Tools for HIV Counselling for the Asia-Pacific

- Counselling forms and protocols
- Client education charts
- Assessment tools

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fhi Family Health International

World Health Organization
South-East Asia Region Western Pacific Region

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Acknowledgements

This HIV Counsellors Toolkit was developed for trainers, counsellors in training, and working counsellors to assist them in delivering high-quality HIV testing and counselling services. This toolkit could not have been developed without the help of many people working in HIV counselling, care support, and treatment throughout the Asia and Pacific region. We are truly grateful to our training participants, including those in the field who took the time to give us valuable feedback, and other colleagues for their creative inspiration, technical input, practical guidance, and editorial review.

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This toolkit builds on materials presented in the Voluntary HIV Counselling and Testing *Manual for Training of Trainers*, WHO Regional Office for South-East Asia (SEARO), New Delhi, India, 2004; *ART Adherence Counselling Training Resources*, FHI China, Beijing, China, 2006; and *Staying Healthy for Mothers Living with HIV*, FHI Cambodia, Phnom Penh, 2004.

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Preface

HIV Counselling Resource Package for the Asia Pacific Region

Antiretroviral treatment offers hope of arresting a communicable disease that was once untreatable and remains incurable. The prospects of surviving HIV and living longer should in many ways lessen the fear of HIV testing and the consequent discovery of HIV-positive status. Yet, the advent of antiretroviral therapy and new drugs have not provoked wide test-seeking behaviour, and the uptake of voluntary and confidential counselling and testing services has been slow.

In 2005, in some countries, particularly those in sub-Saharan Africa, 12%-25% of women and 8%-24% of men living with HIV learnt of their HIV status only after participating in a survey. An estimated 0.1% of adults in Asia and the Pacific have been tested, and it is believed that less than 10% of those living with HIV are aware of their status.

The urgent need to help more adults and children, especially in vulnerable, marginalized communities, find out their HIV status and receive treatment is beyond question. But HIV testing-whether client- or provider-initiated–is more than simply uncovering HIV cases. The quality of counselling and respect for the right to opt out of testing, as well as support measures for coping with the results, are just as important. Counselling, before or after testing, should increase knowledge of HIV prevention and enhance primary health care and positive prevention, as well as curative care when positive status is confirmed. The quality of counselling also shows itself in the quality of referrals, follow-ups, treatment adherence, and care, including nutritional, psychosocial and medical support, such as cotrimoxazole prophylaxis, to sustain the well-being of adults and children living with HIV.

This comprehensive HIV counsellors resource package answers the pressing need to improve the quality of counselling as countries step up their drive to contain the AIDS epidemic. Prepared over two years by WHO and UNICEF with technical assistance from the Family Health International Asia-Pacific Regional Office, it is designed to equip trainers, counsellors in training, and working counsellors in the Asia Pacific Region with essential skills and knowledge to deliver high-quality HIV testing and counselling services in a range of approaches and settings. The HIV counsellors handbook, trainer's session plans, participatory learning activities, and HIV counsellor toolkit found here were updated from the *Voluntary HIV Counselling and Testing Manual for Training of Trainers* (2004) prepared jointly by the WHO South-East Asia Regional Office and the UNICEF East Asia and the Pacific Regional Office.

The newer features of the current package reflect the new types of tests being used by health care providers. The provider-initiated testing and counselling approach is based on the UNAIDS/WHO Policy Statement on HIV Testing (2004), which was drafted after numerous rounds of consultations to deal with the low uptake of Voluntary and Confidential Counselling and Testing worldwide.

The expansion of client- and provider-initiated testing and counselling services in health care settings must be carefully considered. HIV testing and counselling strategies, particularly for high-risk and vulnerable populations, must be implemented in an ethical manner that respects human rights. Utmost priority must be given to training and supervising health care providers, particularly in counselling clients, obtaining their informed consent, keeping HIV test results confidential, referring clients for treatment and giving them better access to appropriate services, and reducing stigma and discrimination. Understanding of the role and effectiveness of HIV counselling and counsellors-an area that deserves further support and investment-must improve.

We hope that this comprehensive resource package informs and inspires greater efforts to upgrade HIV prevention, care and support and that it strengthens the capacity and quality of health care, as well as its links with communities and families affected by AIDS, towards greater universal access and the fulfillment of the Millennium Development Goals.

Dr Shin Young-soo
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UNICEF South Asia
Regional Office

How you can get HIV

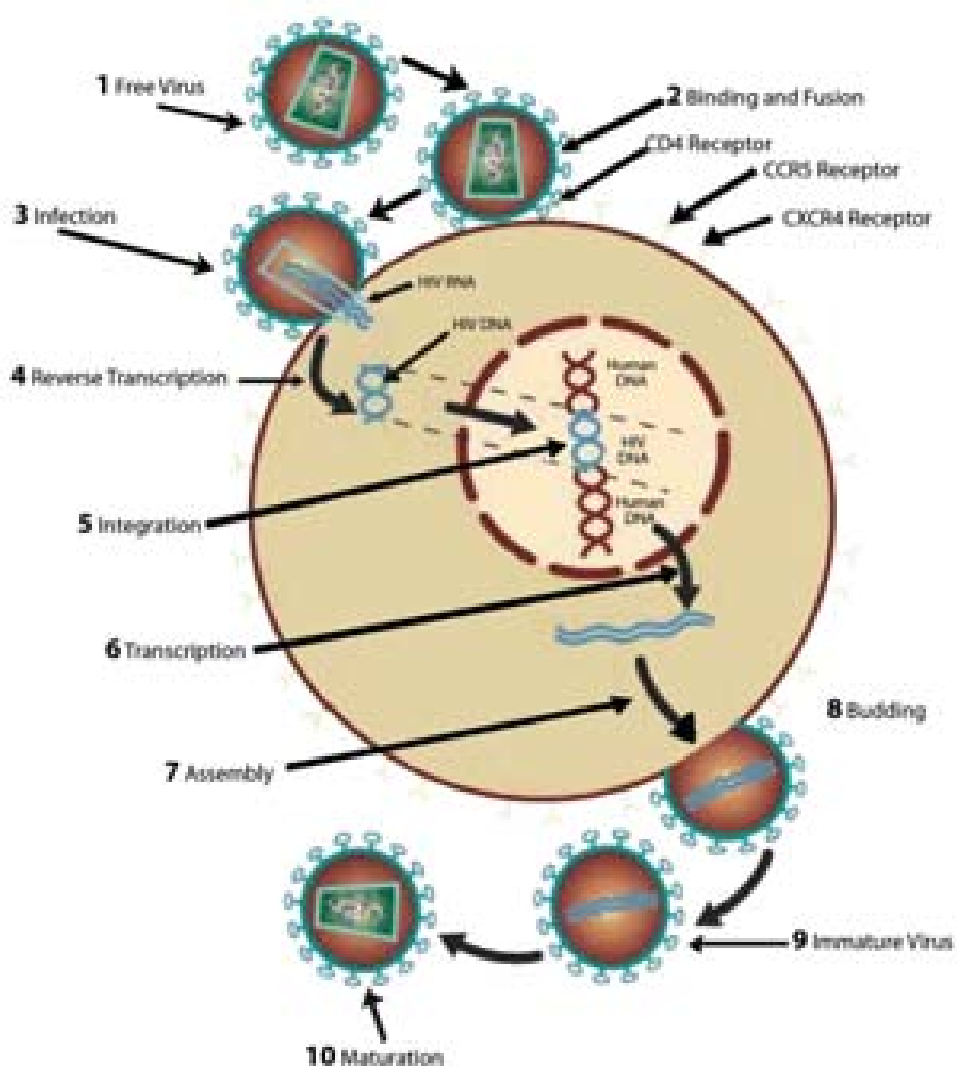
Pictures from the HIV/AIDS Educational Flipchart, Family Health International, China, 2007

Tool 1.1: HIV transmission

You cannot get HIV from…

Pictures from the HIV/AIDS Educational Flipchart, Family Health International, China, 2007

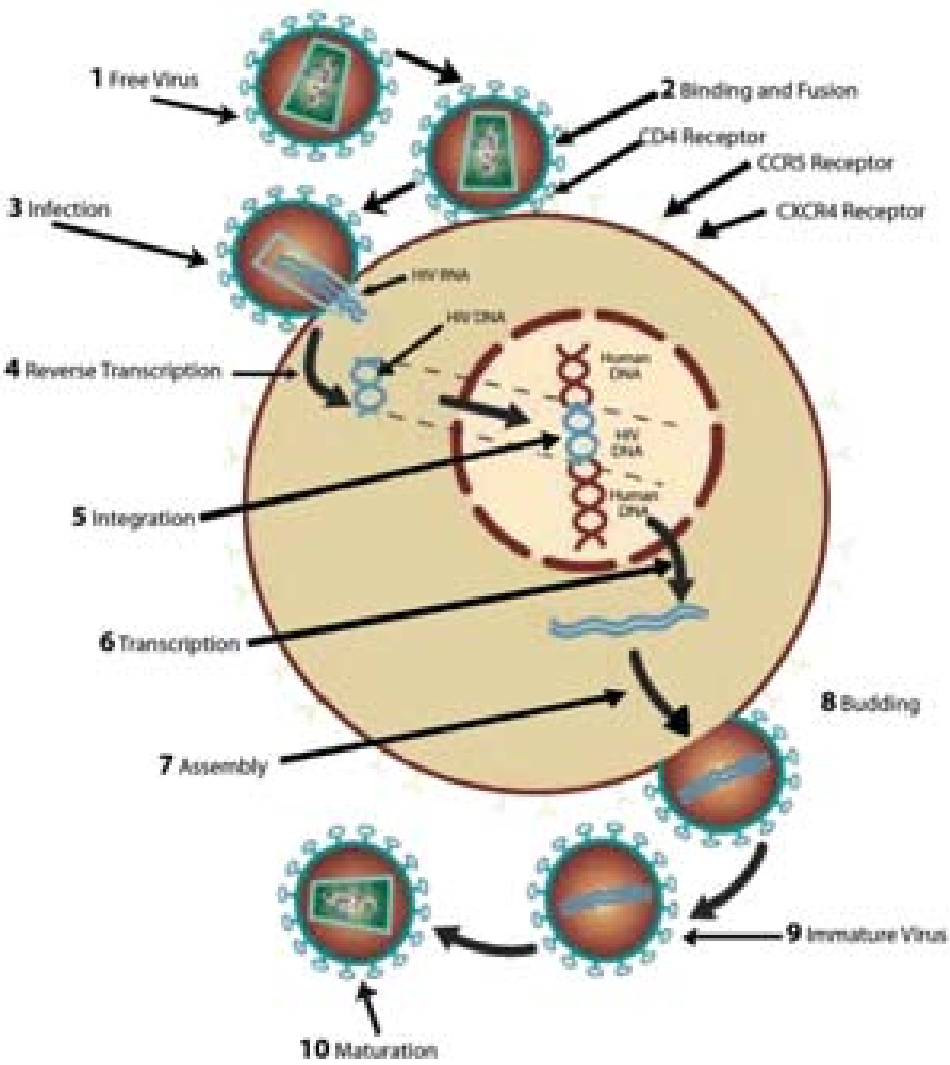
HIV replication



1. Free Virus
2. Binding and Fusion: Virus binds to CD4 molecule and one of two "co-receptors" (either CCR5 or CXCR4). Then the virus fuses with the cell.
3. Infection: Virus penetrates cell. Contents are emptied into cell.
4. Reverse Transcription: Single strands of viral RNA are converted into double-stranded DNA by the reverse transcriptase enzyme.
5. Integration: Viral DNA is combined with the cell's own DNA by the integrase enzyme.
6. Transcription: When the infected cell divides, the viral DNA is "read" and long chains of proteins are made.
7. Assembly: Sets of viral protein chains come together.
8. Budding: Immature virus pushes out of the cell, taking some cell membrane with it. The protease enzyme starts processing the new proteins in the newly forming virus.
9. Immature Virus: It breaks free of the infected cell.
10. Maturation: The protease enzyme finishes cutting HIV protein chains into individual proteins that combine to make a new working virus.

Adapted from fact sheets produced by AIDS Infonet, a project of the New Mexico AIDS Education and Training Center.

HIV replication



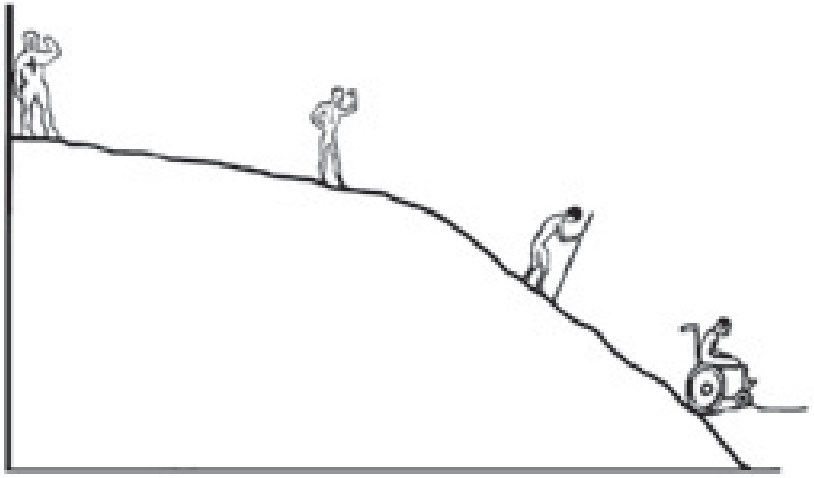
1. Free Virus
2. Binding and Fusion: Virus attaches itself.
3. Infection: Virus merges with the cell and releases chemicals.
4. Reverse Transcription: The chemicals the virus needs to make copies of itself change to combine with the cell's own chemicals.
5. Integration: The chemicals of the virus bond with the chemicals of the cell.
6. Transcription: The cell begins to make chemicals that will make copies of the virus instead of itself.
7. Assembly: The chemicals come together to make a new virus.
8. Budding: Undeveloped virus pushes out of the cell while the chemicals continue making the virus.
9. Immature Virus: New copies of the virus break free of the infected cell.
10. Maturation: Additional chemicals combine to make a new working virus.

Adapted from fact sheets produced by AIDS Infonet, a project of the New Mexico AIDS Education and Training Center.

Explaining HIV in the body

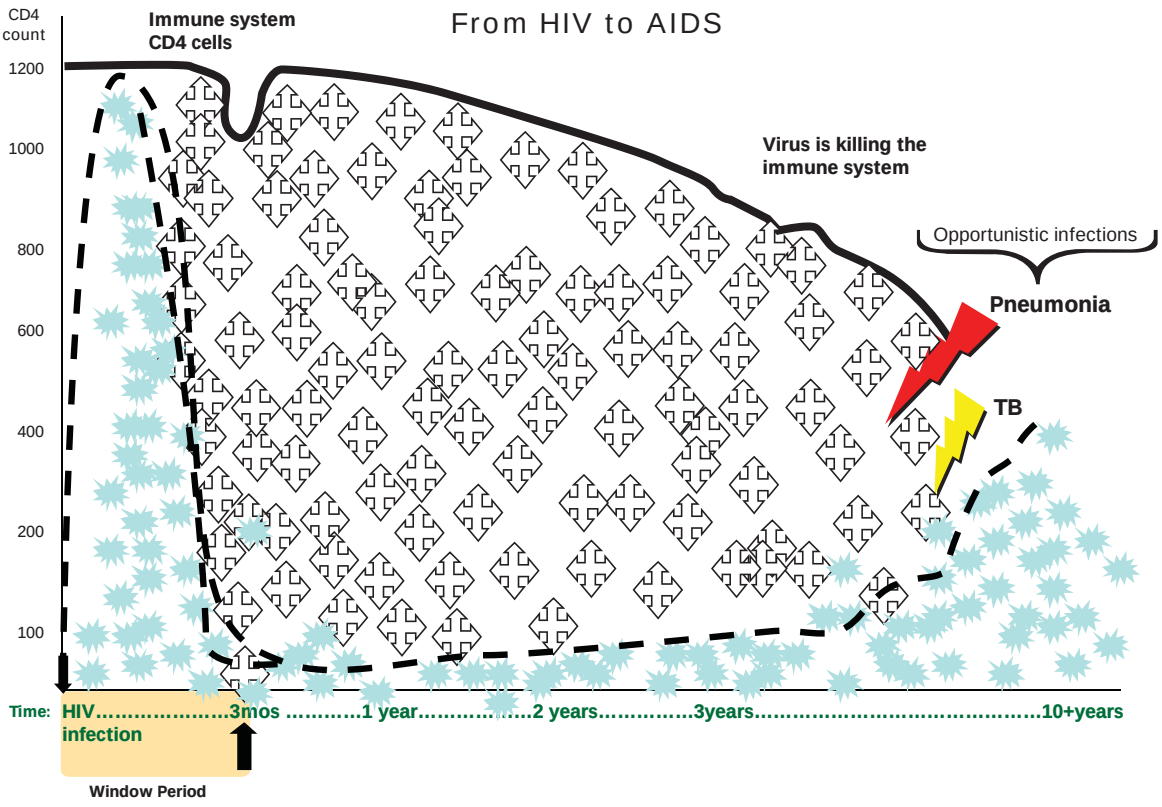
From HIV infection to AIDS (1)

How HIV attacks your body: What happens over time



Source: WHO IMAI Patient Education Chart, 2008

From HIV infection to AIDS (2)

