NEW HIV DIAGNOSIS WORKSHOP

A SERVICE MANUAL

A service manual for the delivery of a new HIV diagnosis workshop to people living with HIV.

Contents

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The HIV Foundation Asia and APMGlobal Health developed The New HIV Diagnosis Workshop Manual. We welcome reproduction and modification by other organizations that wish to utilize this resource. Please acknowledge the authors of this manual and our organisations.

SECTION ONE: ABOUT THE MANUAL

The New Diagnosis Workshop Manual has been produced to support orientation of people with HIV to living well with HIV. This manual is primarily designed to provide advice and resources for group facilitators and educators of new diagnosis workshops.

This manual covers basic skills and knowledge necessary for group counsellors and educators to deliver the workshop. The workshop agenda and materials provide a structure for delivery of the workshop over one, six-hour day. The workshop structure can be tailored to fit the skills and needs of the group counsellors and educators involved. If changes are made to the material we recommend you adhere as much as possible to the learning points describes for each module.

The manual is not a Standard Operating Procedure. It has been written to provide guidance at specific points in the workshop process. The manual aims to assist facilitators and educators who are delivering *peer* support – i.e. where the facilitator or educator is themselves a person living with HIV and/or identifies as coming from a marginalized population. The manual is also intended to assist those delivering non-peer based services including professional social workers or welfare practitioners who may or may not be living with HIV or identify with people from marginalized populations.

Note that we have not provided an evaluation form with this manual as it is simply a workshop guide.

About the workshop

The workshop is a one-day group session that provides participants with the chance to share their experiences, reactions and fears at receiving their HIV diagnosis, to provide an opportunity to meet others in the same situation to make friends and to impart basic knowledge and skills that can help participants to live well with HIV. Many newly diagnosed people living with HIV are lost to follow-up soon after diagnosis as the diagnosis is overwhelming. This workshop aims to connect with them immediately after initial diagnosis and offer information and support so that they can connect with health care and are not lost to follow-up.

A Note on Language

This Service guide is designed to be generic enough to fit any host organization that is planning to deliver a new diagnosis services. This approach means that language is used throughout the manual to reflect the general nature of the advice given.

Host Organization: A host organization is one that has decided to deliver a PLHIV Support and Case Coordination Service and is using this manual to establish and manage the project.

A note on Staff and Volunteers: The manual uses the terms staff and volunteers interchangeably. It also refers to ‘caseworkers’. This is in acknowledgement that host organizations will have varying human resources systems for managing service delivery. Some organizations use paid staff exclusively, others use volunteers exclusively. Still others employ a mix of paid staff and unpaid or subsidized volunteers for the delivery of services. The manual does have a view about any of these human resource systems and seeks to support the existing structures of host organizations and allow them to decide for themselves how to manage human resources.

Before you start

The room used for the workshop should be private and secure. This means the doors should be closed and that any people outside cannot hear what is happening inside the room.

People should not get up and move in and out of the room during the workshop – this is essential to establishing safety and trust.

People outside the workshop should not be able to enter the workshop space while the workshop is happening. This means either having a person outside the space that stops people entering or locking doors while sessions are occurring. Again, this is essential to establishing safety and trust with the participants.

Helpful hints

Before this session you need to determine whether (a) a participant does not read or write or (b) a participant is visually impaired. It is best to ask questions of individuals related to literacy and sight impairment well before the workshop starts. There is no need to draw attention to this - simply provide support to this individual without referring to it.

Before the workshop you need to ask invited participants to bring copies of blood test results if they have them and to bring all the HIV treatment they are taking now. The HIV treatment should include ART as well any preventive treatment for opportunistic infections.

Acronyms and Abbreviations

AIDS	Acquired Immune Deficiency Syndrome
ARV	Antiretroviral treatment
ART	Antiretroviral treatment
BCC	Behavior Change Communication
CBO	Community-Based Organization
CCM	Country Coordinating Mechanism
DIFD	Department for International Development (UK)
FSW	Female Sex Worker(s)
GFATM	Global Fund to Fight AIDS, Tuberculosis and Malaria
HCT	HIV Counseling and Testing
HIV	Human Immunodeficiency Virus
ICT	Information and Communication Technology
IEC	Information, Education and Communication
KAP	Key Affected Population
MARP	Most-At-Risk Population
MSM	Men who have Sex with Men
MOH	Ministry of Health
NSP	National HIV and AIDS Strategic Plan
PEPFAR	President’s Emergency Fund for AIDS Relief
PLHIV	People living with HIV
STI	Sexually Transmitted Infection
TG	Transgender person/people/populations
UNAIDS	Joint United Nations Programme on HIV/AIDS
USAID	United States Agency for International Development
WHO	World Health Organization

SECTION TWO – WORKSHOP STRUCTURE OVERVIEW

The purpose of this section of the New diagnosis Workshop Manual is to detail a description of the workshop's agenda and structure. Group facilitators and educators can use this section of the manual in their planning, preparation and delivery of the workshop. It can be useful to refer to this section of the manual during the workshop itself.

SESSION 1 – WELCOME AND INTRODUCTIONS

Session 1 is welcome and introductions. Facilitators introduce themselves, explain the purpose of the workshop and ask participants to introduce themselves to each other.

<table>
<tr><th colspan="2">Learning Objectives</th></tr>
<tr><td colspan="2">1. Participants will know the names of the facilitators in the workshop.
2. Participants will know each other's names and something about each other.
3. Participants will understand the purpose of the workshop and the ways in which the facilitators will protect their privacy during the workshop.</td></tr>
<tr><th>Materials Needed</th><th>Timing</th></tr>
<tr><td>1. White board and markers.</td><td>10.00am – 10.15am (15 minutes).</td></tr>
<tr><th colspan="2">Advice for this introduction session</th></tr>
<tr><td colspan="2">Tell us your name, tell us something about how you felt before coming here, tell us why you are coming here today and what you hope for from the day (e.g. "My name is Sam, I was afraid to come here today, I hope to make friends with some people who facing the same situation that I am."
Focus your attention on people who are not talking or participating. Remember to engage them so they become more comfortable with speaking and not just listening during the entire workshop.
Explain the steps you have taken to ensure focus, privacy and trust for the workshop.</td></tr>
</table>

SESSION 2 – SETTING THE GROUNDRULES

Session 2 Setting the Groundrules is a short session that provides an opportunity for facilitators and participants to agree on what they need to keep the workshop focused and safe for everyone. Implementing this session can be done in many ways. Facilitators can list a series of Groundrules on flipchart paper for discussion or they can simply ask participants what they need to feel safe together.

Learning Objectives

4. Participants will know the names of the facilitators in the workshop.
5. Participants will know each other's names and something about each other.
6. Participants will understand the purpose of the workshop and the ways in which the facilitators will protect their privacy during the workshop.

Materials Needed	Timing
2. White board and markers.	10.00am – 10.15am (15 minutes).

Preparation

The most common ground rules raised include:

Be ready for each new session on time / don't be late – ask participants to be ready to start each new session of the workshop at the time it is due to start.
Turn off mobile phones during sessions – ask participants to please switch off their mobile phones and don't use them during workshop sessions.
No 'advice' to others – talk about yourself - use 'I' statements – ask participants to please speak about their own experiences and avoid telling people what they 'should' do.
Be supportive to each other – ask participants to give each other their complete attention by not talking over others and not talking when someone else is already speaking.
Be constructive – ask participants to avoid criticizing others and to provide constructive feedback that is caring and thoughtful.
Equal time for all – ask participants to give everyone a chance to talk.
Confidentiality – agreeing to keep everything said here in the room. What happens when we meet each other at a party, on the street? We need to respect the privacy of each other. We don't need to acknowledge each other. What happens when someone asks 'how do you know this person?'
Tell us if you are unhappy – ask participants to please approach a facilitator is there is a problem, if they are uncomfortable or if they offended or upset.
Stay for the entire day – ask participants to remain in the workshop for the entire day.

