Causes of Mental Health Issues for PLHIV

It is important to differentiate **medical causes** from **psychological causes** of mental health problems.

Some infections can attack the brain and cause mental health symptoms.

If your client is behaving or speaking strangely consider the possibility of a brain infection, especially if they also have headache or poor physical condition.

In this case, diagnosis and treatment of the specific infection will be required. Facilitate **urgent review** by the HIV clinical care team.

Some medications for treating HIV can cause **psychological side effects** in some people.

Efavirenz is one medication that is known for its ability to cause psychological side effects, from mild mood changes to severe depression.

Efavirenz is no longer part of first line treatment (although there are many people in Timor-Leste who are still taking Efavirenz with no problems).



Annex 1 Example Client Feedback Questionnaire

Client Feedback Questionnaire				
Your opinion is important to us! It will help us understand what we're doing well and areas where we could improve. Your responses will remain private and anonymous so please speak your mind.				
Please give your opinion on how our clinic is going in these areas	Not Good (1) 😞	In the Middle (2) 😐	Good (3) 😊	Very good (4) 😄
Helping you to feel comfortable and relaxed in the clinic				
Being friendly, respectful, and professional				
Keeping information private and confidential				
Listening to you carefully				
Explaining information clearly				
Encouraging you to ask questions and talk about your concerns				
Including you in decisions about treatment				
Having the medical knowledge and skills required to take care of you				
Taking blood, including explaining reason for the blood test				
Keeping the clinic environment clean and nice				
Arranging your clinic appointments				
Following up well by phone/messaging				
What is something you think we are doing well our clinic?				
What can we do to improve?				
Thank you for completing this survey! 😊				

Annex 2 Example Confidentiality Agreement

Letter of Nondisclosure and Confidentiality Agreement

Full name:

Contact No.:

Date:

Staff from:

I who sign in this document with all my conscience declare that in regards to all patient-related information made available to me, I will):

1. Keep all information provided to me related to patient/client status, medical record, discussions, research and other related program activities in strict confidence
2. I will not disclose any of this information to anyone, except if necessary to the healthcare worker at the workplace
3. By signing, I understand well that when breaking this agreement, I'm ready to get any penalty according to the process.

Signature of staff

Print name/title

Annex 3 Example Appointment Reminder Card

<p style="text-align: right;">Tif: (000) 000 - 0000</p> <p>Apontamentu</p> <hr/> <p>Data:</p> <hr/> <p>Oras:</p> <hr/> <p>Karik ita labele tuir ita nia apontamentu, favor ida bele telefone ba ami obrigada</p>	<p style="text-align: right;">Tif: (000) 000 - 0000</p> <p>Apontamentu</p> <hr/> <p>Data:</p> <hr/> <p>Oras:</p> <hr/> <p>Karik ita labele tuir ita nia apontamentu, favor ida bele telefone ba ami obrigada</p>
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Annex 4 Remaining on Treatment – Barriers and Strategies for PLHIV

BARRIERS	POSSIBLE STRATEGIES TO TRY
I'm worried about getting side effects from ART	<ul style="list-style-type: none"> • Use a well-tolerated ART regimen like TDF/3TC/DTG to avoid side effects • Discuss with HIV care team if regimen change may be indicated • Headache and nausea from EFV generally self-resolve after a few days. Meanwhile, can try paracetamol for headache and ginger tea for nausea • Avoid insomnia from DTG by taking it in the morning, not at night • Counselling according to the Stages of Readiness (focussing on Stage 2)
There are too many tablets	<ul style="list-style-type: none"> • Discuss with HIV care team about options for reducing pill burden • Remind client that some of the tablets (e.g., TB treatment or Cotrim prophylaxis) are only temporary • Counselling according to the Stages of Readiness (focussing on Stage 2)
I forget	<ul style="list-style-type: none"> • Take medicine at the same time every day to help it become a habit • Combine taking medicine with an established activity (e.g., brushing teeth, eating breakfast) to help it become a habit • Set a daily alarm reminder on mobile phone • Text reminder messages • Ask family members to help remind to take medicine • Counselling according to the Stages of Readiness (focussing on Stage 2)

Busy life gets in the way	<ul style="list-style-type: none"> • Take medicine first thing in the morning before the day gets too busy • Keep some tablets in a small plastic bag in your handbag, wallet, pocket etc in case you spend the night away from home • Counselling according to the Stages of Readiness (focussing on Stage 2)
I think the tablets should be taken with food, and sometimes I don't have any food	<ul style="list-style-type: none"> • Discuss with HIV Care team and partners (Estrela Plus, Esperansa, NAC) about accessing social support for PLHIV with food insecurity • Explain that taking the tablets just with water is fine
I'm afraid people will see the tablets and ask questions	<ul style="list-style-type: none"> • Remove labels from ART bottles • Have a plan for what to say about the tablets if asked • Counselling to support HIV status disclosure
When I see the medicine, I think negative thoughts about HIV and feel bad	<ul style="list-style-type: none"> • Explore possibility of self-stigma and depression • Strengths-Based counselling • Counselling according to the Stages of Readiness (focussing on Stage 2) • Help client develop active coping strategies, including How to Change Your Thoughts to Change Your Mood
I have low energy/motivation to take medicine	<ul style="list-style-type: none"> • Explore possibility of self-stigma and depression • Strengths-Based counselling • Counselling according to the Stages of Readiness • Help client develop active coping strategies, including How to Change Your Behaviour to Change Your Mood