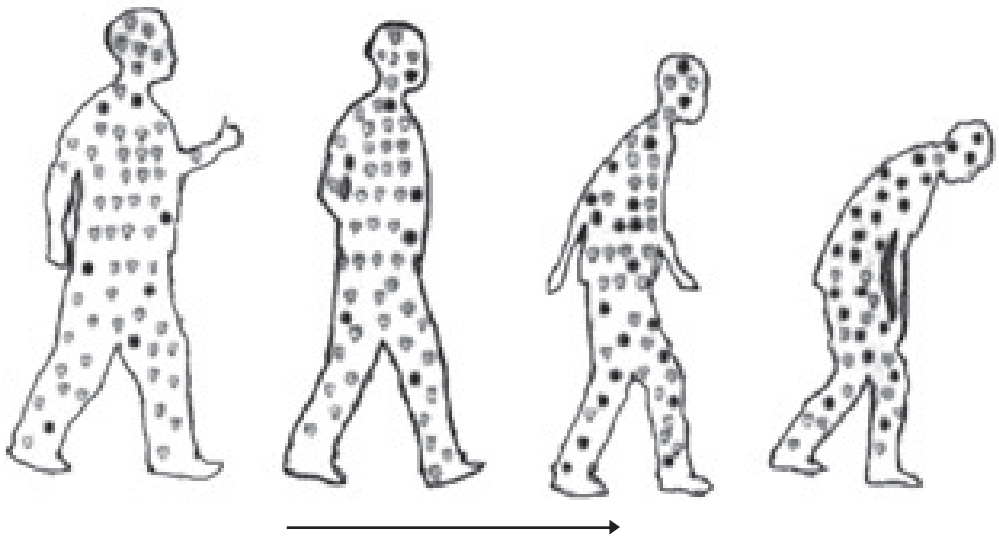


From HIV infection to AIDS (3)

Picture 1	Picture 2	Picture 3	Picture 4
			
Newly infected with HIV HIV-negative "Window period" 1–3 months Can transmit HIV	**HIV+ without AIDS** HIV+ Healthy for 2–10 years No symptoms Can transmit HIV	**Early AIDS** HIV+ Starts to get sick with various infections Can transmit HIV	**Late AIDS** HIV+ Body is very weak and easily gets infections Can transmit HIV

From HIV infection to AIDS (4)

Legend: ♡ CD4 cells ● HIV



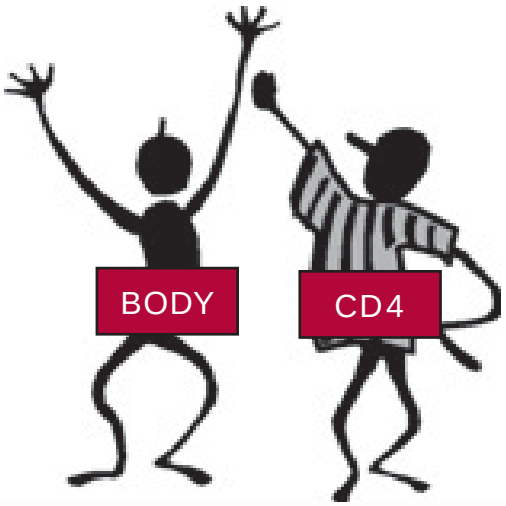
Beginning: skin diseases, minor loss of weight

After 5–10 years: chronic diarrhoea, brain problems, other opportunistic infections

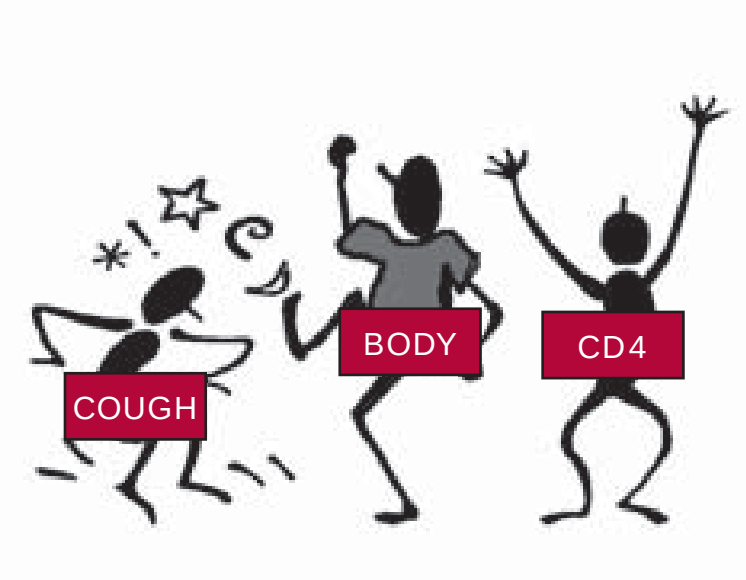
Source: WHO IMAI Basic Clinical HIV Care, ART, and Prevention Training Course Participant's Manual, 2008

From HIV infection to AIDS (5): How HIV attacks our health

1. The CD4 cell is a kind of white blood cell. The CD4 is a friend of our body.

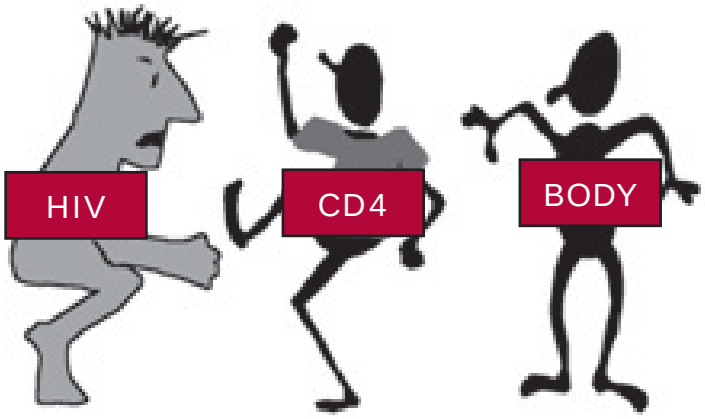


2. Problems like cough try to attack our body, but the CD4 fights them to defend the body.

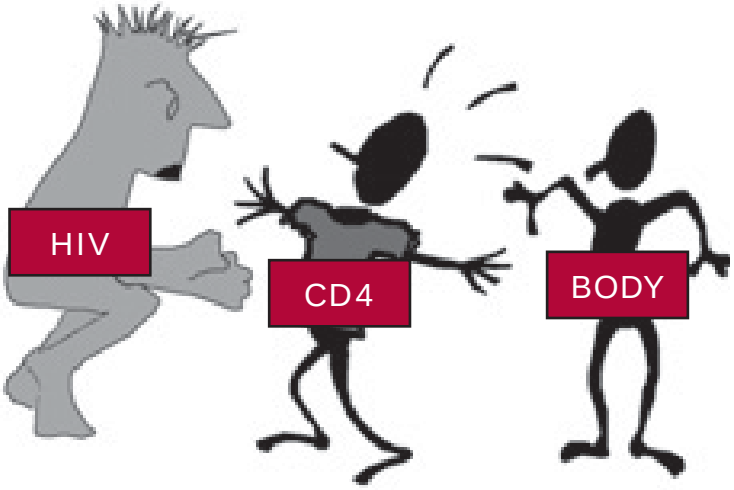


3. Problems like diarrhoea try to attack our body, but the CD4 fights them to defend the body.

4. Now, HIV enters and starts to attack the CD4.

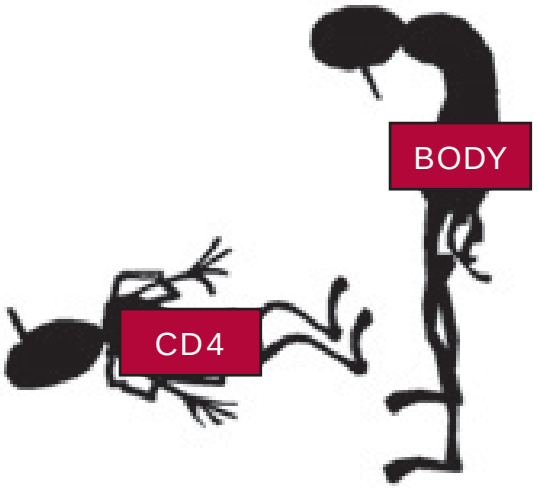


5. The CD4 notices he cannot defend himself against HIV!

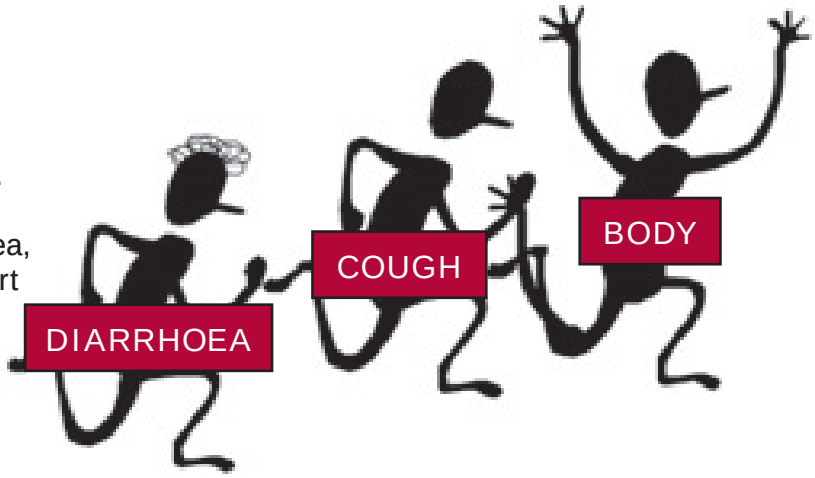


6. Soon, CD4 loses its force against HIV.

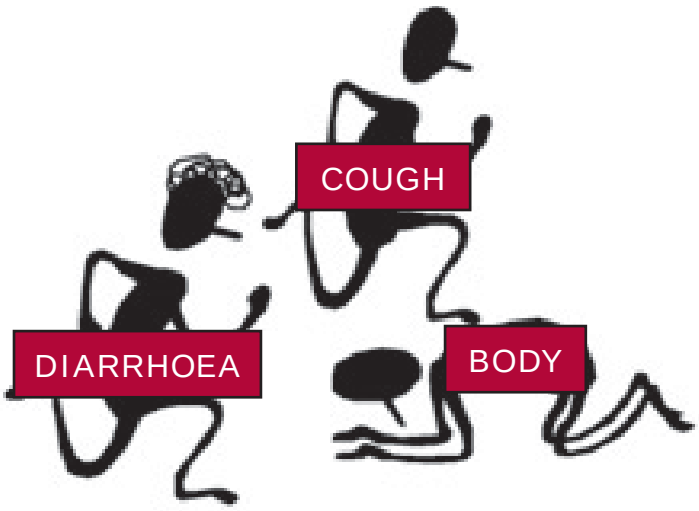
7. CD4 loses the fight. The body remains without defence.



8. Now, the body is all alone, without defence. All kinds of problems, like cough and diarrhoea, take advantage and start to attack the body.



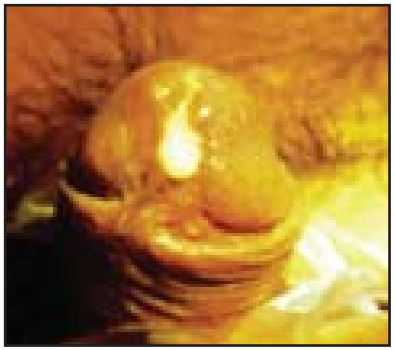
9. In the end, the body is so weak that all disease can attack without difficulty



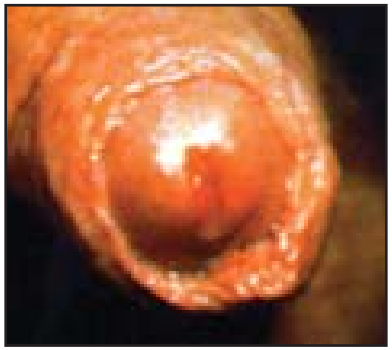
Source: WHO IMAI Basic Clinical HIV Care, ART, and Prevention Training Course Participant's Manual, 2008

Sexually Transmitted Infections

Urethral discharge, Male

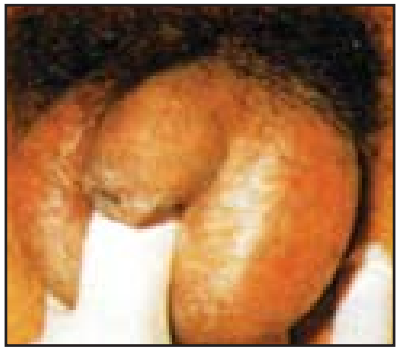


Gonorrhoea

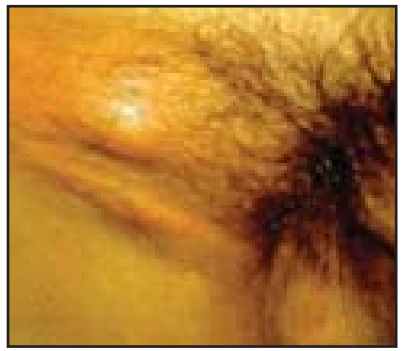


Chlamydia

Epididymitis

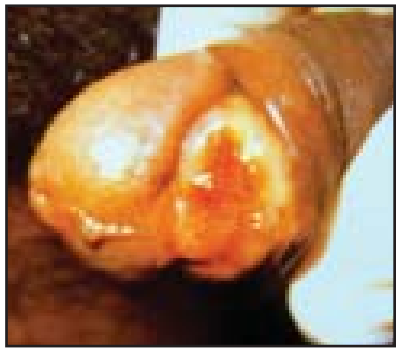


Scrotalswelling

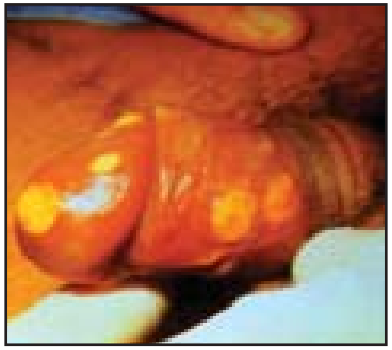


Swollen lymph nodes

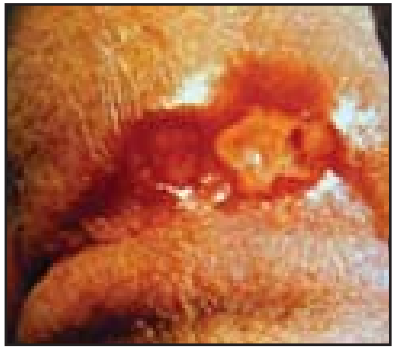
Genital ulcer syndrome (GUS), Male



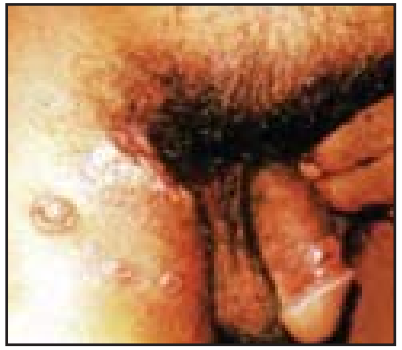
Syphilis



Chancroid



Genital Herpes

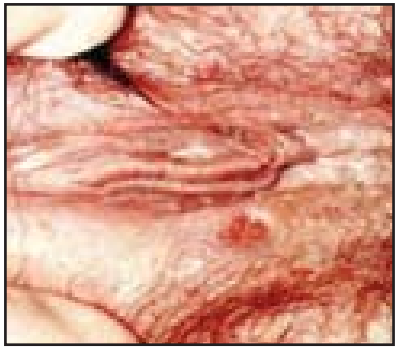


Granuloma inguinale

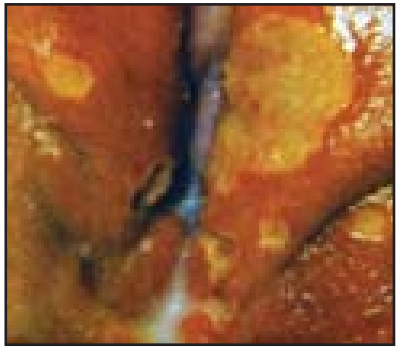
All pictures from the Ministry of Public Health, Thailand

Tool 1.4: STI

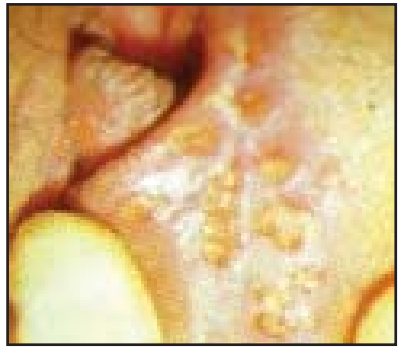
Genital ulcer syndrome (GUS), Female



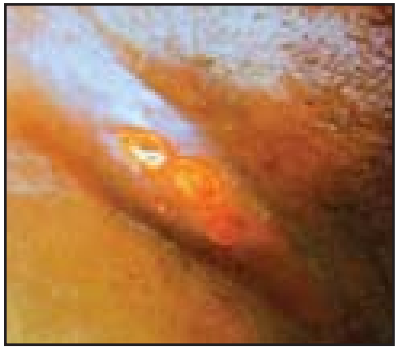
Syphilis



Chancroid

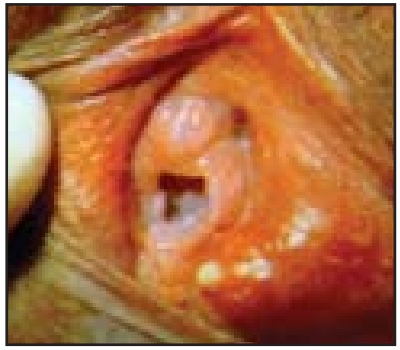


Genital Herpes

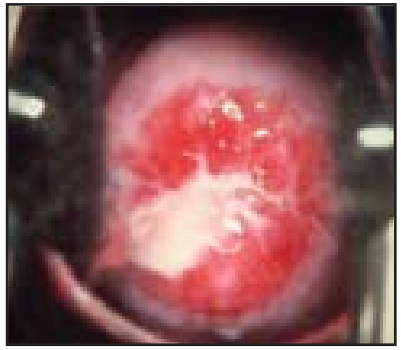


Lymphogrannuloma

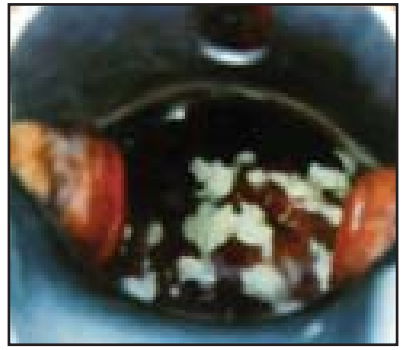
Lower genital tract and pelvic inflammatory disease (PID) related infections



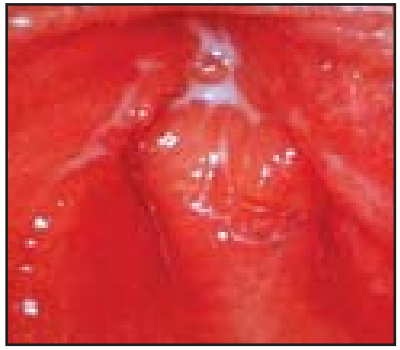
Gonorrhoea



Chlamydia

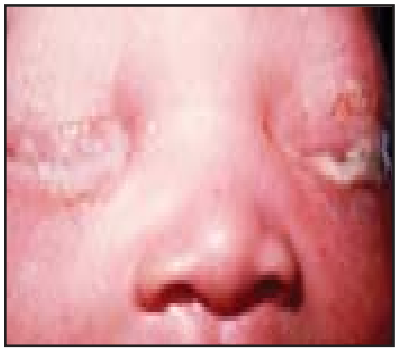


Candidiasis



Trichomoniasis

Neonatal conjunctivitis

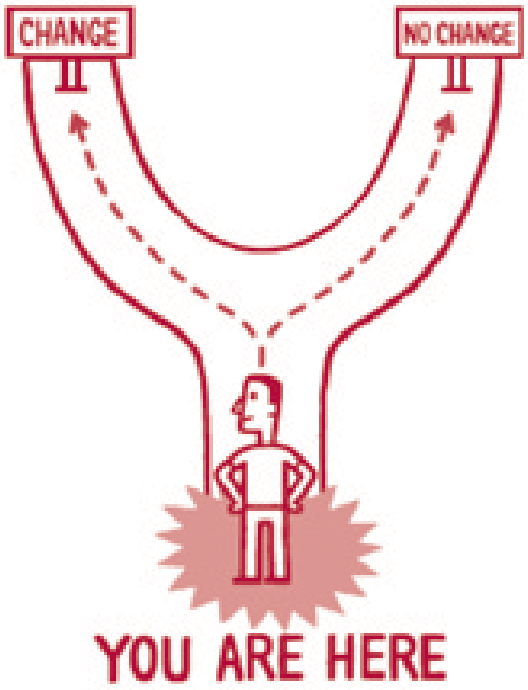


All pictures from the Ministry of Public Health, Thailand

Where are you in the change process?