SESSION 3 – TALKING AND LISTENING

INTRODUCTION

This *talking and listening session* is a group discussion (sometimes called an 'encounter group') session. It is an opportunity for participants to talk about their experiences of and reactions to being newly diagnosed with HIV. It is a chance to listen to the experiences and reactions of others in the same situation. Its purpose is to facilitate participants' understanding that they are not alone in their experience of new HIV diagnosis. Most importantly, it aims to instil in participants a desire to connect with others who are living with HIV.

HELPFUL HINT:

Before this session you need to determine whether (a) a participant does not read or write or (b) a participant is visually impaired. It is best to ask questions of individuals related to literacy and site impairment well before the workshop starts. There is no need to draw attention to this - simply provide support to this individual without referring to it.

<table>
<tr><th colspan="2">Learning Objectives</th></tr>
<tr><td colspan="2">1. Develop the capacity to reflect on one's experiences of living with HIV.
2. Develop skills in speaking about one's personal experience of HIV.
3. Develop skills in listening to and affirming other's experience of HIV.
4. Develop awareness that one is not alone with HIV – that others share one's feelings and reactions to being diagnosed with HIV.
5. Develop an understanding that social interaction with others living with HIV is beneficial.</td></tr>
<tr><th>Materials Needed</th><th>Timing</th></tr>
<tr><td>1. A box with a lid on it and a slot on the lid.
2. Paper and pens for each participant.
3. Tissues.</td><td>10.00am – 12 noon (2 hours).</td></tr>
<tr><th colspan="2">Preparation</th></tr>
<tr><td colspan="2">It is helpful to prepare by considering the sorts of themes that will emerge in this session before beginning. Doing so helps you prepare for the emotional reactions that participants may:
• Disclosing to family, friends, partners – participants often fear telling their loved ones they have HIV; they often seek the experiences of other group members about disclosing.
• Fear of never finding love – participants often express a fear that, now they live with HIV, they have lost their opportunity to find love, to get married and to have children.
• Hostile service experiences at diagnosis – some participants will disclose poor service experiences during their HIV diagnosis.
• Please read Addendum 1 About Group Counseling.</td></tr>
</table>

A Detailed Description of Session 3 - Talking and Listening

Overview of the process

The steps in *Session 3 Talking and Listening Session* are as follows:

STEP ONE: Explanation of the process to be followed.

STEP TWO: Paper and pen are handed to each participant.

1. Participants are invited to write down:
    a. A statement/a paragraph that describes their experience of new diagnosed with HIV.
    b. A statement/ a paragraph that describes the feelings they have experienced.
    c. Any questions they would like answered throughout the day about HIV.
2. Once they have completed this task they fold these pieces of paper up and place them in a box in the centre of the circle.

STEP THREE: These are then distributed randomly to others to read out loud and to react to.

STEP FOUR: The facilitator(s) supports thinking about and discussion about the issues raised by asking questions and, when necessary, sharing their own experience.

STEP 1 – Explain the process

Start by explaining the process that will be followed during the session:

THE GROUP FACILITATOR SAYS: "This first session is an opportunity for us to share our feelings and experiences about being diagnosed with HIV and living with HIV.

- We are going to distribute paper and pens to each of you.
- We want you to write down on the piece of paper your experience of being diagnosed with HIV, how you felt, how you feel now and any concerns or questions you still have.
- This is a chance to ask for a discussion about things that you'd like to hear others talk about.
- We want this process to be **anonymous**, so please don't write your name down on the paper.
- Write very clearly because someone else is going to read what you have written out loud to the group.
- Once you have finished, fold the paper up and place it in the box in the middle of the circle.
- We will then shake-up the box and distribute the paper randomly to each of you."

TIP: You will have to repeat this explanation or parts of it several times during the process

STEP 2 – Writing something about HIV diagnosis

Start by distribute the paper and pens and provide time for each participant to think quietly. They write down their story, any questions or things they'd like discussed.

THE GROUP FACILITATOR SAYS: "So now you are writing down something about your experience being diagnosed with HIV, how you felt, how you feel now and any concerns or questions you'd like answered or discussed."

- The facilitator may need to repeat some parts of the explanation several times.
- The facilitator may need to spend some time with each participant to help them articulate and write down their story.
- This is a period of silent reflection in which participants are remembering and thinking about their experiences and feelings about being diagnosed.
- Once participants have completed their stories they should fold up the piece of paper and place it in the box in the centre of the circle.

TIP: Remember to support any one who is sight impaired or unable to read or write.

STEP 3 – Distribute the stories

Once all participants have completed their stories and placed them in the box, shake up the box and re-distribute the stories randomly to the participants. Ask them to

- Read the stories to themselves (not out loud at this point).
- Sit in silence for a minute and think about their own reaction to what they are reading.
- Consider the following questions: "Do I share feelings or experiences that I am reading?" "What do I want to say to this person?" "Can I answer any of the questions this person has?"

STEP 4 – Facilitate discussion

Go around the group one-by-one, asking participants to read what is written on their piece of paper out loud to the rest of the group. Then ask each person to answer the following questions:

- How do you feel about what you've just read?
- Do you have similar experiences or feelings to this person's experiences or feelings? If yes, can you explain? If no, can you explain?

Once the individual has read and explained their own feelings ask the rest of the group:

- Does any one else share this concern/have this experience? Can you explain your experience to us?

SESSION 4 – LIVING WELL WITH HIV

Session 4 – Living Well with HIV is an HIV education session. It is an opportunity for newly diagnosed PLHIV to learn what they need to know to live a long and successful life with HIV and to share what they know already with each other. The session provides a chance to listen to the experiences and reactions of others on a range of health seeking issues. The purpose of the session is to increase participants' knowledge and skill so they feel they can manage their own health over the long term.

Learning Objectives

7. Develop an understanding that emotional reactions to being tested for and being newly diagnosed with HIV will change and become easier to live with over time.
8. Develop practical knowledge and skills about living well with HIV including:
    a. How HIV works in the body.
    b. Testing and health monitoring for HIV.
    c. The top 6 most common HIV related illnesses.
    d. How HIV treatment works to prevent people with HIV getting sick.
    e. How and why to take HIV treatment every day, on time, every time.
9. Develop practical knowledge and skills to deal with gender and sexuality related health issues.

Materials Needed	Timing
3. White board and markers. 4. Toilet paper. 5. Small table in the centre of group circle.	1.00pm – 3.30pm (2 hours and thirty minutes).

Preparation

This section of the workshop provides information on living well with HIV. The manual provides facilitators/educators with short information modules that include dialogue, key messages, and dot points of the key issues, process steps and diagrams.

It is helpful to prepare by reading through each module carefully. Having each module available to you during the session will also assist you to keep to the key messages you wish to impart.

MODULE 1: Testing for HIV

YOUR KEY MESSAGE:

"An HIV test is a choice to live healthy and well. A negative HIV result helps you to stay HIV free. While a positive HIV result gives you the chance to live a good and healthy life too: because there's effective treatment now for people living with HIV. No matter what the result, getting tested helps you to live your dreams and to do what you really want to do with your life."

WHAT TO ASK PEOPLE ABOUT HIV

What do you think or feel about HIV?
What do you know about it?
What was your experience of HIV testing?

WHAT TO SAY ABOUT HIV

HIV is transmitted through unprotected anal and vaginal sex and by sharing needles.

It's possible to stay HIV-free. Using condoms and water-based lube for anal and vaginal intercourse helps to protect you and your partners from getting or passing on HIV to each other.