I don't really believe I have HIV	<ul style="list-style-type: none"> • Explore possibility of self-stigma and depression • Counselling according to the Stages of Readiness (focussing on Stage 1) • Help client develop active coping strategies, including Working Towards Acceptance
I don't think I need this medicine anymore; I gained weight and now I feel fine	<ul style="list-style-type: none"> • Strengths-Based counselling • Counselling according to the Stages of Readiness (focussing on Stage 5)
I'm too stressed about other things to think about taking medicine every day	<ul style="list-style-type: none"> • Strengths-Based counselling • Counselling according to the Stages of Readiness • Help client develop active coping strategies
Sometimes I drink too much alcohol and don't take my medicine because of that	<ul style="list-style-type: none"> • Explore possibility of self-stigma and depression • Counselling for behaviour change (regarding stopping drinking alcohol) according to the Stages of Readiness and including a Strengths-Based approach • Help client develop active coping strategies
I have no money for transport to the clinic	<ul style="list-style-type: none"> • Discuss with HIV Care team about options (help with transport costs, phone follow up, home visit) • Ask partner organisations about possibility of picking up client and taking to the clinic Estrela Plus: 7522 0561/ 7403 0902/ 8001 099 Maloa ART Centre: 7605 0945 / 7710 3635

I always run out of tablets; it is hard for me to get to the clinic every month	<ul style="list-style-type: none"> • Dispense 3 or more months of ART at a time • Talk to HIV Care team about option of door delivery
I don't really feel comfortable coming to the clinic to collect my medicine	<ul style="list-style-type: none"> • See Creating a Friendly Environment
My family thinks I should take traditional medicine instead of ART	<ul style="list-style-type: none"> • See Adherence and Traditional Medicine • Explain taking both traditional medicine and ART together is okay • Counselling according to the Stages of Readiness • Providing information to the family if client agrees

Annex 5 Evidence-based tools for HIV prevention, for individuals and for healthcare workers/counsellors

Individuals	Healthcare Workers / Counsellors
HIV Testing	
<p>“Know Your Status” – get an HIV test early</p> <p>Repeat HIV testing if ongoing risk (sex without condoms)</p>	<p>Make your health centre friendly and welcoming to encourage people to come for testing</p> <p>Provide skilled and empathetic Pre and Post Test Counselling</p> <p>Ensure HIV Determine testing is done correctly, according to the SOP</p>
Successful Linkage to Treatment (“Treatment As Prevention”)	
<p>Connect with the HIV care team and a Peer Counsellor if your HIV test has come back positive</p> <p>Starting ART is the best step you can take to protect your own health</p> <p>Your HIV team will support you to take medication every day, so that you can keep the Viral Load at Undetectable levels</p> <p>PLHIV will not transmit HIV to others when the virus is consistently suppressed – known as U=U (Undetectable = Untransmissible)</p>	<p>Ensure everyone who tests positive for HIV is linked to care by following the HIV Successful Linkage SOP</p> <p>Establish trusting client-provider relationships so PLHIV feel supported to start ART</p> <p>Support PLHIV to remain engaged in care with good adherence to ART</p> <p>Use your clinical skills to address any medical problems early</p> <p>Monitor Viral Load regularly to ensure viral suppression is maintained</p>
PEP and PrEP	
<p>If you are HIV negative and had a high-risk HIV exposure within the last 72 hours you can take PEP (Post Exposure Prophylaxis) to reduce the risk of HIV transmission</p> <p>If you are HIV negative and regularly at risk of acquiring HIV you can take PrEP (Pre-Exposure Prophylaxis) to reduce your risk of acquiring HIV</p>	<p>Include PEP and PrEP as part of your ART centre’s service if you have had training about this.</p> <p>PrEP and PEP currently have limited availability in Dili only</p>

Condoms with Counselling	
<p>Use condoms for sex – correctly and consistently</p>	<p>Offer condoms to clients at every visit</p> <p>Promote the importance of condoms, especially for HIV negative people and PLHIV who have not yet achieved a suppressed Viral Load</p> <p>Provide counselling on how to use condoms correctly and how to negotiate use of condoms before sex</p> <p>Condoms are free, effective, and available across the country</p>

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