Identify a behaviour that you would like to change:

- How important is changing it to you?
- How confident do you feel?
- How ready are you to take steps to change this behaviour?



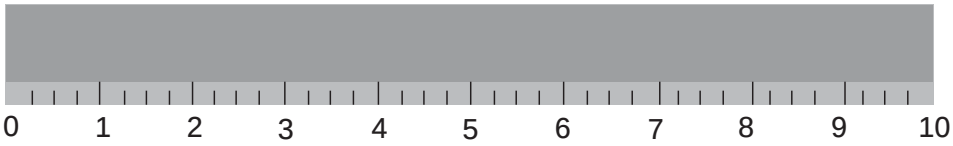
The questions on the next page may help you to get a better picture of where you are in the change process.

The readiness ruler

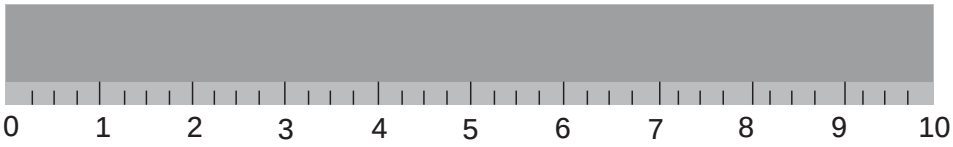
Do you feel you need to make a change in your life? Your (*targeted behaviour*) may be only one of the things you hope to change. Your **motivation** to change this behaviour can vary, depending on other things that are happening.

On each of the rulers below, circle the number (from 0, least, to 10, most) that best fits how you are feeling right now.

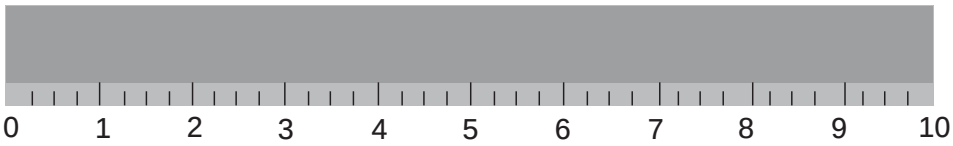
1. How **important** is it to you to change *(targeted behaviour, e.g., use condoms, reduce or quit using alcohol or other drugs)?*



2. How **confident** are you to make the change?



3. How **likely** is it that you will fall back on past behaviours in the long term?



Some questions to think about:

- Why are you at your current score and not at 10?
- What would it take for you to move to a higher score?
- What has made this change important to you so far, or, why are you not at zero?
- What would it take to make this change even more important to you?
- What support would you need to make a change, if you chose to do so?

This exercise can also be used to explore readiness to change other behaviours as well. Feel free to discuss any of the information on this form with me.

_____

Signature of counsellor

_____

Name and credentials (print)

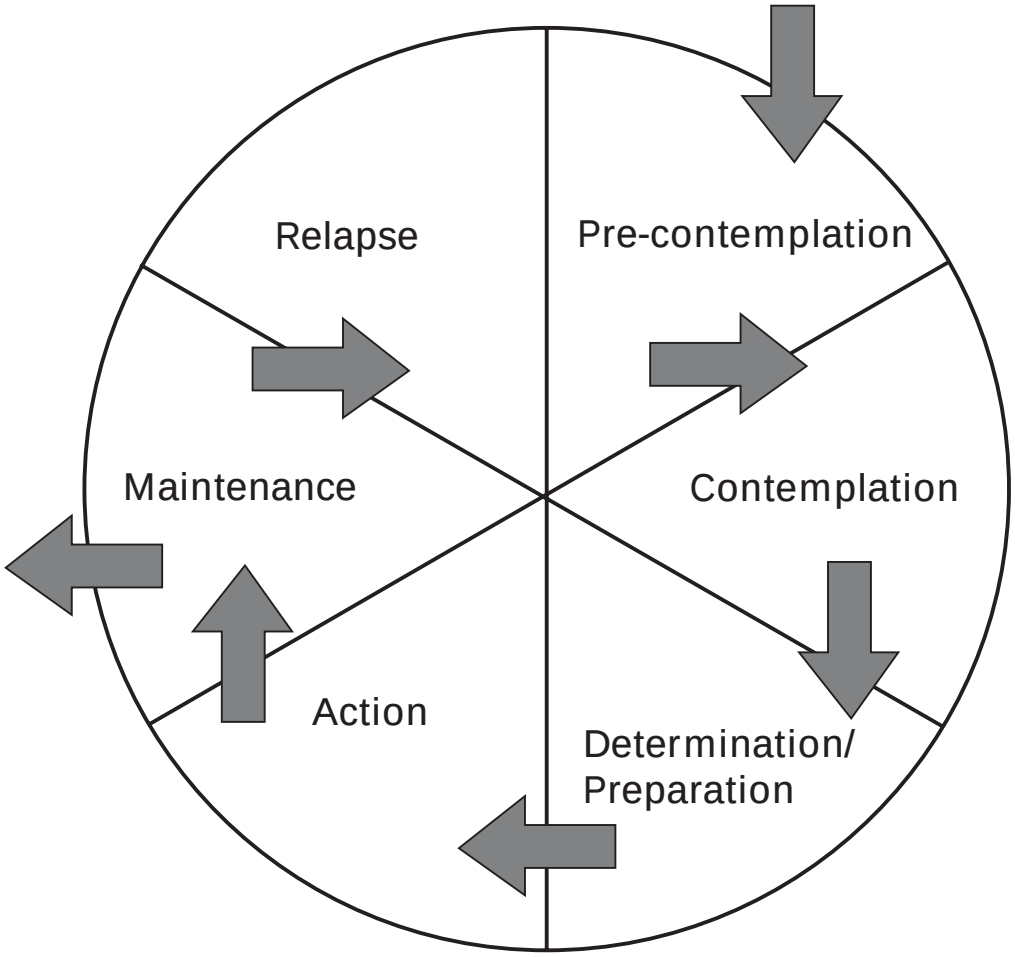
_____

Contact information

Counsellor's assessment

For counsellor's use

Counsellor: Assess the client's readiness for change during the session and mark the client's stage of change on the chart after the session.



Notes:

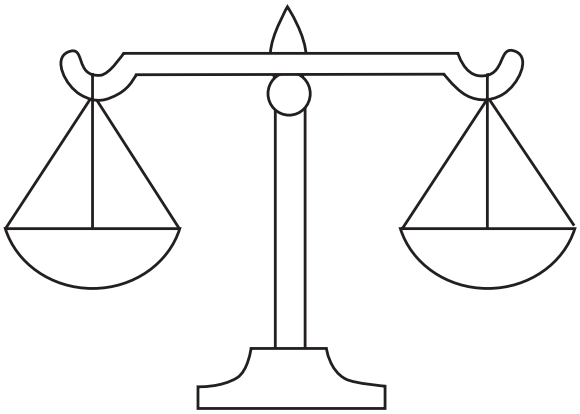
Decision making

Rational decision making

One of the first steps towards successfully changing behaviour(s) is reaching a clear decision that you want to change.

In this exercise, you will think about and record some of the important advantages and disadvantages of changing or continuing your current behaviour(s). You will stack up what you have to lose against what you have to gain.

Fill in the table below. When you are finished, review your answers and weigh your reasons for change. Which way does your decisional balance tip?*



** Note: If the client cannot clearly identify reasons for change, the counsellor may ask additional questions to identify reasons and assess the advantages and disadvantages of each.*

Changing your current (*write down targeted behaviour*)	
What's good about it?	What's not so good about it?
Changing your current behaviour	
What's good about it?	What's not so good about it?

For counsellors: This is a tool that will help assess a client's motivation to change behaviours.

Goal setting and commitment to change

Thank you for attending this appointment to talk about some of the things that have been going on in your life. The purpose of this treatment process is to work with you to come up with helpful solutions that fit your personal goals and priorities.

You are asked to complete this form because some people find that written feedback and information can help them make decisions about behaviour change, look at different treatment options, or just reflect on how substance use issues affect their lives.

Setting goals for change:

1. What is your goal for changing (*add targeted behaviour*)?

Behaviour: _____

❑ Eliminating ❑ Modifying ❑ Same as now ❑ Undecided

2. What is your goal for changing (*add secondary/related behaviour*)?

Behaviour: _____

❑ Eliminating ❑ Modifying ❑ Same as now ❑ Undecided

3. What is your goal for any other occasional behaviour(s) you engage in?

Behaviour(s): _____

❑ Eliminating ❑ Modifying ❑ Same as now ❑ Undecided

A note about risk

How or whether you engage in certain behaviours is your own personal decision. However, if you continue to engage in these behaviours, you will expose yourself to increased risks.

Pre HIV test counselling interview form

Site Name: _____

Client code: | | – | | | Laboratory no: | | – | | | Date: _ _/ _ _/ _ _

1. No names should be recorded on this form. In confidential testing, names and contact details are to be stored in a separate location.		
Additional identifying data (could be a client logo, etc.):		
2. Number of previous HIV test:		
Last test date/time: _ _/ _ _/ _ _	Result (*check one*): ❑ HIV-positive ❑ HIV-negative ❑ Indeterminate ❑ Cannot remember	
	Last test was done within 3 months of exposure risk ❑	
3. Individual risk assessment:		
Client has regular partner:[1] ❑ 1 = YES, 2 = NO	Is any regular partner HIV-positive? ❑ 1 = YES 2 = NO 3 = Unknown	
In case of minor: HIV status of mother ❑ 1 = HIV-positive, 2 = HIV-negative, 3 = Unknown HIV status of father ❑ 1 = HIV-positive, 2 = HIV-negative, 3 = Unknown		
Indicate code and date of most recent potential exposure		
Sex with ❑ men ❑ women or ❑ both		
(*tick only when there is exposure risk*)	**Last time this risk occurred**	**Window period (tick only if within the window period)**
Accidental exposure in the workplace[2] ❑		❑
Tattoo, scarification, piercing ❑		❑
Blood products / Organ ❑		❑
Vaginal intercourse ❑		❑
Oral sex ❑		❑
Anal intercourse ❑		❑
Sharing injecting equipment ❑		❑
Client requires repeat HIV test because of window-period exposure: **YES / NO** (**circle**) If YES, date of repeat test: _ _/ _ _/ _ _		
Client risk was with a known HIV-positive person ❑		
Client is pregnant ❑ Client's partner is pregnant ❑	If **Yes**, stage of pregnancy: ❑ 1-3 months ❑ 4-6 months ❑ At least 7 months	
Client uses contraception regularly ❑ Client's partner uses contraception regularly ❑	Family planning referral required: ❑ YES ❑ NO	
Have you ever been forced to have sex without your consent? ❑	Referral required: ❑YES ❑NO	

[1] Regular partner could be husband or wife, boyfriend or girlfriend, or regular sex client seen over a period of time. There could be more than one partner.

[2] This does not refer to sex work but rather to exposure to blood-borne pathogens in the course of work (e.g., a needle stick injury or muco-cutaneous exposure sustained by a nurse, doctor, ambulance assistant, police officer, cleaner, etc.).

Client indicates history of STI infection	❑	Treatment referral required:	❑YES❑NO
Client's partner has history of STI infection	❑	Treatment referral required:	❑YES❑NO
Client reports symptoms of TB	❑	Treatment referral required:	❑YES❑NO
Client's partner has symptoms of TB	❑	Treatment referral required:	❑YES❑NO

4. Brief statement of self reported medical history of client.
Write a brief note here regarding past significant or current illnesses that may affect diagnosis (e.g., hepatitis B or C):

5. Assessment of personal coping strategies:	
ASK "How do you think you would cope if you test shows that you have HIV?" Briefly note any changes? (*Note client response and tick any of the boxes below that apply*)	
Client indicates suicide intent if test result is HIV-positive If yes, ask the following:	❑ Yes:
Client has prior history of self harm or suicide attempt	❑ Yes
Client indicates intent to harm another if test result is HIV positive	❑ Yes
Client indicates potential risk of violence if status disclosed to partner	❑ Yes
Client has adequate personal support network	❑ Yes

6. Orientation on condom use:			
❑ Delivered orally	❑ Written leaflet given	❑ Demonstration	❑ Client practice
Number of condoms provided to the client:			

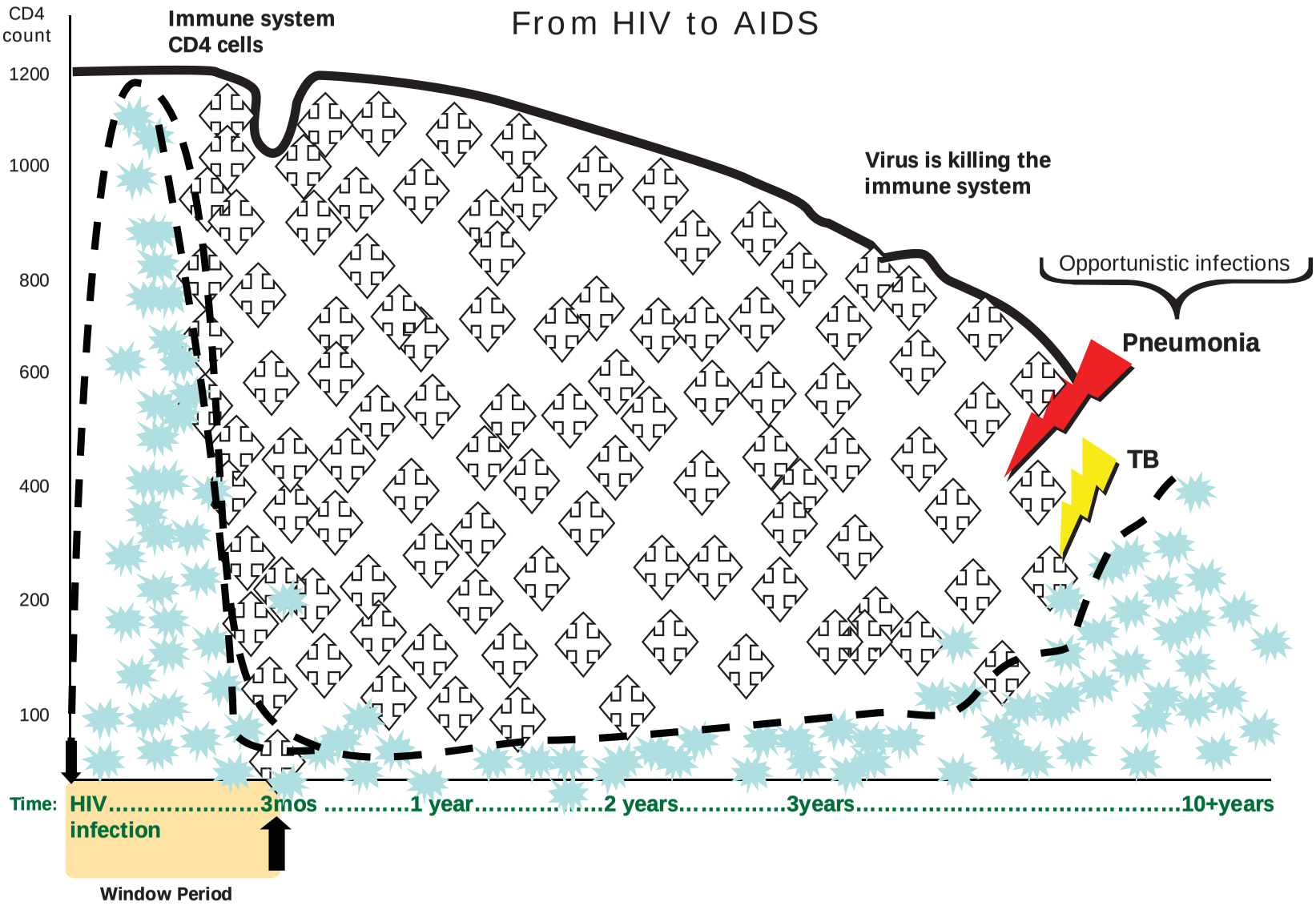
7. Orientation on HIV prevention for injecting drug user		
❑ Delivered orally	❑ Written leaflet given	❑ Not applicable

Additional notes:

Counsellor's signature: _____

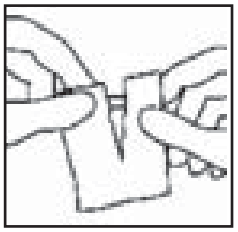
Counsellor's name: _____ Date: _____

The window period



Correct condom use

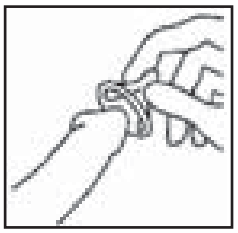
Male condom



Check the expiry date (sometimes the date of manufacture) on the condom wrapper or package. If the expiry date has passed, do not use the condom.