There's good news about HIV – there's effective HIV treatment that helps people live long and healthy lives.

The earlier a person knows they have HIV the better their chances of living well.

It's possible to have a relationship with someone who doesn't HIV so that they stay HIV free by using condoms during sex and reducing your viral load using HIV treatment.

WHAT TO SAY ABOUT HIV TESTING

HIV testing is **confidential** and **private**. Even though we meet in the same places as you and your friends, we don't tell *anyone* about your health results, ever.

You don't have to be alone through the testing process. We're here to help you. We can go with you, wait with you for the results and afterwards too.

If you test HIV negative, we'll help you understand how to stay HIV free.

If you test HIV positive, we'll help you too. You won't be alone. We'll help you get what you need to live well with HIV.

HELPFUL SERVICE HINTS

Be honest – when you know the answer to a question answer it. When you don't, offer to find out and let the person know when you see them again. Don't mislead people, ever: especially about HIV, sexual health or drug-use questions.

Accept people for who they are – don't judge people for what they do, what they disclose to you or the choices they make to test or not to test, to treat or not to treat. Be a non-judgmental friend to the people you meet.

Do what you promise to do – follow through on the things you promise to do. If you can't do something then say that you can't do it.

MODULE 2: Newly diagnosed with HIV

YOUR KEY MESSAGE:

"A positive HIV result gives you the chance to live a good and healthy life: because there's effective treatment now for people living with HIV. Knowing your test result helps you to live your dreams and to do what you really want to do with your life.*"*

GAME: WHEN WERE YOU DIAGNOSED?
Chart participant time of diagnosis on a continuum from the day of the workshop 'today' back in time to the person who has been diagnosed the longest in the group. (See Diagram Aid on the next page). The goal is to facilitate info sharing between clients and help the most recently diagnosed see that crisis, shock, fear and anxiety recedes over time. Importantly, this process helps people with HIV in the room 'teach each other' without the need for the facilitator.

WHAT TO SAY ABOUT NEW DIAGNOSIS

You are not dying – many people with HIV live normal and healthy lives with HIV and you can too.

You are not alone – there are many other people living with HIV. We can help you to meet some of them. We can also help you to learn to live with this news and help you decide what to do next.

You can live life as you did before – living with HIV doesn't mean you are sick or disabled. Today you know you have HIV but your life doesn't have to change a lot. If you are sick, the sooner you treat the quicker you can return to better health.

Take your time – relax and breathe. You don't need to You don't need to do anything – take some time to think about things for a few days.

MORE ABOUT LIVING WITH HIV

HIV is a virus. HIV is a virus that damages your body. Being told that you have HIV means that you have HIV in your body. If you don't look after your HIV health then HIV can make you sick. But if you take care of your HIV health you can live a long and successful life.

Love and HIV. You can still find love when you have HIV. You can still have a family and children when you are living with HIV. Talk to your doctor about treatment that can help.

You don't need to tell anyone right now. But it can be helpful to tell someone you trust and that you know will be supportive and caring.
Some important questions:
Will they tell other people that you have HIV? Are they going to gossip? If yes, then not telling them is a good idea.
Will they be angry or upset with you? If yes, then delay telling them until you've had more time to think it through.
Will they judge you? If yes, then delay telling them until you've had more time to think.

HELPFUL SERVICE HINTS

Listen more than you talk. The easiest way to establish a caring relationship with a person newly diagnosed with HIV is to focus on **listening much more than talking**. Keep the attention on the person with HIV and not on yourself. This can be hard to do - especially when the client keeps asking questions or is asking for you to share your own experiences.

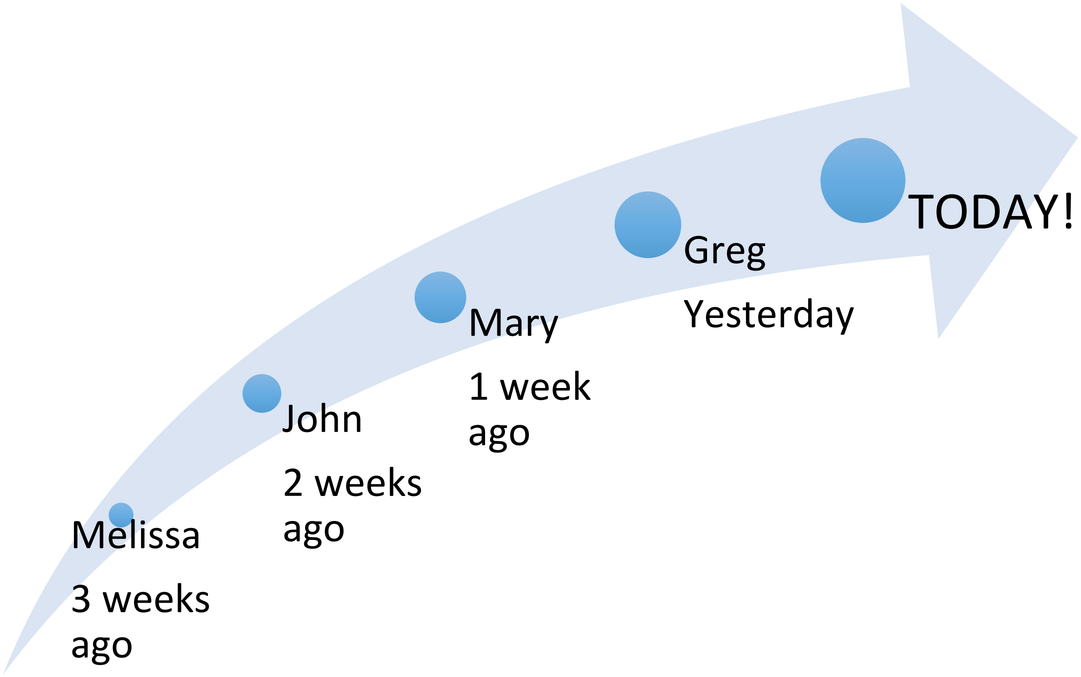
Diagram Aid #2 New Diagnosis with HIV

This interactive process involves workshop facilitators asking participants to disclose the date of their HIV diagnosis and then charting participant's answers on a continuum (like the diagram below). It is recommended that you make this a physical activity: use toilet paper to stretch out a long line across the entire middle of the workshop floor and then put one facilitator at the end of the line. This facilitator says: "I'm standing here at the end of this line. Where I'm standing represents *today*. The rest of this line represents the past. I want you to order yourselves along this timeline according to the person most recently diagnosed with HIV to the person who has been living with the knowledge of their HIV positive status the longest". (The result of this should be the person most recently diagnosed closest to the facilitator on the line and the person who has been living with the knowledge of their HIV status the longest at the very end of the line).

If you wish, you can ask people to then place something that they own along the line and then sit back down or you can keep people standing along the line.

Now, go through the follow process:

1. Start with the person most recently diagnosed. Ask them to describe their current thinking and feelings about living with HIV.
2. Move to the next most recently diagnosed and ask them to describe their current thinking and feelings about living with HIV.
3. Continue this process until you reach the person who has been living with HIV the longest and ask the same questions.



MODULE 3: How HIV works in the body

YOUR KEY MESSAGE:

“If you look after your HIV health you can live a long and healthy life with HIV. Knowing how HIV works in your body can help you make the right choices for your health and wellbeing.”

WHAT TO ASK ABOUT HIV IN THE BODY

Asking questions about previous experiences of HIV helps to check a client’s assumptions and misunderstand and to correct them if needed.

What do you know about HIV?
Do you know anyone else living with HIV?
Have you ever known a person with HIV?

WHAT TO SAY ABOUT HIV IN THE BODY

The immune system protects you from illness.

HIV is a virus that damages the human immune system. Being told that you have HIV means that you have HIV in your body.