Open the package slowly and carefully.

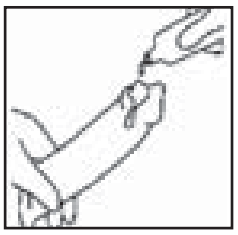
Remove the condom from the packet carefully if you are wearing rings or have long or jagged fingernails so as not to rip the condom.



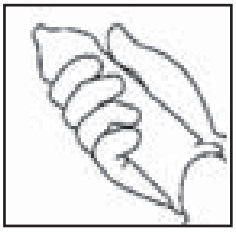
Before putting on the condom, pinch the reservoir end with your fingertips or lips to expel air. This will reduce breakage and make space for semen. Some people like to put one or two drops of lubricant on the tip of the condom to increase sensitivity; however, this is not always needed, as most condoms are already lubricated.

The appropriate time to put on a condom is when the penis is ERECT. The condom needs to be put on before the penis comes in contact with the vagina, anus, or mouth of the sexual partner. Carefully roll the condom down to the base of the shaft of the penis. Check to see that there is no air in the condom (the tip of the condom should be slack or empty looking).

Note: For uncircumcised men, be sure to pull back the foreskin before putting on the condom.



Important: Lubricate the outer surface of the condom and make sure the vagina or anus of your sexual partner has enough lubricant before intercourse. Insufficient lubrication increases the chance that the condom will break or will cause vaginal or anal irritation through too much friction. You should only use water-based lubricants. Never use oil-based lotion, vaseline, baby lotion, or oil (such as massage oil) because the oil will weaken or dissolve the condom.

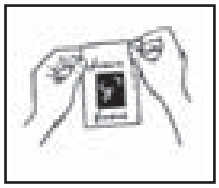


After you have sex, remove the condom from the erect penis by holding the base of the condom and sliding it off; be careful not to allow the semen onto your hands or your partner's vagina or anus. Wash off any fluids.

Remember: One condom per sex act.

Dispose of used condoms properly. Put the used condom in the bin. Do not flush it in the toilet, as it will block the plumbing system. Do not use a condom twice!

Female condom



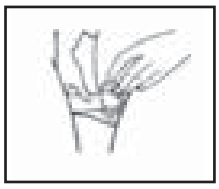
Tear the wrapper of the female condom lengthwise. The female condom must be inserted before intercourse.

Use your thumb, index finger, and middle finger to grasp the ring at the closed end of the female condom. Pinch the sides of the base together so that the base becomes smaller.

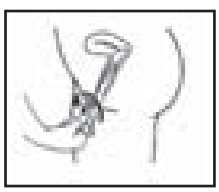
Sit in an appropriate position (for example, in a squatting position or with one leg elevated by being placed on the corner of a chair) and slowly insert the ring of the female condom, which you have pinched together, as deeply as possible into the vagina.

Insert fingers into the female condom until you touch the base of the internal ring. Then push the ring deeper into the vagina to the base of the pubic bone by bending the fingers and inserting them deeper, about 2-3 inches.

When the female condom is in place, a portion will remain outside the vagina. This is normal. The outer ring will expand during sexual intercourse and will not be a hindrance.



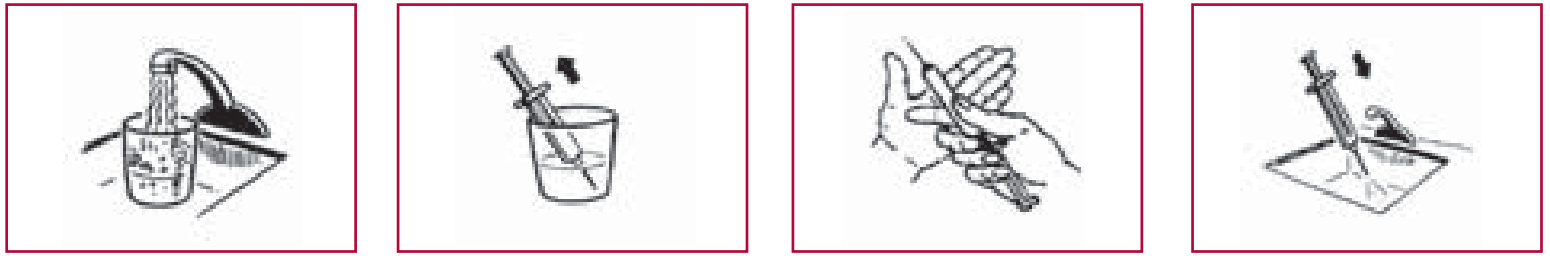
At the time of penetration you must assist the entry of the penis into the condom by holding the outer ring of the condom. This is the most important step in the use of the female condom.



After sex, the female condom may be removed. Prevent the spilling of semen by twisting the mouth of the condom. Then slowly and gently pull the condom out of the vagina. The female condom should be used only once. Dispose of the female condom properly. Do not throw it into the toilet bowl.

Safe injecting

Rinse with water 3x

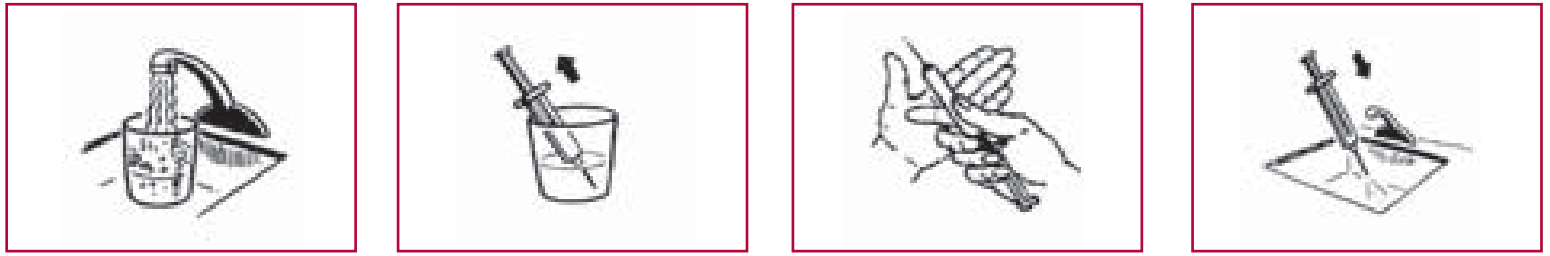


Draw up fresh, clean, cold tap water from the first container into the needle and syringe. Do not use hot water or water that is too cold, as this may cause blood to clot inside the needle and syringe. Shake and tap the syringe to loosen the blood. Squirt the water out. Repeat this process 2 more times. If required, keep rinsing until you cannot see any traces of blood.

Rinse with bleach 2x

Draw up bleach from the second container into the needle and syringe and shake for at least 30 seconds. The bleach must be in contact with the virus for at least 30 seconds for the virus to be destroyed. Squirt the bleach out of the needle and syringe. Repeat the bleach process at least 1 more time.

Rinse with water 6x



Draw up fresh, clean tap water from the third container into the needle and syringe. Do not use water from the first glass, as it may be contaminated with blood. Shake the syringe and tap it, then flush the water out of the needle and syringe. Repeat this process at least 5 more times, until all of the bleach is removed.

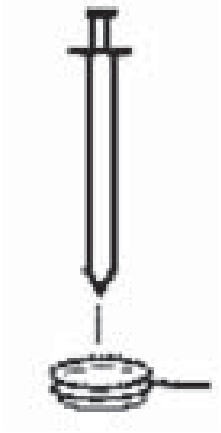
IMPORTANT: Full-strength bleach (5.25% hypochlorite) should destroy HIV after 30 seconds. However, in order for bleach to kill hepatitis B that might be in the syringe or cooker, the bleach must be left in the syringe and cooker for at least 2 full minutes. It is not known for certain whether bleach kills hepatitis C, even after 2 minutes.

Tool 4.4: 3 x 2 x 6

Counselling Tool

Safe injecting

Remember to clean your works!



Cookers

Spoons

Water glass

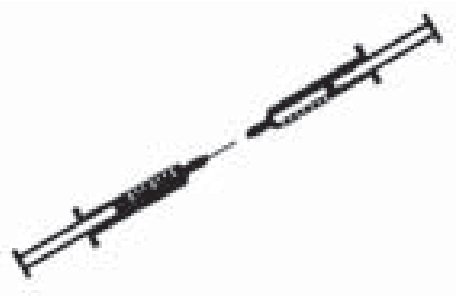
Soak in bleach for at least 2 minutes after each use.

Cotton/Filters

Dispose of these after use

Use sterile needles and syringes for:

Front loading



Back loading

IMPORTANT: Full-strength bleach (5.25% hypochlorite) should destroy HIV after 30 seconds. However, in order for bleach to kill hepatitis B that might be in the syringe or cooker, the bleach must be left in the syringe and cooker for at least 2 full minutes. It is not known for certain whether bleach kills hepatitis C, even after 2 minutes.

Post–HIV test counselling form

Client code: | | – | | | | | Laboratory no: | | – | | | |

Client test date: _ _/ _ _/ _ _ Place of testing: _____

1. Result provided: *(Please tick)*

❑ 1. HIV antibody–negative ❑ 2. HIV antibody–positive ❑ 3. Indeterminate

2. For HIV-negative result provision only:

Checklist of counsellor actions:

- ❑ Provided and explained client result
- ❑ Checked for window period and subsequent exposure
- ❑ Advised client to retest — YES/NO *(Please circle)* If YES, retest date: _ _/ _ _/ _ _
- ❑ Provided risk reduction counselling
- ❑ Made referral — YES/NO *(Please circle)*
- ❑ If YES, obtained signed consent for release of information — YES/NO *(Please circle)*

Details of referral:

3. For indeterminate result only:

- ❑ Explained the possibility that testing was done during the window period
- ❑ Urged client to avoid unprotected intercourse or sharing of injecting equipment
- ❑ Scheduled retesting at this centre in 12 weeks (4–6 weeks for pregnant clients)
- ❑ Provided stress management and supportive counselling

4. For HIV-positive result provision only:

Checklist of counsellor actions:

- ❑ Checked result before providing it to client
- ❑ Assessed client's readiness for results
- ❑ Provided and explained the result
- ❑ Provided brief information about follow-up and support
- ❑ Assessed client's capacity to cope with result
- ❑ Assessed suicide risk *(follow suicidal risk assessment form)*
- ❑ Discussed strategies for partner disclosure (to whom, what, when, and why; *use structured problem-solving form*)
- ❑ Checked to make sure the client can get home safely

4.2: Coping management plan:

- ❑ Helped client plan how to cope in the next 48 hours
- ❑ Assessed suicide risk
- ❑ Provided IEC material
- ❑ Discussed transmission reduction strategies
- ❑ Made referral — YES / NO

If YES, obtained signed consent for release of information

Details of referral:_____

5. Type of support required:	
Ongoing counselling support	Comments:
Medical/Treatment support	Comments:
Peer-group support/Positive-network support	Comments:
Financial support	Comments:
Specialized mental health support	Comments:
Others	Comments:
Not required	Comments:

6. Orientation on condom use:			
❑Delivered orally	❑Written leaflet given	❑Demonstration	❑Client practice
Number of condoms provided to the client:			

7. Orientation on HIV prevention for injecting drug user		
❑Delivered orally	❑Written leaflet given	❑Not applicable
8. Referral offered (*write down name of organization*):		❑**Feedback from referral received**
9.Date of follow-up counselling: _ _/ _ _/ _ _		

Notes:

–––––––––––––––––––––	–––––––––––––––––––	–––––––––
Counsellor's name	**Counsellor's signature**	**Date**

Referral form

To the receiving referral agency:

This client has signed a form authorizing the release of confidential information. Please let us know about the outcome of this referral.

Detailed client notes and assessments are attached	❑ YES	❑ NO
If NO, they are available on request	❑ YES	❑ NO

Client code: **Date referral made:** _ _/ _ _/ _ _

Name and address of client (if required and client has agreed to release the information):

Referred to (specific contact person at referral agency):

Address of referral agency / individual provider:

Telephone number:

Referral feedback to be sent to (referring counsellor address and phone contact):

Type of assistance sought for the client:

- ❑ HIV medical assessment and treatment
- ❑ STI medical assessment and treatment
- ❑ TB assessment and treatment
- ❑ Family panning advice or contraception
- ❑ Antenatal or postpartum care (*circle which*)
- ❑ Psychological or psychiatric assessment and treatment
- ❑ Drug/Alcohol counseling/treatment
- ❑ Welfare assistance (housing, financial, schooling for children, etc.)
- ❑ Legal
- ❑ Others (*specify*):

Summary background information:

Detailed client notes and assessment are attached	❑YES	❑NO
If NO, they are available on request	❑YES	❑NO

Counsellor's name: **Signature:** **Date:**

Consent for release of information

Client code:
Date of birth:
Client name (if release is agreed to): _____
Contact details (if release is agreed to): _____

If client cannot read this form, please read all instructions to the client. No coercion is to be exerted. Let the client know that this agreement can be revoked at any time.

I, _____, consent to _____'s
(Name of client) (Name of doctor/counsellor)

Tick (✓) what you agree to. Cross (×) what you do not want to be provided.

- ❑ Releasing information to referral agency
- ❑ Releasing information to partner
- ❑ Releasing information to family member

****

For release of information to referral agency: Tick (✓) what you agree to. Cross (×) what you do not want to be provided.

I agree to the counsellor/doctor's providing the following information for the purposes of referral:

❑ My HIV test results ❑ My medical records ❑ My counselling information
❑ My financial information ❑ My contact details ❑ Other (specify)

This information is to be provided to:……..
(Name of staff member of referral agency)
at the ……
(Name of centre)

I understand that, where information is provided for referral purposes, I am consenting to that organization's providing information back to my counsellor about my referral.

****

For release of information to partner

I consent to the following:

- ❑ The counsellor's telling my partner/family in my presence
- ❑ The counsellor's being present while I disclose to my partner/family, and the counsellor's answering questions
- ❑ The counsellor's telling my partner/family I am HIV positive when I am not present
- ❑ The counsellor's telling _____ (nominee's name) so that he or she will tell my partner or family on my behalf.

Is there anything you do not want the counsellor to disclose to partner/family/other? *(Record here)*

(Signature of client) (Signature of doctor/counsellor)

Date signed: _ _/ _ _/ _ _

Suicide risk assessment interview guide

Introduce this topic by using one of the following according to the circumstance of the client:

During post-test counselling for HIV positive result with a client who indicated he or she would commit suicide if the result was positive

"I am concerned that during pretest counselling you said you would commit suicide if you received a positive result…. I am wondering if you still feel that way."

During post-test counselling for HIV positive result with a client who did not disclose suicide intent during pretest counselling

"Often when people first learn that they have HIV they feel so overwhelmed that they want to end their lives or harm themselves. I am wondering if you feel that way now or feel you may feel that way after you leave my office today."

During the routine post-diagnosis follow up of an HIV positive client

"Often the pressures of living with HIV are so overwhelming that some people feel that their life is not worth living and they think of taking steps to end their life or hurt themselves in some way. I am wondering if you ever feel that way, and if you do, how often you think of this."

Follow-up questions to be asked:

How often do you think of suicide?

❑Occasionally ❑More than once a day ❑Constantly thinking about suicide

How long do the thoughts usually last?

❑Very short ❑Sometimes for over an hour ❑All day

On a scale of 0 to 10, with "0" being the best you can feel and "10" the worst, how bleak are your thoughts? Which number on the scale would stand for those thoughts?

……

0 1 2 3 4 5 6 7 8 9 10

Do you have a specific plan for how you would do it? ❑YES ❑NO

How?
When?
Where?

Do you have the things you would need to do this? ❑YES ❑NO

Ask specifically about firearms, drugs, or pesticides (or whatever else the client indicated that he or she would use in the suicide plan).

Have you made any preparations ❑YES ❑NO

(e.g., writing a note; giving away prized possessions)?

What?

Have you ever attempted suicide in the past? ❑YES ❑NO

How?
When?
Where?

Do you feel your family or friends are concerned and willing to help you with your situation?

Help is available and people are willing to help ❑
Help is available but not often, or the client indicates he doesn't want to ask for it ❑
Family or friends not willing to help or are hostile and express anger at the client ❑

Do you have close friends and relationships with people? ❑**YES** ❑**NO**

How has your mood been lately? Describe how you have been feeling.
For clients who have just received a positive test result this question can be asked in terms of how they were over the last month before they received their test result.

Do your moods often change?
For clients who have just received a positive test result, this question can be asked in terms of how they were over the last month before they received their test result.

Has your appetite for food changed?
For clients who have just received a positive test result, this question can be asked in terms of how they were over the last month before they received their test result.

If you are having sex, are you experiencing any difficulties?
For clients who have just received a positive test result, this question can be asked in terms of how they were over the last month before they received their test result.

What would need to change in your life in order for you not to think of suicide? (*Knowing that HIV cannot be cured, do you need other things to change? Which other things?*)

Suicide risk assessment matrix

Warning: To be used ONLY by counsellors who have been trained to use this tool
Instructions: Conduct the suicide risk assessment interview using the Suicide Interview Cue Card
Client Name: _____ Date: ____/____/____ Counsellor: _____

Details	Lower risk	Medium risk	High risk
Suicide plan • Details • Availability • Time • Lethality of method • Chance of intervention	• Vague • Means are not available; will have to get them • No specific time • Pills, slashed wrists • Others present most of the time	• Some specifics • Means are available; has them close by • Within a few hours • Drugs and alcohol, car wreck, carbon monoxide • Others available if called upon	• Well thought out; knows when, where, how • Has means in hand • Immediately • Gun, hanging, jumping • No one nearby; isolated
Previous suicide attempts	• None, or one of low lethality	• Multiple of low lethality, or one of medium lethality; history of repeated threats	• One that is highly lethal or multiple or moderate • Several attempts over past weeks
Stress	• No significant stress	• Moderate reaction to loss and environmental changes	• Severe reaction to loss or environmental changes • Many recent social or personal crises
Symptoms • Coping behaviour • Depression	• Occasional suicidal thoughts • Daily activities continue as usual with little change • Mild; feels slightly down	• More than one suicidal thought a day • Some daily activities disrupted; disturbance in eating, sleeping, schoolwork • Moderate; some moodiness, sadness, irritability, loneliness, and decrease of energy	• May resist help • Constant suicidal thoughts • Gross disturbances in daily functioning • Disillusioned, paranoid, has lost touch with reality • Overwhelmed with hopelessness, sadness, and anger (verbal or physical); feelings of worthlessness • Extreme mood changes
Resources	• Help available; significant others concerned and willing to help	• Family and friends available but unwilling to help consistently	• Family and friends not willing or hostile, exhausted, or injurious • Significant self neglect
Communication aspects	• Direct expression of feelings and suicidal thoughts	• Inter-personalized suicidal goal (*"They'll be sorry – I'll show them"*)	• Very indirect or non-verbal expression of internalized suicidal goal (guilt, worthlessness)
Lifestyle	• Stable relationships, personality, and school performance	• Recent acting up and substance abuse; acute suicidal behaviour in stable personality	• Suicidal behaviour in unstable personality; emotional disturbance; repeated difficulty with peers, family, and teachers
Medical status	• No significant medical problem	• Declining health	• Chronic debilitating illness • Significant weight loss

Post-diagnosis follow-up counselling form (for each follow-up visit)

Client number: **Date:** _ _ _/ _ _ _ _/_ _ _ _

Date of original HIV diagnosis:

1. Medical follow-up

For newly diagnosed clients or clients new to your service.

Have you seen an HIV doctor since you were originally diagnosed HIV-positive?

❑YES Date: ❑NO Reason?

When was the last time you saw an HIV doctor? Date:

What has the doctor (or nurse) told you about your health? (*Brief note*)

Did the doctor (or nurse) give you any medicine to take? Details:

Are you having any difficulties taking the medication (correct dose, correct way, and correct time)?

---

2. Brief psychological coping assessment

Over the last month/or if recent diagnosis (*tick the appropriate box*):

Has the client experienced any of the following?[1]

❑A persistent sad, anxious, or "empty" mood
❑Too little or too much sleep
❑Reduced appetite and weight loss, or increased appetite and weight gain
❑Loss of interest or pleasure in activities once enjoyed
❑Withdrawal from friends, relatives, or others client is normally close to
❑Agitation, restlessness, or irritability
❑Persistent physical symptoms that do not respond to treatment
❑Difficulty concentrating, remembering, or making decisions
❑Hallucinations (hearing voices or seeing things others cannot hear or see)
❑Fatigue or loss of energy
❑Feelings of guilt, hopelessness, or worthlessness
❑Thoughts of death or suicide[2] (briefly note the thoughts)

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[1] If the client has experienced five or more of these symptoms for longer than two weeks or if the symptoms are severe enough to interfere with daily routine, conduct a more detailed assessment if you are a psychiatric nurse, psychiatric social worker, or psychologist; if not, refer to a doctor or a qualified mental health professional.

[2] If the client has had suicidal thoughts, conduct a detailed suicide risk assessment (tool T5.1).

3. Social and welfare

Does the client experience difficulties with any of the following?

Accommodation	❑YES ❑NO	Details:
Finances	❑YES ❑NO	Details:
Food, medications	❑YES ❑NO	Details:
Relationships (partner, family, friends)	❑YES ❑NO	Details:

4. Positive prevention

4.1 Partner disclosure

Already disclosed? ❑YES ❑NO

Notes on outcome of any disclosures / reasons for non-disclosure:

Future disclosure plan

- ❑ Client will disclose by himself or herself
- ❑ Client would like to disclose in presence of counselor
- ❑ Counselor to disclose on behalf of client without the presence of the client (who must complete signed release of information)
- ❑ Client wishes counselor to disclose in his or her absence
- ❑ Client will disclose to a trusted third party and request that individual to make disclosure on the client's behalf

4.2 Transmission risk reduction

Use of condoms

- ❑ Doesn't use condoms with any sexual partners
- ❑ Uses condoms with regular partner only
- ❑ Uses condoms with all partners EXCEPT regular partner
- ❑ Uses condoms with ALL partners

Does the client indicate that s/he have difficulties with sexual functioning?

❑ YES ❑ NO

If yes (Indicate which)

Arousal ❑ Difficulty maintaining erection ❑ Difficulties with ejaculation

Does the client indicate that the above mentioned problems make it difficult to use condoms?

❑ YES ❑ NO

Details of any treatment or referrals the client has received or requires:

Has the client used any non-prescribed drugs or alcohol in the last month?

❑YES[3] ❑NO

Sharing needles and equipment?	❑YES	❑NO	Details:
Drug dependency assessment / management referral required?	❑YES	❑NO	
Client is pregnant? ❑Yes ❑No ❑NA Partner is pregnant?	❑YES	❑NO	
If Yes, stage of pregnancy:			
❑ 1-3 months ❑4-6 months ❑ More than 6 months			
On ARV prophylaxis?	❑YES	❑NO	❑NA
Client's partner uses contraception regularly?	❑YES	❑NO	❑NA
Family planning referral required?	❑YES	❑NO	
Pregnancy test referral required?	❑YES	❑NO	❑NA
Client support plan (attached) completed?	❑YES	❑NO	
Consent for release of information signed for referrals?	❑YES	❑NO	❑NA

[3] If yes, conduct the detailed Drug and Alcohol Assessment" (T9.2) in the toolkit.

Key issues	Key support strategies

Additional counseling notes:

Counsellor's signature

Name of counsellor
Date:

Psychological problem screening checklist

Work your way down the checklist until you get a positive response. At that point, exit the checklist and refer to the relevant flowchart.

No.	Problem	Refer to flowchart
1.	Is the individual confused or disoriented, or is his or her consciousness impaired? Can you identify any factors associated with a physical cause?	Screen for physical cause
2.	Is there evidence of suicidal thoughts or acts? *"How do you see the future?"* *"Do you ever feel that life is not worth living?"* *"Have you ever thought you would like to end it all?"*	Suicidal thoughts or acts
3.	Does the individual hold incredible beliefs, or see or hear things that others cannot see or hear? *"Do you ever hear voices when nobody is around?"* *"Has anything strange been going on around you?"* *"Has anyone been following you or acting suspiciously near you?"*	Delusions or hallucinations
4.	Is the individual agitated, unable to sit still, talking constantly, impulsive, or argumentative? *"Has your energy increased a lot lately?"* *"Have you been feeling very restless lately?"*	Agitation or excitement
5.	Is the individual mute, withdrawn, or slow to respond to comments or questions?	Withdrawn behaviour
6.	Is the individual's speech strange or difficult to understand?	Abnormal speech
7.	Does the individual report difficulty thinking or concentrating? *"Have you been having difficulty concentrating?"* *"Have you been more forgetful than usual?"*	Concentration or memory difficulties
8.	Is there evidence of a depressed mood, or a loss of interest in normal activities? *"Have you been feeling sad, depressed, or hopeless lately?"* *"Have you lost interest in things, or feel that you lack energy?"* *"Have you felt self-critical or less worthy as a person?"*	Depression
9.	Is the individual overly worried or fearful? *"Do you have any symptoms of anxiety such as shaking, sweating, palpitations, breathlessness, dizziness, or light headedness?"* *"Do you worry a lot about everyday problems?"* *"Do you have any unusual habits, like checking or cleaning more than other people?"* *"Do you experience upsetting thoughts that you find hard to put out of your mind?"*	Anxiety or worry

Presenting problem 1: Screen for physical cause

The foremost question to be considered in the assessment of any neuropsychiatric problem is whether or not a physical cause is likely to be responsible for the problem.

Any of the following symptoms will require immediate medical assessment by a doctor since the symptoms may constitute a medical emergency:

- Impaired, clouded, or depressed consciousness
- Recent onset of confusion, disorientation, and impaired memory
- Periods of complete inactivity during which there is a loss of awareness of surroundings for short periods
- Fever
- Diabetes
- Seizure earlier in the day
- Signs of head injury or history of recent head injury (within about 2 weeks)

If any of these symptoms are present:

- Refer **IMMEDIATELY** to a doctor or hospital for medical assessment.
- Keep the individual under observation while waiting for assessment or transport.
- Remove sources of stimulation.
- If the individual is a known diabetic, give sugar solution (e.g., tea with sugar).

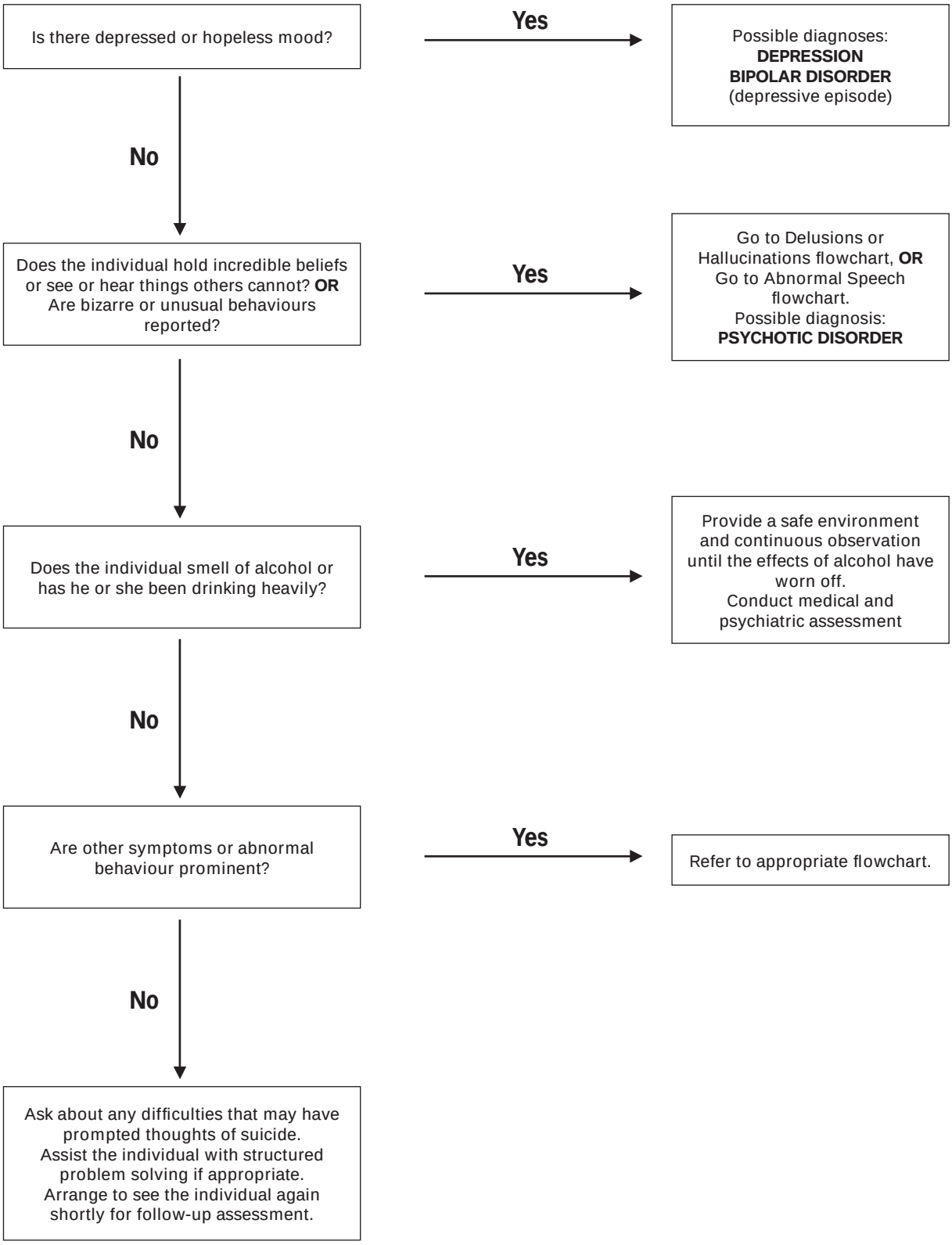
Possible diagnoses: **DELIRIUM, opportunistic infection (brain or systemic), toxic effects of medication, other medical condition.**

Presenting problem 2: Suicidal thoughts or acts

Assess suicide risk

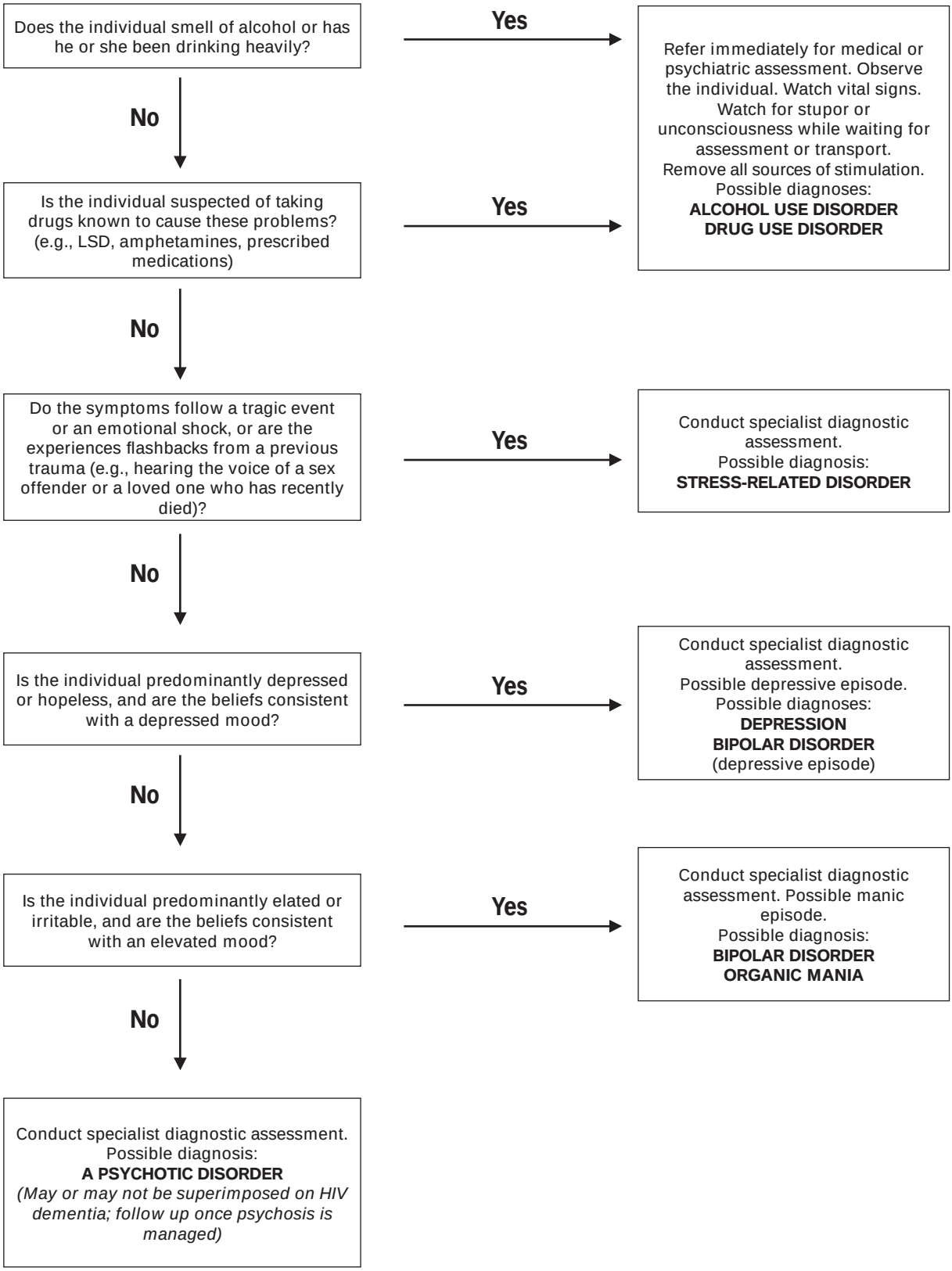
(See Suicide Assessment and Management, Counselling Tool 5.1)
If suicide risk is apparent, seek diagnostic consultation with a specialist.

Assess for other symptoms or abnormal behaviours. In particular:



Presenting problem 3: Delusions or hallucinations

The individual holds incredible beliefs or sees and hears things others cannot.
Could the condition be due to a physical cause? (*See Presenting Problem 1*)



Presenting problem 4: Agitation or excitement

Agitation refers to observable and excessive motor activity that is associated with the experience of inner tension. The activity is usually non-productive and repetitious (e.g., an inability to sit still, pacing, hand wringing).

Could the condition be due to a physical cause? (See Presenting Problem 1)

Does the individual smell of alcohol or has he or she been drinking heavily?

Yes → Provide a safe environment (follow internal procedures). Reassess when alcohol has worn off. If behaviour is normal, discuss alcohol use with the individual and provide education.