HIV destroys immune cells called CD4 cells.

HIV has the ‘key to the lock’ of CD4 cells.

HIV turns CD4 cells in to ‘**virus making factories’**.

HIV reproduces inside CD4 cells and releases more HIV in to the blood stream.

CD4 cells die and weaken the immune system.

HIV treatment prevents HIV destroying CD4s.

WHAT TO SAY ABOUT HIV AND AIDS

HIV is a virus and can be transmitted between people. HIV stands for Human Immunodeficiency Virus.

AIDS is a syndrome caused by HIV and cannot be transmitted between people. AIDS stands for Acquired Immune Deficiency Syndrome.

HIV and AIDS is not the same thing.

AIDS is a series of symptoms and illnesses that appear because the immune system cannot protect the body from illness.

If you don’t maintain your HIV health then it will damage your immune system. If you do take care of your HIV health then **you can have good health and live a long life.**

When HIV is left untreated the body experiences illnesses called ‘**opportunistic infections’**. This is because they take the *opportunity* of a weakened immune system to take hold in the body.

Opportunistic infections are treatable and preventable with drug treatment.

HELPFUL SERVICE HINTS

Be positive and optimistic – there is lots of good news about HIV. It’s important to keep saying, “now you know you have HIV you can live a long and healthy life.”

Diagram Aid for How HIV Works in the Body

The diagram below highlights the seven important points to make about how HIV works in the body. This diagram can be projected on to a screen and used to facilitate this session or facilitators can refer to the diagram to ensure that they have covered all points on it.

1. HIV has the 'key to the lock' of blood cells called CD4 cells.

2. HIV enters CD4 cells and merges with RNA.

3. HIV turns each CD4 cell in to a 'virus making factory.'

4. HIV releases new HIV particles in to the blood stream from CD4 cells.

5. Eventually CD4 cells die and cannot be replaced.

6. Without treatment this results in a weakened immune system and illness.

7. CD4 count below 500 requires treatment.

Key points in the lifecycle of HIV

1. HIV and CD4 cells
2. HIV and the ‘key to the lock’
3. CD4 ‘virus making factories’
4. Releasing new virus
5. Weakening immune system
6. CD4s at 500/350/200 cells
7. Treatment stops HIV

MODULE 4: Testing and monitoring when you live with HIV

YOUR KEY MESSAGE:

"You can take control of your HIV health by checking your HIV blood results on a regular basis. Whether you're taking HIV treatment or not, monitoring your blood results is the best way keep well and healthy over the long term."

PROCESS: VL LOW/ CD4 HIGH

In a red pen, draw a line from one corner of the whiteboard diagonally to the other. In a blue pen, draw a line from the opposite end of the whiteboard diagonally to the other. Use this diagram to explain test results with the red line representing HIV viral load and the blue line representing CD4 count. Final statement should be: "You want your viral load to go down and your CD4 count to go up.

KNOW YOUR TESTS

You need to have blood tests every three-six months to monitor the health of your immune function and the progress of HIV in your body. There are two important tests that you need:

The CD4 test tells you how strong your immune system is. A nurse draws blood and counts the number of CD4 cells in the vial of blood taken. A low CD4 result indicates that HIV is progressing in your body. A high CD4 cell result indicates that HIV has not progressed or damaged your immune system. A high CD4 test result is better.

The HIV viral load test tells you how strong the virus is in your body. A nurse draws blood and counts the number of viral particles in the vial of blood taken. A high viral load result indicates that HIV is very active in your body. A low viral load result indicates that HIV is not so active in your body. A low viral load result is better.

GAME: WHAT'S YOUR CD4 RESULT?

Ask participants who have had a CD4 test and received the result to tell you the number of their CD4 result. Chart their results on a continuum (See Diagram Aid on next page). Explain the implications of participant CD4 results.

If your CD4 test result is 200 or below then your doctor should immediately advise you to take preventative treatment for what is called 'opportunistic infections'. You will usually start preventative treatment first and then, once stable on that treatment, your doctor will advise you to start HIV antiretroviral treatment.

If your CD4 test result is 350 or below then your doctor should immediately advise you to take antiretroviral treatment.

If your CD4 result is 500 or above then it's simply important to keep monitoring and take the advice of your doctor. However, when treatment is made available for people with CD4 results above 500 you should start treatment, of course always on the advice of your doctor.

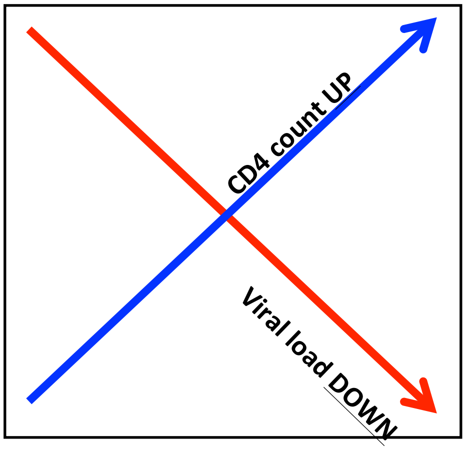
KINDS OF HIV TREATMENT

Preventative Treatment – Preventative treatments are drugs that stop you getting serious illnesses related to HIV. If your CD4 test result is low and your viral load test result is high then your doctor may recommend that you start taking some preventative treatment.

Antiretroviral treatment – Antiretroviral (ARV) treatments are drugs that lower your HIV viral load and increase your CD4 cells. If your CD4 test result is low and your HIV viral load is high then your doctor may recommend you start taking ARV treatment to prevent progressing to AIDS.

DIAGRAM AID #4: Testing and Monitoring

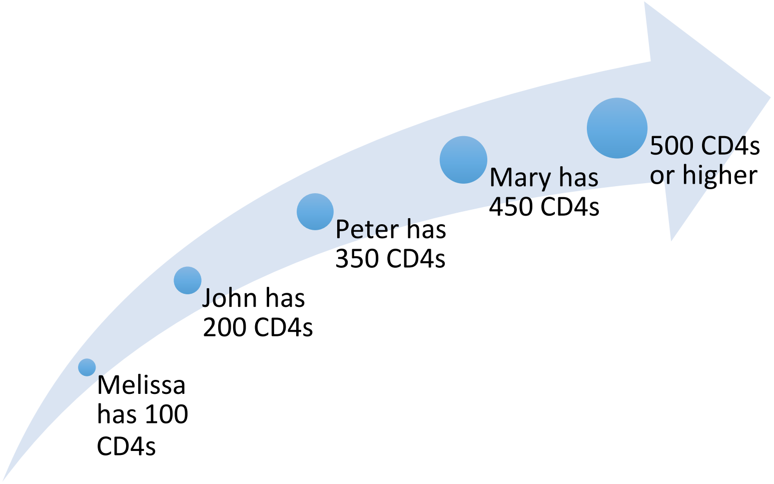
PROCESS: VL DOWN/CD4 UP



In a red pen, draw a line from one corner of the whiteboard diagonally to the other. In a blue pen, draw a line from the opposite end of the whiteboard diagonally to the other. Use this diagram to explain test results with the red line representing HIV viral load and the blue line representing CD4 count. Final statement should be: "You want your HIV viral load to go down and you want your CD4 count to go up.

GAME: WHAT'S YOUR CD4 RESULT?

Ask participants who have had a CD4 test and received the result to tell you the number of their CD4 result. Chart their results on a continuum (See Diagram Aid below). Explain the implications of participant CD4 results.