No ↓

Is the individual suspected of taking drugs known to cause agitation or excitement (e.g., cocaine, amphetamines, hallucinogens, prescribed medications such as lithium, sedatives, antipsychotic drugs)?

Yes → Refer immediately for medical assessment. Advise discontinuation of medication until such assessment. If behaviour becomes normal, discuss drug use with the individual and provide education.

No ↓

Do the symptoms follow a tragic event, an emotional shock, or severe stress?

Yes → Provide a safe environment and support, and assess for other symptoms or abnormal behaviour within 2 days. Manage as for **STRESS RELATED or ANXIETY DISORDER.**

No ↓

Is there a history of depressed mood or hopelessness within the past 2 weeks?

Yes → Conduct specialist diagnostic assessment. Assess suicide risk. Arrange for continuous observation. Possible diagnosis: **DEPRESSION**

No ↓

Conduct neuropsychiatric assessment. Provide a safe environment and observe continuously until assessment or transport is available.
Possible diagnoses:
BIPOLAR DISORDER
PSYCHOTIC DISORDER
ORGANIC MANIA
(follow up once underlying HIV dementia is ruled out)

Presenting problem 5: Withdrawn behaviour

The individual is slow to respond to commands and questions. (Individuals who are quiet because they are anxious, angry, or intimidated by a new environment are excluded).

Could the condition be due to a physical cause? (See Presenting Problem 1)

Is there a suspected overdose of drugs known to cause withdrawn behaviour (e.g., prescribed antipsychotic, antidepressant, sedative, or epileptic medication)?

Yes → Refer immediately for medical or psychiatric assessment. Observe the individual. Watch vital signs while waiting for assessment or transport.

No ↓

Does the individual smell of alcohol or has he or she been drinking heavily?

Yes → Provide a safe environment (follow internal procedures). Reassess when alcohol has worn off. If behaviour is normal, discuss alcohol use with the individual and provide education.

No ↓

Is there a history of depressed mood or hopelessness within the past 2 weeks?

Yes → Conduct specialist diagnostic assessment. Arrange for continuous observation. Possible diagnosis: **DEPRESSION**

No ↓

Does the individual hold incredible beliefs or see or hear things others cannot? OR Does the individual display unusual or abnormal motor activity?

Yes → Conduct specialist diagnostic assessment. Possible diagnosis: **PSYCHOTIC DISORDER**

No ↓

Do the symptoms follow a tragic event, an emotional shock, or severe stress?

Yes → Provide support and assess for other symptoms or abnormal behaviour within 2 days. Manage as for **STRESS-RELATED or ANXIETY DISORDER**

No ↓

Is there suspicion or evidence of cognitive impairment?

Yes → Conduct neuropsychological assessment. Possible diagnosis: **HIV ENCEPHALOPATHY/ DEMENTIA**

No ↓

Assess for other mental health problems. Withdrawn behaviour may not be related to a mental health problem.

Presenting problem 6: Abnormal speech

Recent onset of speech or sounds that do not make sense.

Could the condition be due to a physical cause? (See Presenting Problem 1)

Does the individual smell of alcohol or has he or she been drinking heavily?

Yes → Provide a safe environment (follow internal procedures). Reassess when alcohol has worn off. If speech is now normal, discuss alcohol use with the individual and provide education.

No

Is the individual suspected of taking drugs known to cause these symptoms (e.g., prescribed medications, especially if elderly)?

Yes → Refer for URGENT medical assessment.

No

Is the individual depressed or hopeless?

Yes → Conduct specialist diagnostic assessment.
Possible diagnoses:
DEPRESSION
BIPOLAR DISORDER
(depressive episode)

No

Is the individual elated or irritable?
Is the individual talking constantly?

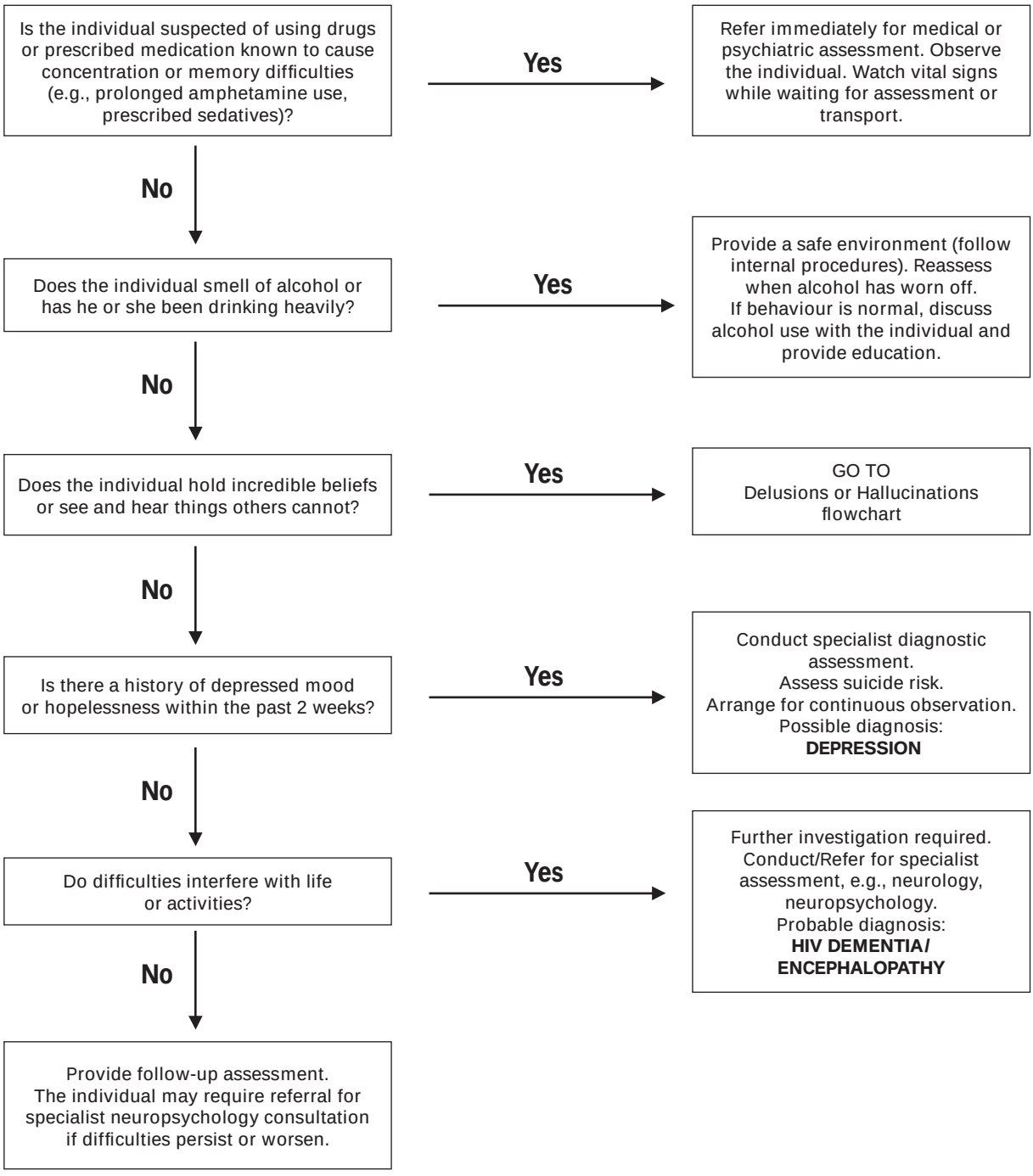
Yes → Conduct specialist diagnostic assessment.
Possible manic episode.
Possible diagnoses:
BIPOLAR DISORDER
ORGANIC MANIA

No

Conduct specialist diagnostic assessment.
Possible diagnoses:
PSYCHOTIC DISORDER
HIV ENCEPHALOPATHY/ DEMENTIA

Presenting problem 7: Concentration or memory difficulties

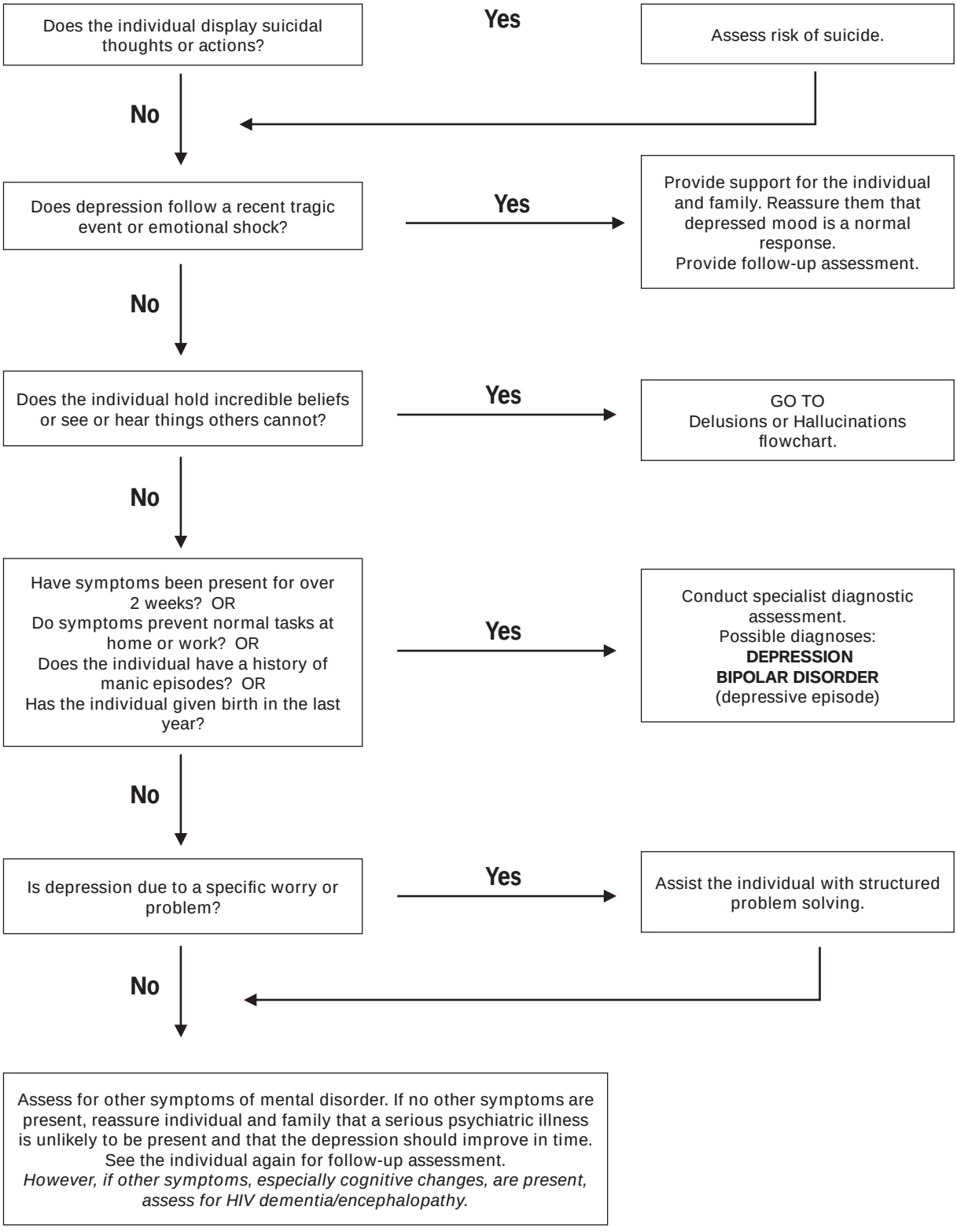
Could the condition be due to a physical cause? (See Presenting Problem 1)
Check again if the concentration or memory difficulties had a sudden onset.



Presenting problem 8: Depression

Marked by sad or hopeless mood; loss of interest in normal activities; feelings of worthlessness, sin, or guilt; sleep or appetite disturbances; many symptoms with no apparent cause.

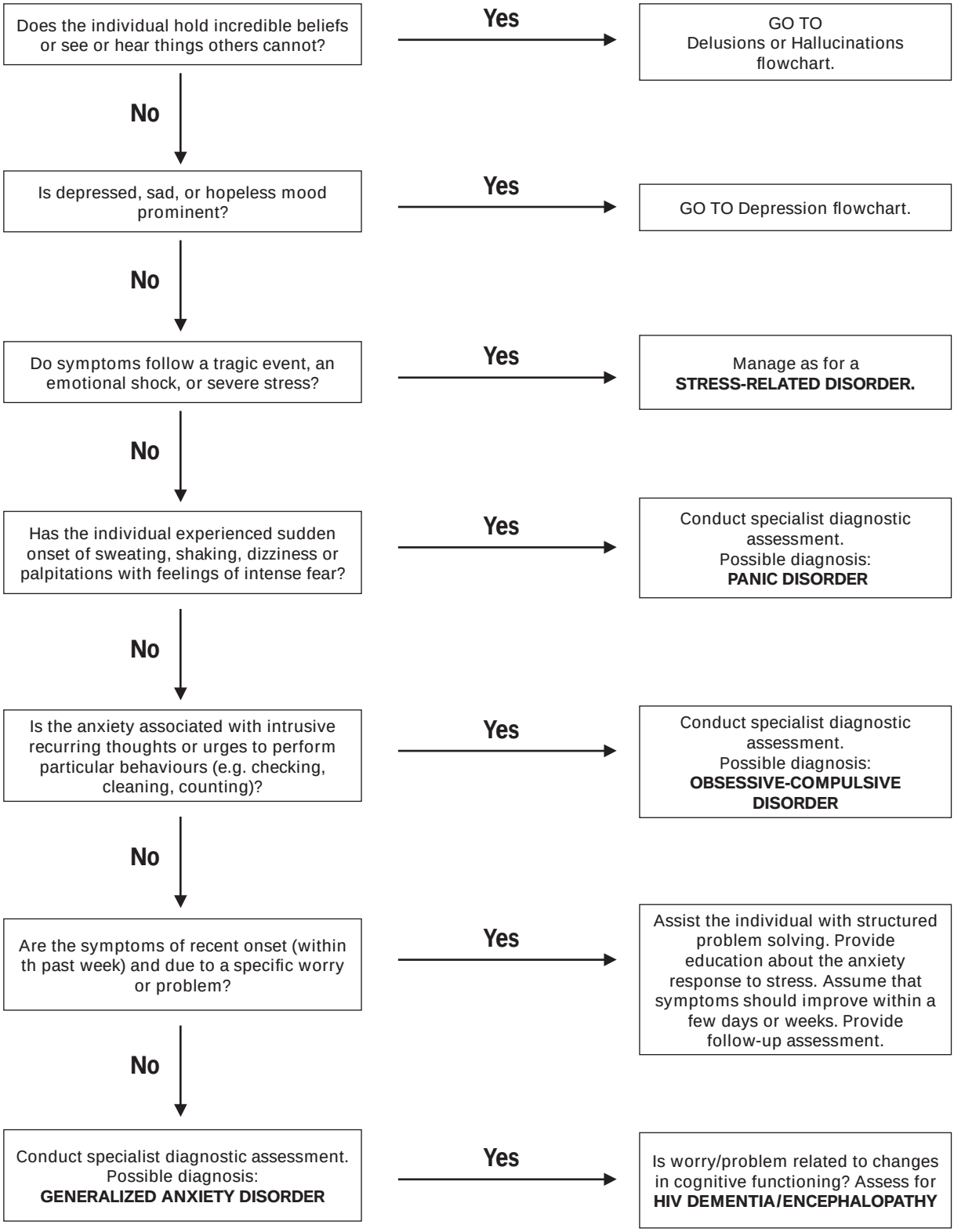
Could the condition be due to a physical cause? (See Presenting Problem 1)



Presenting problem 9: Anxiety or worry

Expressed fear; excessive worry; symptoms of anxiety such as shaking, palpitations, breathlessness, light-headedness.

Could the condition be due to a physical cause? (See Presenting Problem 1)



Pretreatment adherence counselling: Checklist and summary record form

Client's name/code……..
Date of counselling session……

Tick	Review client's understanding of HIV and AIDS:
	What is HIV? AIDS?
	Opportunistic infections
	CD4/Viral load
	Client's understanding of his/her health status
	Effect of treatment
	Need for adherence (explain)
	Review anticipated barriers to adherence and progress made:
	Poor communication
	Low literacy (e.g., cannot read medication instructions)
	Inadequate understanding of HIV and AIDS
	Lack of social support
	Failure to disclose status
	Alcohol and drug use
	Mental state
	Travel or work difficulties
	Review the treatment program and importance of adherence:
	Drug regimen
	Dummy pill demonstration
	What ART does (e.g., improves immunity, less OIs/ART, but not a cure)
	Need for continued prevention
	Side-effects and what to do
	Follow-up
	Importance of adherence and consequences of non-adherence
	Review proposed adherence promotion strategies:
	Buddy reminder (discuss role of support person)
	Other reminder cues
	Review the treatment program and proposed adherence promotion strategies for client with drug or alcohol dependency referred for detoxification or oral substitution therapy
	Take client's address and establish contact system with treatment centre
	Schedule next counselling session and complete appointment card

Source: Adapted by K. Casey from Population Council/Family Health International. *Adherence to antiretroviral therapy in adults: A guide for trainers.* Population Council India, 2004. pp. 46–50.

How antiretroviral therapy works

WHAT ARE ANTIRETROVIRAL DRUGS?

HIV is a retrovirus (from "reverse transcriptase virus"). So drugs against HIV are called antiretroviral drugs (ARVs):

Giving ARV drugs in the correct way, with adherence support, is called ARV therapy (ART).