100 CD4s or lower	200 CD4s or lower	350 CD4s or lower	499 CD4s or lower	500 CD4 or higher
Significant damage to your immune system. Preventative and ARV treatment urgently required.	Significant damage to your immune system. Both preventative and antiretroviral treatment immediately required.	Damage to your immune system. Only antiretroviral treatment is needed unless you have symptoms indicating an opportunistic infection.	May indicate early damage to your immune system. Swollen lymph glands, night sweats, fungal infections such as candida (thrush), athlete's food and tinea are common.	Usually no symptoms present. Monitor and take the advice of your doctor.

MODULE 5: Top 6 Opportunistic Infections

YOUR KEY MESSAGE:

"All opportunistic infections can be prevented, managed or cured. The good news is, even if your CD4 count is low or you have symptoms of an OI you can prevent, manage or cure these infections."

OPPORTUNISTIC INFECTIONS (OIs)

Serious and life threatening OIs occur usually when the CD4 count is between 250 to 200 or lower. The top SIX OIs include:

TOP 6 OPPORTUNISTIC INFECTIONS

OI 1: TUBERCULOSIS (TB)

All people diagnosed with HIV should be tested for TB. Co-infection with HIV and TB is very serious. Worldwide TB is the leading cause of death among people with HIV.

TB is a 'bacteria' and is passed to others by coughing or sneezing or being in a confined, baldy ventilated space with others.

TB diagnosis: blood test or a chest x-ray.

Active TB: determining whether TB is 'active' or 'inactive' may require a sputum smear (coughing mucus up from the airway).

Inactive TB: someone with 'inactive' TB cannot spread TB. Inactive means the person has fought off active TB. But should their immune system weaken inactive TB may become active again.

Treatment for TB is *antibiotics* used in combination. I*soniazid, Rifabutin, Myambutol ad Pyrazinamide*. Drug resistant TB is an emerging problem that makes treatment and cure of TB complicated for some people. Talk to your doctor about treatment options and side effects.

Studies show that people with HIV are at increased risk of TB. Those with lower CD4 results are at even higher risk.

OI 2: PNEUMOCYCSTIS JEROVECI

Pneumocystis Jeroveci used to be called Pneumocystis Carinii Pneumonia or PCP. It is of pneumonia caused by a 'fungus'. You are at increased risk of PCP when you're CD4 is below 250. PCP can be life threatening.

HIV positive smokers are three times more likely to get PCP.

Symptoms include shortness of breath and/or fever. Dry cough, pain or tightness in the lungs. Weight loss and diarrhoea.

PCP diagnosis: a chest x-ray, measuring the amount of oxygen in the blood and/or looking at a PCP sample for PCP organisms.

PCP treatment: antibiotic called *cotrimoxazole*, sometimes called *dapsone* and sometimes *septrin*.

OI 3: CYTOMEGALOVIRUS (CMV)

CMV is a virus from the herpes family. Like other herpes viruses it is sexually transmitted in semen, vaginal secretions, through blood and saliva and can be transmitted from mother-to-child through breast milk.

CMV retinitis is the most common symptom. CMV retinitis untreated can cause blindness.

CMV diagnosis: an ophthalmological examination of the eye or a biopsy.

Treatment for CMV: intravenous *ganciclovir* and *foscarnet* given in combination - intravenous for both CMV retinitis and gastrointestinal CMV. Injections directly in to the eye required to prevent blindness.

New complications and ART: ARVs prevent and treat CMV. But increased *uveitis* (inflammation of iris) and *vitritis* (inflammation of back of the eye) among those diagnosed with CMV and started ART have been reported.

OI 4: MYCOBACTERIUM AVIAM COMPLEX (CMV)

MAC is a ‘bacteria’ found in soil, water and other places in the environment. It attacks lungs, the intensives or it may be ‘disseminated’ though the body. Disseminated MAC can be life threatening.

MAC diagnosis: MAC can be diagnosed with a blood test but sometimes requires a bone marrow sample.

Symptoms of MAC include fever, night sweats, abdominal pain, fatigue and diarrhoea.

MAC treatment and prevention uses *antibiotics* and the most common ones are *clarithromycin*, *azithromycin* and *ethambutol* in combination. Once CD4 count is above 100 your doctor may recommend that you stop taking MAC treatment. Pregnant women should not take *clarithromycin* as prevention or treatment for MAC.

OI 5: TOXOPLASMOSIS (Toxo)

Toxoplasmosis is a ‘parasite’ carried by cats, birds and other animals and found in soil, cat faeces and in meat, particularly pork.

Toxoplasmosis diagnosis: can be detected using a blood test. Toxo encephalitis (Toxo in the brain) can be detected through a CT scan or an MRI.

Toxo symptoms include headaches, confusion, motor weakness, fever and seizures.

Toxo treatment and prevention is recommended for people with HIV with CD4s below 200. Preventative treatment is called *cotrimoxazole*, which is sometimes called *dapsone* or *septrin*. It is usually given in combination with a drug called *pyrimethamine*).

OI 6: CANDIDIASIS (THRUSH)

Candidiasis is a ‘fungus’ that is sometimes called *candida* or *thrush*. Candidiasis can live on the skin and in the mouth or elsewhere in your body.

About candidiasis: People who don’t have HIV can get candidiasis if their immune function is compromised by stress, smoking, alcohol or diabetes. People may also be susceptible to candidiasis when they take antibiotics that kills harmless bacteria in the body and creates an imbalance that allows candida to take its place. Inhaled corticosteroids for asthma and other respiratory conditions can also lead to candidiasis.

Symptoms of Candidiasis: on gums, the tongue, inner cheek and throat candida grows in white clumps or causes red blotches called erythema. Vaginal candidiasis can cause a discharge that can either be thick and yellow-white or clear and watery. Men can get genital candida under the foreskin. Women are more susceptible when they are pregnant and can pass candida from mother-to-child during labor.

Diagnosis: symptomatic diagnosis is most common. Doctors may take a sample or a skin sample. Blood tests may be taken for conditions associated with candidiasis.

Treatment and prevention: Anti-fungal treatments are generally effective. These include *Intraconazole* and *fluconazole*. *Ketoconazole*, sometimes called *Nizoral* is no longer recommended because of potential liver toxicity.

Oesophageal candidiasis (in the gullet) can be a more serious condition making it painful to eat. People with low CD4 results (below 100) are at increased risk when candida can grow in the lungs and also become systemic.

MODULE 6: HIV Treatment (ART)

YOUR KEY MESSAGE:

"Antiretroviral treatment is not a cure for HIV. But taken daily and as recommended by your doctor it can keep HIV in check so you can live a healthy and happy life."

HIV AND ANTIRETROVIRAL TREATMENT

HIV is a *retrovirus*. *Retro* means slow acting which means that HIV may take many years to make a person with HIV sick. HIV treatment is called *antiretroviral* treatment.

HIV is a virus and like all viruses HIV changes or *mutates*. Because HIV changes it can become *resistant* to antiretroviral treatment (ART). If this happens then ART is no long effective against HIV. Because HIV changes, taking just one ART drug doesn't work in the long term. More than one drug is needed to keep HIV in check.

Taking ART involves taking three or more *classes* of ART drugs every day. Because of that, ART is also called *combination therapy*.

The goal of taking ART is to reduce the level of HIV viral load in your blood to *undetectable* levels (below 40 or below 20 viral copies) and to increase your CD4 count to 500 or more or keep it as high as possible over the long term.

Once you start taking ART you shouldn't stop unless your doctor tells you to. If your ART combination stops working your doctor may ask you to change your ART combination.

You must take your ART every day, on time, every time. This is to stop HIV developing resistance to your combination, so that your ART can keep HIV in check.

GROUP EXERCISE: WHAT'S YOUR COMBINATION?

Ask participants who are already taking ART to put their ART out in the middle of the circle.

Ask participants to explain to the group what combination they are taking when they take and their experience taking that ART combination.

Use the ART that participants are taking to educate about ART and its side effects.

THE INDUCTION PERIOD

The induction period is when you first begin taking your ART combination. It lasts from day one of starting treatment up to anywhere between six and twelve weeks. In the induction period for ART you may experience side effects that will reduce over time.

HINT: purchase antiemetics (to stop nausea and vomiting), antidiarrheals (to stop diarrhoea) and paracetamol (to stop headaches and fevers) the day you get your first ART combination. Keep these medications with you all the time during the induction period. Use them as recommended.

FIRST LINE ART

First line ART refers to the very first ART combination that you take to keep HIV in check. In most cases an ART combination called *Atripla* is given as first line treatment.

Atripla is the name of a combination of three drugs: efavirenz (600mg), emtricitabine (FTC) (200mg) and tenofovir (245mg) combined in to one pill and taken once a day. It is taken on an empty stomach, preferably at bedtime. Side effects can include skin rash, sleep disturbances, abnormal dreams, feeling sick (nauseous), vomiting, headache, depression or suicidal thoughts.

Nevirapine is the name of an ART in the same class as efavirenz. Some doctors may give you nevirapine in place of efavirenz.

SECOND LINE ART

Truvada, Atazanavir and Norvir (booster) are names of four drugs used in combination. Truvada is a fixed dose combination of emtricitabine and tenofovir in one pill. This second line combination is best taken with food but can be taken on an empty stomach. It is one of each pill taken per day. Side effects can include

Kaletra and Combivir are names of four drugs used in combination. Kaletra is 200mg of a drug calls lopinavir combined with the booster drug Ritonavir 50mg (Norvir). Combivir is 300mg of zidovudine (sometimes called AZT) and 150mg of lamivudine (sometimes called 3TC).

CLASSES OF ART

You may be surprised to learn that ART doesn’t actually attack HIV. Instead, ART works on CD4 cells. ART works to protect CD4 cells by stopping HIV using CD4 cells to produce more HIV in the body (called *replication*).

ART *inhibits* particular chemicals or chemical processes that occur on the surface of CD4 cells and inside CD4 cells. Those chemicals or chemical processes are called:

Necleoside reverse transcriptase
Non-nucleoside reverse transcriptase
Nucleotide reverse transcriptase
Protease
CCR5 (ART class may not be available in your country yet, check with your doctor)
Fusion (ART class may not be available yet)
Integrase (ART class may not be available yet)

Nucleoside Reverse Transcriptase Inhibitors (NRTIs) and **Nucleotide Reverse Transcriptase Inhibitors** (NtRTIs): sometimes called "nukes."

These drugs block an important step in the HIV reproduction process. They block HIV in its attempt to use enzymes to build new genetic material inside CD4 cells.

NRTIs include Abacavir (Ziagen), Emtricitabine (FTC), Lamivudine (3TC), Zidovudine (AZT).

NtRTIs include just one drug Tenofovir (Viread).

Non-Nucleoside Reverse Transcriptase Inhibitors (NNRTIs): are also called "non-nukes." They work on CD4 cell enzyme to prevent them functioning correctly. By doing this they prevent HIV from making copies of itself inside CD4 cells.

NNRTIs include Efavirenz (Stocrin), Etravirine, and Nevirapine.

Protease Inhibitors (PIs): These drugs inhibit CD4 cell enzyme that that HIV uses to assemble new virus particles.

PIs include Atazanavir, (Reyataz) Lopinavir, Ritonavir (Norvir).

Entry/Fusion Inhibitors: These medications work to block the virus from ever entering or attaching to CD4 cells in the first place. Just one entry inhibitor is one the market and it is called Maraviroc (Celsentri).

Integrase Inhibitors: Prevents HIV from inserting its genetic code into a CD4 cells genetic material.

Integrase Inhibitors include Raltegravir (Isentress), Elvitegravir (Vitekta) and Dolutegravir (Tivicay)

MODULE 7: HIV Treatment Adherence

YOUR KEY MESSAGE:

“Adherence *to HIV treatment helps to keep HIV in check over the long term. Adherence means taking your HIV treatment as directed by your doctor - every day, on time, every time.”*

WHY IS ADHERENCE IMPORTANT?

Taking HIV drugs every day at the same time is critical to keeping HIV in check in the long term.

The currently available treatment doesn’t cure HIV. It reduces the amount of virus in your body so that HIV doesn’t make you sick.

You need to keep the level of HIV drugs in your bloodstream high enough by taking your treatment every day, on time, every time.

Not taking your HIV treatment properly can mean the levels of HIV drugs in your blood reduce and then HIV can develop *resistance* to the combination you are taking.

Resistance means the HIV drug combination you take has stopped working properly against HIV.

REASONS THAT WE FORGET

Simply forgetting: most people with HIV report that they simply forget to take their treatment.

Routine change: includes travel for holidays or work, shift work, a sudden life crisis.

Worrying that people will find out: taking medications in places where people don’t know you have HIV can make it hard to comply.

Feeling sad or depressed: depression or sadness is reported as a reason people forget or even stop taking their HIV drugs.

Drug side effects or other sickness: experiencing side effects can make people with HIV reluctant to keep taking it.

Stock outs: when the hospital or clinic you attend runs out of HIV drugs.

TOOLS TO ENCOURAGE ADHERENCE

There are simple things you can do to remember to take your HIV treatment and to plan for when you are likely to forget to take your treatment.

SIMPLY FORGETTING

Link taking your HIV drugs to something else you do each day –brushing your teeth, breakfast in the morning, a hot drink before bed.

Use technology – set alerts using your computer or your mobile phone.

Use notes – notes on doors, walls or mirrors can help you remember.

ROUTINE CHANGE

Using pillboxes or Doset boxes – the ones where you put the pills into little boxes with the day or time on them - can help to both remember that you have to take your HIV drugs and to track when you’ve forgotten in a week or a month. Pillboxes can be purchased from clinics, pharmacies and hospital pharmacies.

Use technology – set alerts using your computer or your mobile phone.

Be self-aware – knowing when you forget means you can plan to help you remember.

WORRYING PEOPLE WILL FIND OUT

Disguise your pillboxes – keep your treatment in your glasses case, pencil case, purse or wallet.

Go to the bathroom – take your HIV drugs in the toilet or bathroom at work or home.

Have a story – tell people who ask that you are taking vitamins or have another illness like diabetes or high blood pressure.

FEELING SAD OR DEPRESSED

Get help from your doctor, your facilitator, your friends, partner or family.

DRUG SIDE EFFECTS AND ILLNESS

Buy antiemetics (to stop nausea and vomiting), antidiarrheals (to stop diarrhoea) and paracetamol (to stop headaches and fevers) the day you get your first ART combination. Keep these medications with you all the time during the induction period for six to twelve weeks. Use them as recommended. If side effects persist talk to your treating doctor.

Serious side effects should be reported immediately to your treating doctor.

Getting a cold or the flu can make you not able to or feel that you don't want to take your treatment. In the case of a serious illness, like food poisoning, you should involve your treating doctor if possible.

STOCK OUTS

If your hospital or clinic stocks out of HIV drugs it may be possible to arrange to get your treatment from a different service provider. Talk to your treatment doctor about the options available.

GETTING A NEW PRESCRIPTION

Some people with HIV forget to get a new prescription in time and then run out of their HIV treatment drugs.

Use a diary – note in your diary a month in advance the date that your treatment will run out. Make an appointment at the clinic or hospital well in advance.

IF YOU FORGET

We recommend you aim for 100% adherence to your HIV treatment. But where this isn't possible here are some suggestions if you forget.

TAKE YOUR HIV DRUGS AS NORMAL

If you remember within a few hours of the time you should have taken your HIV drugs then it is ok to simply take them when you remember. After this, just return to your normal HIV drug timing.