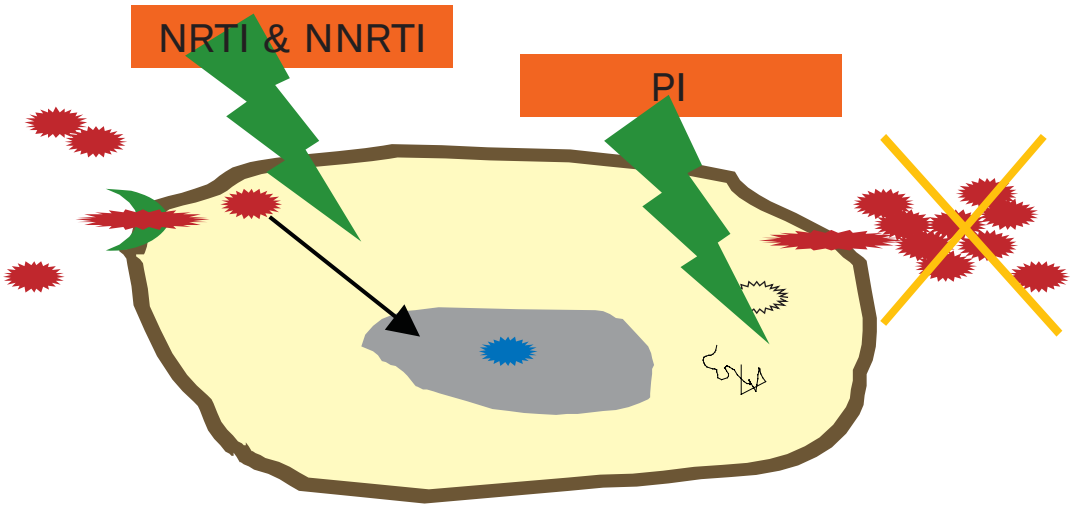
HOW DO ANTIRETROVIRAL DRUGS WORK INSIDE YOUR BODY?

There are **three big groups of antiretroviral drugs** available:

- NRTIs (nucleoside and nucleotide reverse transcriptase inhibitors), divided into NsRTIs and NtRTIs
- NNRTIs (non-nucleoside reverse transcriptase inhibitors)
- PIs (protease inhibitors)

NRTIs and NNRTIs both have the same "target" – they prevent HIV from entering the infected cell's centre, so HIV can't start making new copies.

PIs: When the central part of the body cell makes parts of the HIV virus after infection, these parts have to be cut and put together in the right way before the new HIV copies can leave the cell. Protease inhibitors prevent this cutting and putting together from happening correctly, so the newly produced virus parts cannot leave the infected cell and infect other cells.



The important point is that protease inhibitors and nucleoside/non-nucleoside inhibitors work at different steps in the process that HIV goes through when it makes new copies of itself inside cells.

Graphic adapted from fact sheets produced by AIDS Infonet, a project of the New Mexico AIDS Education and Training Center.

WHY DO YOU NEED TO TAKE MORE THAN ONE ARV?

Combination therapy makes sense for lots of reasons. Here are the most important ones:

It takes a lot of force to stop HIV. HIV makes new copies of itself very rapidly. Every day, many new copies of HIV are made. Every day, many infected cells die. One drug, by itself, can slow down this fast rate of infection of cells. Two drugs can slow it down more, and three drugs together have a very powerful effect.

Antiretroviral drugs from different drug groups attack the virus in different ways. We have learned how different anti-HIV drugs attack HIV at different steps of the process of making copies of itself (first when entering the cell centre, and then when new copies want to leave the cell). Hitting two targets increases the chance of stopping HIV and protecting new cells from infection.

Combinations of anti-HIV drugs may overcome or delay resistance. Resistance is the ability of HIV to change its structure in ways that make drugs less effective. HIV has to make only a single, small change to resist the effects of some drugs. For other drugs, HIV has to make several changes. When one drug is given by itself, sooner or later HIV makes the necessary changes to resist that drug. But if two drugs are given together, it takes longer for HIV to make the changes necessary for resistance. When three drugs are given together, the changes take even longer.

ARVS CANNOT CURE YOU BUT THEY CAN IMPROVE YOUR HEALTH

- ART blocks viral replication, thus preventing further disease progression and immune system damage.
- The body's defence (immune system) gets a chance to recover and fewer opportunistic infections occur.

However, antiretroviral therapy does not cure HIV infection.

WHAT HAPPENS AFTER WE TAKE A DRUG BY MOUTH?

When we take a drug by mouth, it first enters the gastrointestinal tract (stomach, intestines, etc.). In the gastrointestinal tract, the drugs are dissolved and absorbed through the gut wall into the blood. The drug then passes through the liver and is distributed to the tissue. In the end, it is excreted from the body.

When the drugs enter circulation (the blood) they need to reach a level (or concentration) that is high enough to be effective against the virus.

We normally have good drug levels in the blood if:

- We take the correct number of pills prescribed by the health-care worker.
- We do not miss a dose or take a dose too late.
- We take into consideration interactions with other drugs that can lower the concentration.

Imagine our body as a bottle with a small hole in the bottom.
Let's now imagine we want to keep the bottle filled with water.

To keep the bottle full, we need to add in time what has been lost through the small hole. If we are late filling the bottle, the water level drops and the bottle will be half-empty instead of full.

The same is true of drugs in the body: if we do not take our drugs in time, the body will be "half-empty" with drugs and the effect against the virus will not be good.

The HIV virus can defend itself against a low level of drugs, but not against a high level of drugs. This is why we need to make sure that there is always a high level of drugs, by taking our pills correctly.

Reference cards for barriers to adherence[1]

Identifying barriers to adherence

Identifying barriers to adherence is an essential part of patient assessment and patient preparation. Barriers vary from person to person, and from time to time within the same person. Potential or actual barriers to adherence should be identified and discussed with the patient during treatment preparation. Barriers to adherence can be divided broadly into three categories:

- Barriers related to the individual client,
- Barriers related to Health-care delivery, and
- Barriers related to medications.

The client and provider can work together to address and solve barriers related to the individual client and to medications, while the provider needs to advocate changes in the health system to address service-delivery barriers.

Barriers related to the individual client

Barriers to adherence related to the individual client can be further divided into the following:

- Barriers to understanding,
- Barriers to motivation and remembering, and
- Support and logistical barriers.

Barriers to understanding originate in poor communication, language barriers, poor literacy, lack of knowledge or erroneous beliefs about HIV as a disease, or lack of awareness of ART or mistrust of its effectiveness. Barriers to motivation and remembering can stem from forgetfulness, depression or other psychiatric diseases, active alcohol use, active drug use, or an inability to set longer term goals. Finally, lack of support or logistical difficulties are also barriers to adherence. Among these barriers are fear of disclosure of HIV status, difficult life conditions, and unstable living situations.

[1] Source: Adapted by K. Casey from Population Council/Family Health International. *Adherence to antiretroviral therapy in adults: A guide for trainers*. Population Council India, 2004. pp. 46–50.

Barriers to understanding: Communication problems

Communication difficulties may arise from language and cultural differences, or from differences in attitudes and expectations regarding HIV and its treatment between the patient and the providers. Some patients may be defensive about their lifestyle and exhibit negative attitudes. Other patients, often from marginalized or stigmatized groups, may not feel comfortable giving honest answers to the health-care provider. They may not trust the health-care provider or may be too afraid to ask questions when they do not understand the disease or the regimen.

How to address the barrier: Discussing HIV and its treatment in an open and non judgemental way, paraphrasing and repeating information, providing patients with a scientific basis for HIV treatment and related issues – all these help patients develop self-confidence and positive attitudes. Understanding cultural differences and providing counselling in the patient's dialect and language help to solve communication problems.

Barriers to understanding: Language barriers

In many countries in the region, the primary language of a significant number of people with HIV is a dialect other than the central dialect. Providers who speak the same dialect as the client are required for good communication, adequate understanding, and trust and rapport. As much as possible, providers should also avoid using family members as interpreters.The client may not be comfortable disclosing all the needed information in the presence of a family member. Moreover, the family member may not provide a truthful translation of what the client states, and may instead interpose his or her own opinion or viewpoints into the discussion.

How to address the barrier: Staff who can speak several dialects should be hired, especially in areas with a large minority population that speaks a minority dialect. Written instructions and written materials with pictorial illustrations may help if the patient can read the central dialect.

Barriers to understanding: Low literacy

Patients with low literacy may not completely understand their disease or its challenges and complications. They may also not comprehend the instructions provided.

How to address the barrier: Oral repetition of the adherence message, treatment plan, and regimen will help, as will a practice session with dummy pills. A pictorial representation of the message may be used, written information reviewed with each patient, the technical terms explained in simple language, and the patient asked to repeat instructions. Uncomfortable situations that reveal the patient's low literacy should be avoided. This engenders in the patient a sense of efficacy and trust in the provider.

Barriers to understanding: Lack of knowledge or erroneous beliefs about HIV

Clients who understand their HIV disease and the relationship between treatment, adherence, and successful outcomes do better than patients who do not have such understanding. It is important to understand the patient's health beliefs and understanding of HIV. If the patient has misconceptions about the nature of HIV/AIDS or has alternative beliefs about HIV, he or she may seek providers of care outside the legitimate health-care system.

How to address the barrier: The most important step is to build a trusting relationship with the patient in order to facilitate open and frank discussion about his or her beliefs about HIV and health. Providers should communicate in an open and non-judgemental way, with appropriate body language. Explaining HIV in a manner appropriate to the client's level of education and his or her cultural background is also important.

Barriers to understanding: Lack of awareness of ART or mistrust in its effectiveness

Clients who believe in the effectiveness of medications also do better with treatment. If the client does not understand the goals of care and treatment, has unrealistic expectations about ART, or has been disappointed with medical care in the past, he or she may not believe in the effectiveness of ART, and may then be more likely not to adhere to the course of treatment. In addition, mistrust in the effectiveness of ART may cause the client to seek alternative, non-effective, medications such as herbal medicines or other traditional medicines that do not treat or cure HIV, and may have more harmful interactions with ARVs.

How to address the barrier: Discussing HIV and its treatment in an open and non judgemental way, paraphrasing and repeating information, and providing a scientific basis for HIV treatment and related issues will help patients develop self confidence. Presenting a case study or experience from other patients may also help patients develop positive attitudes and confidence in the effectiveness of treatment.

Barriers to motivation and remembering: Forgetfulness

Memory difficulties in an HIV-infected client may indicate an early stage of HIV associated dementia. In general, the early symptoms of HIV-associated dementia are: apathy, memory loss, slowed thinking, depression, and social withdrawal. In addition, the client's work schedule may be too busy, or his or her life may be too chaotic, for the client to remember to take medications.

How to address this barrier: Personalizing the dosing regimen to suit specific aspects of the client's lifestyle may help. For example, if the client works from 8:30 to 19:00 every day, it may be easier for him or her to take a twice daily dosing regimen at 8:00 (before work) and then again at 20:00 (after work). A regimen where the doses are fixed at 10:00 and 22:00 may be more difficult for the client because he or she would have to remember to take the medicines at work. Giving the client practical tips about how to remember medications (daily cues, reminders, assistance from family members or friends) also helps. Additionally, watches, beepers, alarm clocks, or mobile phones may also be used to prompt the client to take the medicines.

Barriers to motivation and remembering: Depression or other psychiatric diseases

Patients with depression and other psychiatric illness may have difficulties adhering to treatment. Patients with advanced HIV disease may develop related conditions such as AIDS dementia that prevent them from caring for themselves and taking medications regularly and correctly. An episode of meningitis or encephalitis may also leave patients in a state of residual confusion.

How to address the barrier: Active depression can be treated with antidepressants. Physicians can assess the patient and provide relevant medical care. Treatment with ARVs helps to resolve some conditions but perhaps not AIDS dementia. Such patients require additional support – from the family, community health workers, and PLHA support groups – to take their medications on time.

Barriers to motivation and remembering: Active alcohol or drug use

Patients with heavy alcohol intake or active drug use have problems adhering to treatment. They may forget to take medications on time or correctly.

How to address the barrier: Counselling is an important tool. Patients should be given scientific information on the link between alcohol, ARV drug metabolism in the liver, and liver damage. ARV medications may have to be stopped or changed if liver damage occurs.

Open and non-judgemental discussion is essential. Linking patients with PLHA support groups and peer groups may be helpful. A family member may be asked to remind the patient to take the medication (but only if the patient has disclosed his or her HIV status). Referring patients to active “de-addiction” programmes, where available, is also useful.

Barriers to motivation and remembering: Inability to set longer-term goals

Sometimes, the diagnosis of HIV may be so emotionally devastating that the client cannot see past day-to-day living to set longer term goals for his or her life. In addition, the client may be distracted by other, more pressing, issues such as heroin addiction, alcohol addiction, or extreme poverty.

How to address this barrier: Before ART begins the client's readiness to commit to lifelong chronic therapy must be assessed. The provider must give the client hope and reassure him or her that it is possible to live well, and longer, with HIV. If the client seems doubtful or too overwhelmed by the diagnosis or too burdened by daily stresses, the provider should help address the acute stressors while at the same time encouraging the client to have a longer-term perspective and goals for himself or herself.

Support and logistical barriers: Discomfort with disclosure of HIV status

Disclosure of HIV status is an important factor influencing adherence. PLHA, fearing rejection or discrimination, may not disclose their status to family members and friends, thereby losing out on social support. In addition, patients may not want to risk making their HIV status known by taking their medications in front of family members, friends, or work colleagues, and may instead choose to skip a particular dose.

How to address the barrier: Counselling can help the patient overcome some of these fears and prepare for disclosure to family or friends. Once the patient is ready to make the disclosure, family members may also need counselling. These family members should be those identified by the patient. If patients are not ready to disclose their status, counsellors can help them identify a person or two outside the family, for example, peers, friends, or PLHA support groups, who could provide psychosocial support.

Support and logistical barriers: Difficult life conditions

Patients without decent housing, employment, or sufficient financial means may perceive such needs as more urgent than proper medication.

How to address the barrier: While the health worker may not be able to address these problems directly, linking patients with church programmes, PLHA support groups, and home-based care programmes may offer some help. Some church programmes donate food and PLHA groups have income-generation activities.

Support and logistical barriers: Unstable living conditions and lack of social support

Patients may be living alone, in shared accommodation, or on the street. Unstable living conditions pose a major barrier to proper medication intake and storage. These patients also tend not to have family or outside support, and thereby miss out on a caring atmosphere, proper nutrition, and stability in their personal lives.

How to address the barrier: Establishing contact with PLHA support groups, if the patient is willing, may be helpful in getting some support. Linking the patient with a home-based care programme and community health workers may provide some psychosocial support and nursing care. Support programmes run by faith based organizations, such as food donation programmes, may provide an additional source of support.

Support and logistical barriers: Logistical difficulties

These include travel, life away from home, changing daily schedules, lack of food, and lack of cool storage (if needed for medication).

How to address the barrier: The counsellor should work with the patient to develop the ability to anticipate problems. Establishing contact with PLHA support groups, if the patient is willing, may be helpful in providing some support, even at a moment's notice.

Barriers related to health-care delivery: Negative or judgemental attitudes of providers

Patients who perceive their providers as having antipathy or a negative and discriminatory attitude towards them are understandably reluctant to adhere to treatment and maintain a regular schedule of follow-up care.

How to address the barrier: Providers must be trained. Regular staff meetings to discuss the follow-up of patients may help providers to understand the issues better.

Barriers related to health-care delivery: Structural barriers

Patient adherence may be adversely affected by structural barriers such as transportation difficulties (distance, time, cost), inconvenient clinic hours, high clinic fees, high laboratory fees, inadequate drug supply in the pharmacy, refusal of treatment by overworked health-care staff, or lack of proper birth or housing registration in the locality.

How to address these barriers: These barriers must be addressed by the health-care management. Providers may help by bringing these issues to the administration's notice.

Barriers related to medications: Regimen complexity

Clients on ART are often also taking other medicines, such as prophylaxis against opportunistic infections. In addition, they may be taking other medications for reasons unrelated to HIV (such as liver protection medications, herbal medicines, vitamin supplements, or other over-the-counter medicines).

How to address this barrier: Pillboxes pre-filled with ART medications may help the client cope better with the regimen complexity of ART. The provider should also find out from the client whether he or she is taking other medicines as well. In general, unessential medicines should be reduced to simplify the client's regimen.

Barriers related to medications: Frequency of dosing

Frequent dosing of medications (such as every six hours) can be a barrier to adherence. Clients may find it difficult to have to wake up in the middle of the night to take medications.

How to address this barrier: In general, regimens using sustained release formulations of medicines that require less frequent dosing (once or twice a day) are much easier for clients to adhere to. The adherence counsellor should ask the client at what time of the day or night the medications are taken. If the client is taking medications more than two or three times a day, the counsellor should ask the prescribing physician if the frequency can be reduced.

Barriers related to medications: High pill burden

Evidence has shown that the more pills a client has to take, the greater the likelihood of non-adherence.

How to address this barrier: In general, to lessen the client's pill burden (as well as the risk of interaction between drugs), unessential medicines should be reduced. The provider should work with both the client and the client's physician to identify and eliminate unessential medications (vitamins, herbal medications, etc.). The provider should also advocate the availability of combination drug pills in the service area. (Combination drug pills are now available only outside China.)

Barriers related to medications: Food requirements or restrictions

Some medications need to be taken on an empty stomach, while others must be taken just before or after meals. Patients having to take different medications at different times may easily become confused. Some medications may also entail food restrictions, such as dairy products, while others do not.

How to overcome this barrier: Before the client begins the ART regimen, he or she should receive careful oral and written instructions from the provider about how the medications should be taken. Simple reminder cards that show the drug, the dosage, and the time of medication (before or after meals, or on an empty stomach) can be useful.

Barriers related to medications: Frequency and severity of side-effects

Many ART medications have side-effects. Common side-effects are nausea, diarrhoea, headaches, peripheral neuropathies, and skin changes. Clients, especially if they are mostly asymptomatic or are feeling well, may be reluctant to continue taking ART medications because of the frequency or severity of side-effects.

How to address this barrier: Before the client begins ART or starts taking a new drug, the provider should discuss possible side-effects with him or her and the two of them should draw up a plan for managing these. Such a discussion is also important because the client may otherwise be too embarrassed or hesitant to bring up some side-effects (e.g., diarrhoea). The client may also benefit from a referral to a PLHA support group. Proper management of side-effects and referral to the prescribing physician are extremely important for long-term adherence.