DON'T DOUBLE DOSE

If you forget, don't double up on your treatment at the next dosing time. Just take the normal amount of HIV drugs as directed by your doctor. Doubling up can make you sick.

Don't let your supply of medication run out. Watch your supply and don't wait until your last minute for getting new supplies.

GROUP DISCUSSION ON THE QUESTION

When are you most likely to forget to take your treatment?

MODULE 8: Sex, Love, Life and HIV

YOUR KEY MESSAGE:

“ Living a good life with HIV is possible. It means making a few adjustments to your life and considering some things you may not have thought of before now.”

SEX, REPRODUCTIVE HEALTH, HIV

The first thing - You can now pass HIV on to others that you have sex with.

HIV can be transmitted during anal or vaginal sex. Using condoms and water-based lubricant during anal sex or vaginal sex can prevent passing HIV on to others. Use condoms and water-based lubricant every time you have anal or vaginal sex.

The second thing - Protect yourself from and manage sexually transmitted infections like gonorrhea, chlamydia, syphilis and herpes.

Using condoms and water-based lubricant can help protect you from some but not all sexually transmitted infections. Now that you have HIV it’s important to protect yourself from these infections and to treat them quickly if you are exposed. You will not always know that you have these infections because you may not have symptoms that let you know there is a problem. Regularly testing for sexually transmitted infections is the best way to stay healthy and to know early. Talk to your doctor about sexually transmitted infections regularly.

If required it is a good idea to get an anal and/or vaginal pap smear once a year to detect cancer associated with human papillomavirus (HPV).

The third thing - If you are a woman thinking of having children but worried that your child may be infected, this is help available for you.

Talk to a doctor because there are medicines available that can help you while also helping your baby be stay free from HIV.

You do need to also take normal precautions during pregnancy for a healthy baby such as not smoking, drinking or taking recreational drugs and eating well to help you and your baby have the best chance of a healthy life.

VIOLENCE AND HIV

Help is available if you have or you are experiencing sexual or other kinds of violence.

Escaping violence: we can help you to escape violence and/or to develop strategies to avoid it.

Getting support from service providers: we can put you in touch with welfare service providers. Take action, legal or otherwise, to protect yourself: we can help you take legal action if you wish to.

Medical help: if you have physical injuries from violence we can support you to access the medical help you need.

Psychological help: if you have flashbacks, bad dreams, uncontrollable anger or other emotions this can signal that you need someone to talk and even treatment for emotional and psychological difficulties you are experiencing as a result of violence.

SESSION FOUR – WHERE TO FROM HERE?

Session 5 – *Where To From Here* is an interactive session that encourages participants to think and talk about their futures. It is an opportunity for participants to think about what they want from their lives from here and then to share their ideas with each other. The session provides a chance to listen to the dreams of others in the group and get advice from others. At the end of this session participants will have a plan of action to live a better life with HIV.

Learning Objectives

Participants will have

1. Developed a plan for living well with HIV.
2. Identified some life goals including their hopes and dreams for the future.
3. Talked together to plan out how they might live their hopes and dreams for the future.
4. Developed practical knowledge and skills to live a better life with HIV.

Materials Needed	Timing
6. White board and markers. 7. Pen and paper	4.00pm– 4.40pm (forty minutes).

A Detailed Description of Session 5 – Where To From Here?

Overview of the process

The steps in *Session 5 Where To From Here* are as follows:
STEP ONE: Explanation of the process to be followed.
STEP TWO: Paper and pen are handed to each participant. Participants are invited to write down three things they'd like to achieve in their lives over the coming year.
STEP THREE: In pairs, discuss what is on each other's list and then share with the larger group.
STEP FOUR: Facilitate discussion aimed to help participants consider how to achieve their goals.

STEP 1 – Explain the process

THE GROUP FACILITATOR SAYS: "This session is an opportunity for you to think about and plan where you want your life to go now. Our goal is to help you plan for living a better life with HIV.

- We are going to distribute paper and pens to each of you.
- We want you to write down three things you hope to achieve for your future over the next year.
- We're going to ask you to share these ideas with the person next to you and with the group.
- Then we're going to plan for any problems and solutions for living a better life with HIV."

TIP: You will have to repeat this explanation or parts of it several times during the process.

STEP 2 – Write down three things you want to achieve

Start by distributing the paper and pens and provide time for each participant to think quietly. They write down three things they hope to achieve, hopes, dreams they have for their future.

THE GROUP FACILITATOR SAYS: "So now you are writing down three things you want to achieve in the future. It doesn't matter how wild or outrageous these things are – you decide yourself what sort of life you want to live."

- The facilitator may need to repeat some parts of the explanation several times.
- The facilitator may need to spend some time with each participant.
- This is a period of silent reflection in which participants are thinking to themselves.

TIP: Remember to support any one who is sight impaired or unable to read or write.

STEP 3 – Sharing your dreams with others

Once all participants have completed their list ask them to talk with the person next to them and share what they written down with each other. Once this is done, ask participants to share their list with the entire group. The process involves:

- Inviting participants to share their list with the person next to them.
- Inviting participants to share their list with the entire group.
- Inviting comment or questions of each other in relation each other's dreams for the future.

TIP: Remember to remind all participants to be supportive and non-judgmental.

STEP 4 – Facilitate discussion

THE GROUP FACILITATOR SAYS: "Now that we've all shared our hopes and dreams for the future, let's talk about what we think are the barriers and the things that will help you to achieve your goals."

Follow this process:

- Facilitate a discussion about the potential barriers and solutions to these problems.
- Facilitate a discussion about things that will help participants to achieve success.
- All dreams are good dreams, no matter how outrageous or unrealistic they may seem to others.
- Include HIV monitoring, treatment and adherence as important facilitators of living life dreams.

SESSION FIVE – ENDING

Session 5 – *Ending* allows participants to share their feelings about the day, the things they have learned fro m the workshop, to share an appreciation of each other and their feelings about the workshop ending. The purpose of the session is to consciously acknowledge the ending and help participants to prepare to go back to their lives.

<table>
<tr><th colspan="2">Learning Objectives</th></tr>
<tr><td colspan="2">1. Participants can articulate what has been both helpful and less helpful to them about the workshop.
2. Participants can express their feelings about the workshop ending.
3. Participants are prepared to go back to their lives.</td></tr>
<tr><th>Materials Needed</th><th>Timing</th></tr>
<tr><td>1. White board and markers.</td><td>4.450pm – 5.00pm (fifteen minutes).</td></tr>
<tr><th colspan="2">Preparation</th></tr>
<tr><td colspan="2">This last session of the workshop asks participants to share their feelings about the workshop and how they feel about it ending. Hand out Client Satisfaction Surveys and ask participants to complete them and return them in a sealed envelope. Underline that these are confidential and there will be no negative consequences for answering honestly or being critical of the workshop process.</td></tr>
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ADDENDUM 1: ABOUT GROUP COUNSELING

Group counseling involves creating a safe space for participants to talk openly and easily about their experiences and feelings. The goal of group counselling in this workshop is to support people with HIV exchanging their feelings, experiences and ideas on living with HIV. This involves being a facilitator of group discussion among people living with HIV. Group facilitators should understand this session to be a 'listening session' in which they ask questions and summarize participants' words. Listening sessions allow people with HIV to listen to each other, share their feelings, as well as disclose what they are thinking and what they have experienced.

In listening sessions, the person with HIV should feel they have time to explore their feelings and thoughts about what is happening in their life right now. Counseling is about establishing a relationship where the individual being supported understands they have the opportunity to talk openly and that it is safe to express feelings without the fear of being judged by their others in the group counselling session.

KEEPING ATTENTION ON GROUP PARTICIPANTS

The easiest way to establish a counseling-based relationship with a person with HIV is for the facilitator to focus on **listening much more than talking**. During group counselling the goal is to keep the attention on the participants and not on yourself. This can be hard to do - especially when participants keep asking questions or are asking for the facilitator's own experiences. A couple of strategies that can help a lot:

- If you are talking more than others in your group most of the time then this is a signal that you are **taking too much attention away from the participants**.
- **'Deflecting'** – participants often ask facilitators to talk about their own experiences with HIV. They often ask facilitators to help them with a particular problem they are having. *Deflecting* involves asking other participants to respond. You may ask whether others have experienced that particular problem and if they can share their what happened to them with the group. This allows you to keep attention off yourself and focused on the group.
- **Allow time for silence**. This can sometimes feel uncomfortable but it helps to signal that you are giving them the power and the opportunity to talk between themselves – leaving some silences in the conversation sometimes leaves room for participants to say what is really on their mind.

USING ACTIVE LISTENING SKILLS

Active listening is a basic communication technique used in counseling, training and conflict resolution which requires the facilitator to feed back what they hear to the client, using *the client's own words*, to re-state what they have heard. Active listening helps to confirm that the facilitator has heard what the client is saying. By using the client's own words the facilitator can avoid confusion about whether the facilitator has understood the client. Active listening is like being a 'mirror' to the client – because the facilitator attempts to use as many of the client's own words as possible. But it can feel at first very unnatural to actively listen.

However, once a facilitator is used to active listening, they find it is a powerful way to empathize and demonstrate genuine concern for the client's situation. Active listening is a practical way to confirm to the client that they are important to the facilitator and that the facilitator is deeply concerned to understand them and to care for them.

This section of the manual describes some basic active listening techniques that facilitators should use when listening to their clients.

Body language and other non-verbal signals – watching the body language and non-verbal cues of clients is helpful to assess how they are feeling. Mirroring the body language of clients can sometimes, in some situations, help them to feel safer and that you are emotionally closer to them. But these tactics should be used carefully.

Mirroring – repeating just one word that the client has used can help the client keep talking about that word and what it means to them.

Example:

Client: When I got my diagnosis I felt terribly afraid.

Facilitator: Afraid.

Client: Yes, afraid. But not just afraid, I felt really, really frightened inside me. I panicked and I couldn't breathe properly.

Reflecting – repeating one sentence the client has used can help them more deeply explore their feelings, issues and experiences surrounding what they have said.

Example:

Client: It suddenly felt like the whole word around me was different.

Facilitator: So it suddenly felt like the whole word around you was different.

Client: Yes, that's exactly right. I felt like nothing was the same, like everything had changed both inside me and outside me all of a sudden.

Using open questions – open questions keep the client talking and exploring himself or herself. Use open questions when you want the client to keep talking and to *uncover* or *unlock* more of what they feel and think about their situation.

Example of open questions:

- What happened? What happened next? What about after that?
- Can you tell me more about that [experience, feeling, idea, person etc.]?
- What was it like to feel/experience that?

Using closed questions – closed questions are helpful went you want to help the client to gradually stop exploring or talking deeply about themselves. Use closed questions toward the end of a listening session to bring the client out of emotionally exploring their feelings and experiences. Closed question usually prompt a one-word answer. Using closed questions can be helpful to begin to separate the client from the depth of feeling they may have been expressing and ultimately to

Examples of closed questions:

- How are you feeling now? Answer: Good.
- Are you comfortable? Answer: Yes/No.
- Are you going home after this session? Answer: Yes/No.
- It’s almost the end of the session, are you nearly ready to stop? Answer: Yes/No.

Summarizing – this is a more advanced form of active listening. It involves using more of the client’s words to ensure that you understand what the client has told you and again, to deepen their exploration of themselves. Often, when you summarize you don’t need to check if the client feels you’re properly understood them – they will tell you straight away and often add more feelings, thoughts and experiences to what you’ve summarized.

Example of summarizing:

Facilitator: “So you were diagnosed with HIV and at first you couldn’t breathe. You were afraid. But not just afraid, you were really, really afraid and you panicked. It suddenly felt like the whole world had changed, both inside you and outside of you.

ADDENDUM 2 – COMMON REACTIONS TO NEW HIV DIAGNOSIS

New diagnosis with HIV is a traumatic and life changing event that can feel like, suddenly, one's life has been 'short circuited' or dramatically disrupted by the information that one is living with HIV. The news that a person is living with HIV can push them out of the limits and habits of their normal daily life and can have an immediate and dramatic impact upon their thoughts, emotions and behaviour. A review of the thoughts and fears that emerge at new HIV diagnosis can help to illustrate why the diagnosis is a life changing and traumatic event.

Initial reactions

Am I dying? A common reaction to the news is an immediate fear of illness and death. "Am I dying?" and "Am I going to die?" are common questions posed by newly diagnosed people living with HIV. Our experience is that you can confidently tell the majority of newly diagnosed people with HIV that they are not dying. You can tell newly diagnosed people with HIV that, while there is yet no cure, there is effective treatment available that can stop HIV causing illness and death. There is no reason that a newly diagnosed person with HIV cannot go on to live a healthy and successful life.

Will I be able to find love? HIV is sexually transmitted and so sex and romance can be important. "Can I still have sex?" and "Will I be able to find love now that I have HIV?" are two common questions among the newly diagnosed. Where a person is in a relationship with a significant partner at the time of their HIV diagnosis there is the immediate concern of how and when to tell them. Diagnosis with HIV in the presence of a compromised immune system or serious illness complicates the news even more. Engaging with the hospital system, immediately initiating ARV treatment and presenting at a clinical service with an HIV related illness can be confronting.

Who should I tell? HIV is often associated with sex, sex work and injecting drug use. HIV has a negative social stigma attached to it. Because of this, many will feel shame, embarrassment and guilt at learning they have HIV. The news can threaten their sense of security in relationship to both friends and family. Feeling suddenly disassociated or disconnected from the intimacy of friends and family is not uncommon. "Who should I tell?" and "When should I tell them?" are two concerns for people newly diagnosed with HIV.

Social and emotional isolation

For young people newly diagnosed with HIV the situation may be even more complicated. For example, should a young person be diagnosed with cancer or diabetes they can return to their parents and tell them. The parents and family are then likely take over the care and support they need to get them the treatment and other services they need. However, should the same young person be diagnosed with HIV they may feel unable to return to their parents and may choose to withdraw from social life. They may tell no one about their HIV diagnosis. Facing HIV on their own, they can be unable to make the decisions that will keep them well. These individuals often disappear from the health service system after they are diagnosed only to re-emerge when very sick with an AIDS-defining illness.

Orientation to living well with HIV

With help, even such a distressing event as learning one is living with HIV, can bring the opportunity to gain insight, to find one's own strengths and to reprioritise what is most important in one's life. Changing to adjust to the diagnosis requires increased self-acceptance, growing self-esteem and self-confidence. It requires a sense that one is not alone in living with HIV and that there are others who will accept you for who you are. It requires getting the right information at the right time to make good health decisions. It requires acting on information in a timely fashion.

Summary

To summarize, new diagnosis with HIV brings up strong feelings. It is not unusual for people newly diagnosed with HIV to feel depressed and sad, to withdraw from their social lives, to feel shame and guilt and to have suicidal thoughts and act on those thoughts. It is not unusual for them to disappear from the health service system.

The capacity to process the information that one is living with HIV - to deal with the changed circumstances that living with HIV creates - requires a supportive environment in which a person newly diagnosed with HIV can get the help they need to get well or to stay well. To get back to a normal way of living and to adjust to the news of HIV diagnosis depends on the help available both at the moment of diagnosis and in the first few months after receiving a new HIV diagnosis.