Pre-ART adherence screening tool

Client name/code: **Date of Birth:**

Instructions:
This tool is to be used in conjunction with the Post-diagnosis follow-up counselling form.

Tell the client:
"*Many clients have difficulty taking medication. I would like to ask you some questions that will assist our clinic in planning your treatment. Please consider and answer the questions carefully. I really want to make sure that you get the best treatment we can offer.*"

SECTION 1

Past experience with medication:

1. What difficulties have you had in the past with taking medication in the correct dose and at the correct time for the complete prescribed period?

_____
_____
_____

2. If you had difficulties, what were some of the reasons you could not take the medication as prescribed?

_____
_____
_____

When you took medication in the past and had unpleasant side effects like nausea or diarrhoea, did you do any of the following (circle YES or NO):

1. Reduce the medication dosage without the doctor's advice? YES / NO
2. Increase the medication dosage without the doctor's advice? YES / NO
3. Stop taking the medication? YES / NO

Attitudes and beliefs about medication (circle YES or NO, or take notes as appropriate):

1. Do you believe medication is harmful to your body? YES / NO
2. Do you believe traditional medicine is more effective than prescribed medication? YES / NO

3. What does your family believe about medication?

_____
_____
_____

4. What about the attitudes and beliefs of close friends, or other people you know with HIV?

_____
_____
_____

Daily routine (circle YES or NO):

1. Do you take meals at regular intervals (same time every day)? YES / NO
2. Do you ever work through a meal break because you are busy? YES / NO
3. Do you eat meals with other people at work? YES / NO
4. Do you eat meals with people at home? YES / NO
5. Are you worried that if other people see you taking medication they will then know you have HIV? YES / NO

6. Is there anything in your daily routine or work that would make it difficult to take medication at specific times?

_____
_____
_____

Potential barriers to attending follow-up medical appointments (circle YES or NO):

1. Do you travel often to other parts of the country/province? YES / NO
2. Are you able to attend the clinic/hospital during service hours? YES / NO
3. Do you have any problems travelling to the clinic/hospital? YES / NO
4. There may be other charges for other treatments or tests. Would it be hard for you to pay those extra charges? YES / NO

Drug and alcohol use[1] (circle YES or NO):

1. Are you now using drugs or alcohol? YES / NO
   If yes, ask which ones (check all that apply:

Solvents	❑	Narcotic	❑
Alcohol	❑	Analgesics	❑
Marijuana	❑	Tranquilizers	❑
Heroin	❑	Opium	❑
Others	❑		

If others, note down which ones:

2. How much of the drugs or alcohol are you using (quantity and frequency)? (Ask about each drug the client has indicated he/she takes.)

Substance	Quantity	Frequency	Substance	Quantity	Frequency
Solvents			Narcotic		
Alcohol			Analgesics		
Marijuana			Tranquilizers		
Heroin			Opium		
Others					

3. If you are not using drugs or alcohol daily do you ever binge (occasional heavy use)? YES / NO

Pregnancy and infant feeding for women (circle YES or NO):

Some medications should not be prescribed to pregnant women.

1. Are you now pregnant? YES / NO
2. Have you had a pregnancy test? YES / NO
3. If not pregnant, are you using contraception? YES / NO
   If using contraception, please circle which form:

   Intrauterine device (IUD) Oral contraceptive pill Condoms Other

4. Are you breast-feed an infant? YES / NO

[1] If the client uses drugs and alcohol daily, he or she should answer these questions and then more detailed questions about drug and alcohol use

SECTION 2

Informal screening for possible HIV related cognitive impairment

Memory and concentration (circle one of the possible answers):

1. a. How well do you remember what has just been said when somebody is talking to you?

   Extremely well | Average, with some small problems | Forget a lot

   b. Has there been any change?

   Much better | No change | Much worse

2. a. How well do you remember events from past years (long term memory)?

   Very well | Average, with some small problems | Forget a lot

   b. Has there been any change?

   Much better | No change | Much worse

3. a. When your family or friends talk to you, can you follow what they say or do you forget what they say even while they are still talking to you?

   Follow well | Average, with some small problems | Cannot follow

   b. Has there been any change?

   Much better | No change | Much worse

Fine-motor skills (circle one of the possible answers):

1. a. Do you have difficulty doing fiddly things with your hands (like dropping things or not being able to pick up very small things)?

   No problems | Average, with some small problems | I have a lot of problems (clumsy)

   b. Has there been any change?

   Much better | No change | Much worse

Verbal fluency (circle one of the possible answers):

1. a. Are you having trouble trying to say what you want to say to people (i.e., you cannot find the words or say the wrong words)?

   No problems | Average, with some small problems | I have a lot of problems (clumsy)

   b. Has there been any change?

   Much better | No change | Much worse

Mood and hallucinations (circle one of the possible answers):

1. a. Are you easily irritated or frustrated nowadays?

No problems	Average, with some frustration and irritability	Really irritable or easily frustrated

b. Has there been any change?

Much better	No change	Much worse

2. a. Are you anxious or do you feel nervous nowadays?

Not anxious	Only occasional worries like everyone else	Feel very anxious, a lot

b. Has there been any change?

Much better	No change	Much worse

3. a. Are you depressed (feel sad, lack motivation) nowadays?

Not depressed	No more than most other people	Very depressed

b. Has there been any change?

Much better	No change	Much worse

4. a. Do you feel manic (extremely active, cannot rest, have difficulty sleeping, talk very fast, spend lots of money without thinking)?

Not at all	Sometimes	A lot

b. Has there been any change?

Much better	No change	Much worse

5. a. Do you ever hear voices or see things that other people say they cannot see or hear? (This does not apply when a client is intoxicated with drugs or alcohol or is in withdrawal.)

Not at all	Sometimes	A lot

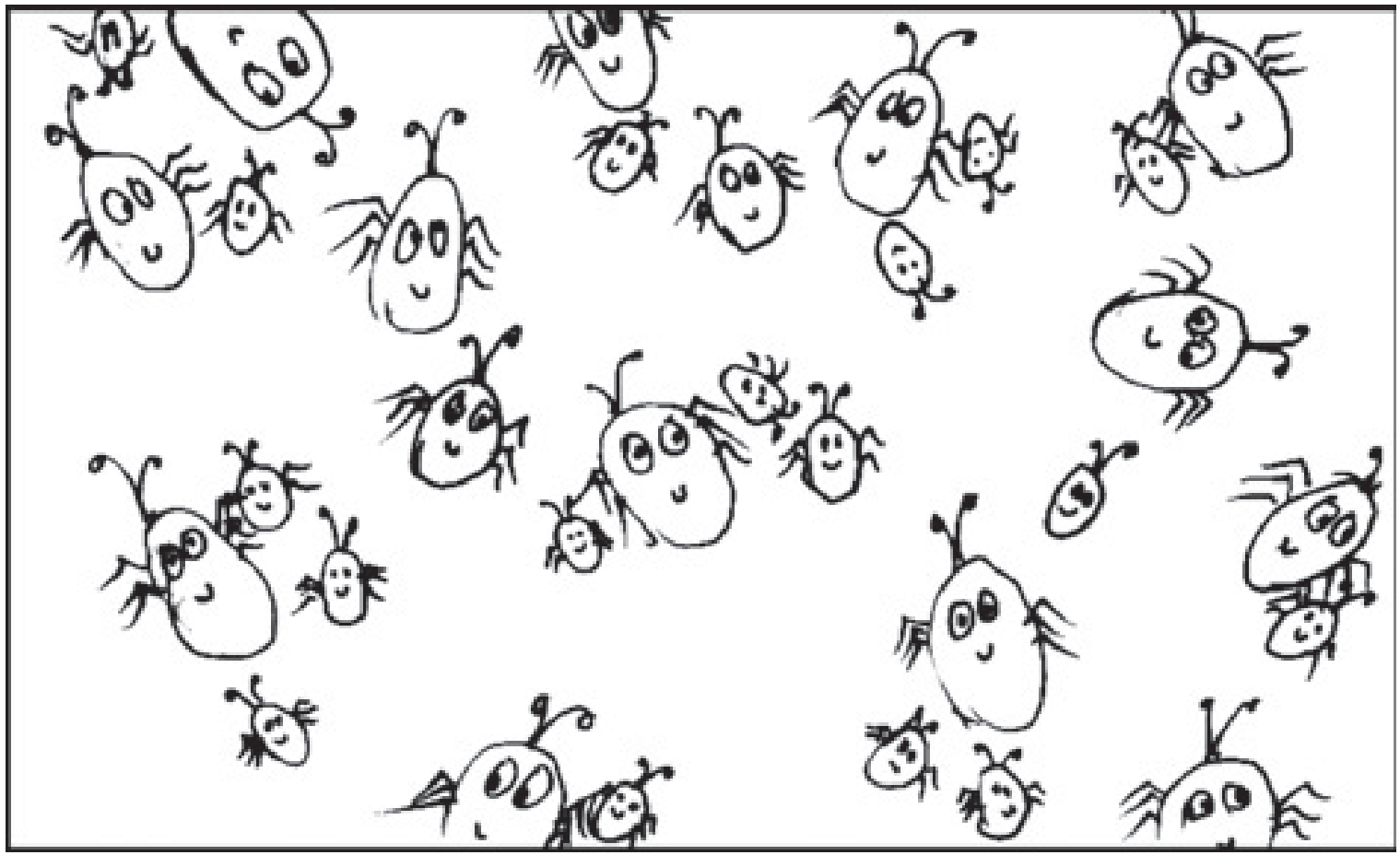
b. Has there been any change?

Much better	No change	Much worse

Counsellor's name:	Signature:	Date:

What causes HIV resistance to ARV drugs?

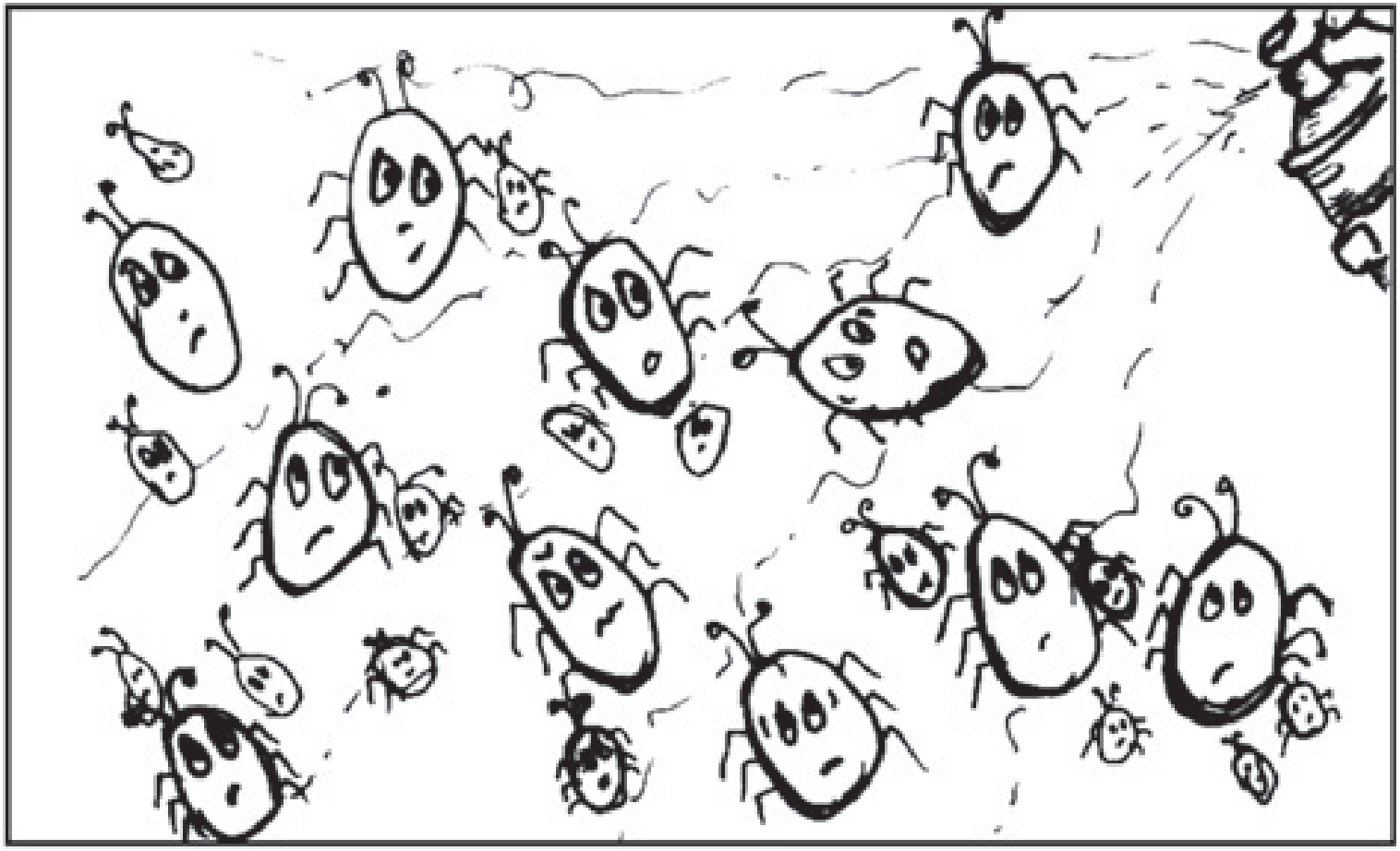
1.



Imagine for a minute that the HIV germs are like small bugs. Just like people, some of the bugs are strong and some are a bit weaker. The bugs can reproduce so there are always new bugs – babies and bugs growing up and having more bugs. They reproduce and the bug families multiply quickly! Children, even bug children, are not exactly the same as their parents. There are differences.

Viruses like HIV also change very quickly as they multiply. Since HIV multiplies so fast, it has a lot of opportunity to change.

2.



Can you see the can of bug spray in the picture?

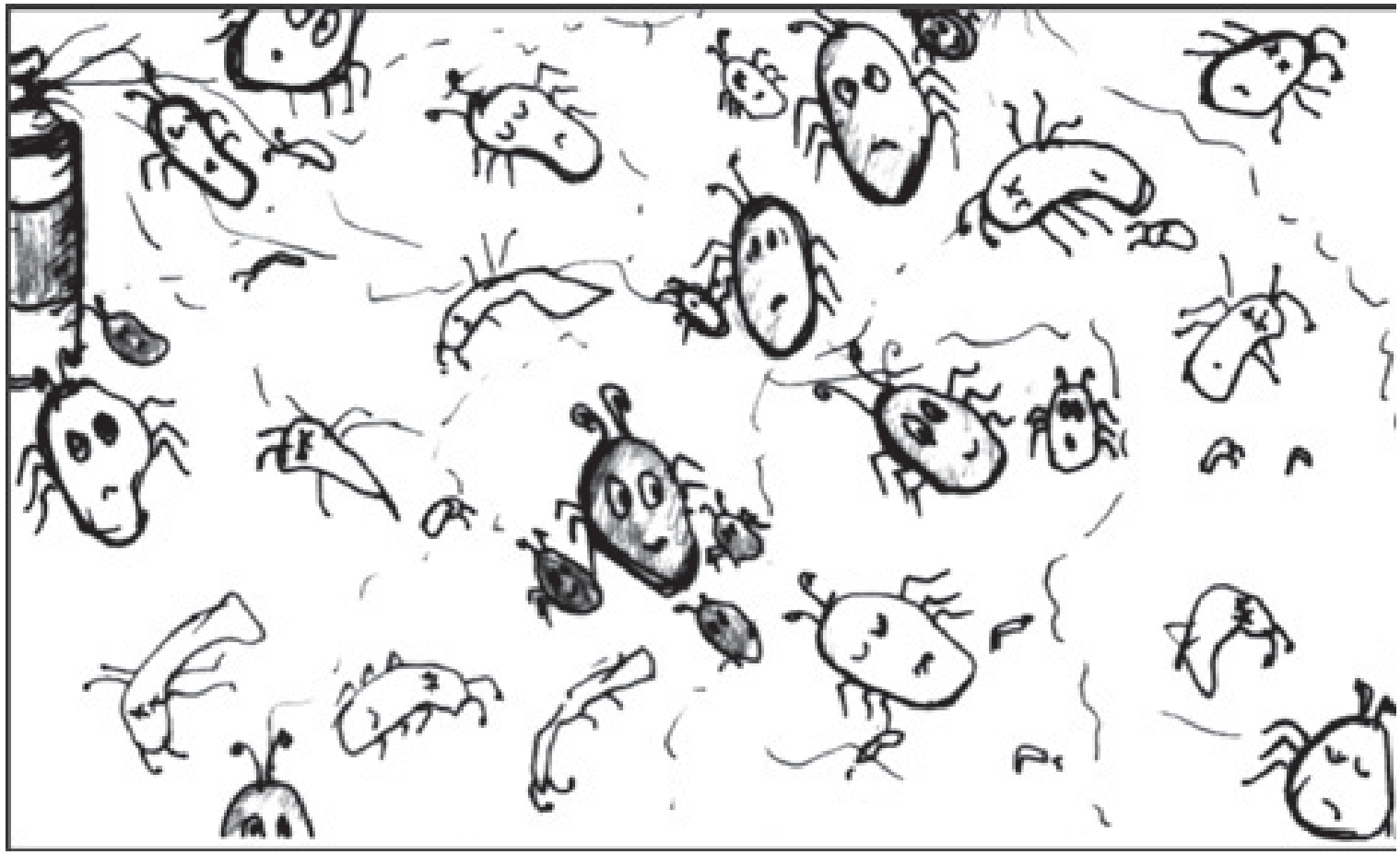
Now imagine that someone is trying to kill the bugs with bug spray. A certain amount of bug spray must be used every day. We know that the spray can't ever kill all of the bugs, but it can keep their number very low, so that the bugs can't cause too many problems.

3.

The first day this is done just right: many bugs die and some are made very weak, while a few of the strong ones aren't bothered.

Remember: All of the bugs that are still alive, especially the strongest ones, multiply. The strong ones make more bugs like themselves. Even the sick ones might have some baby bugs.

4.



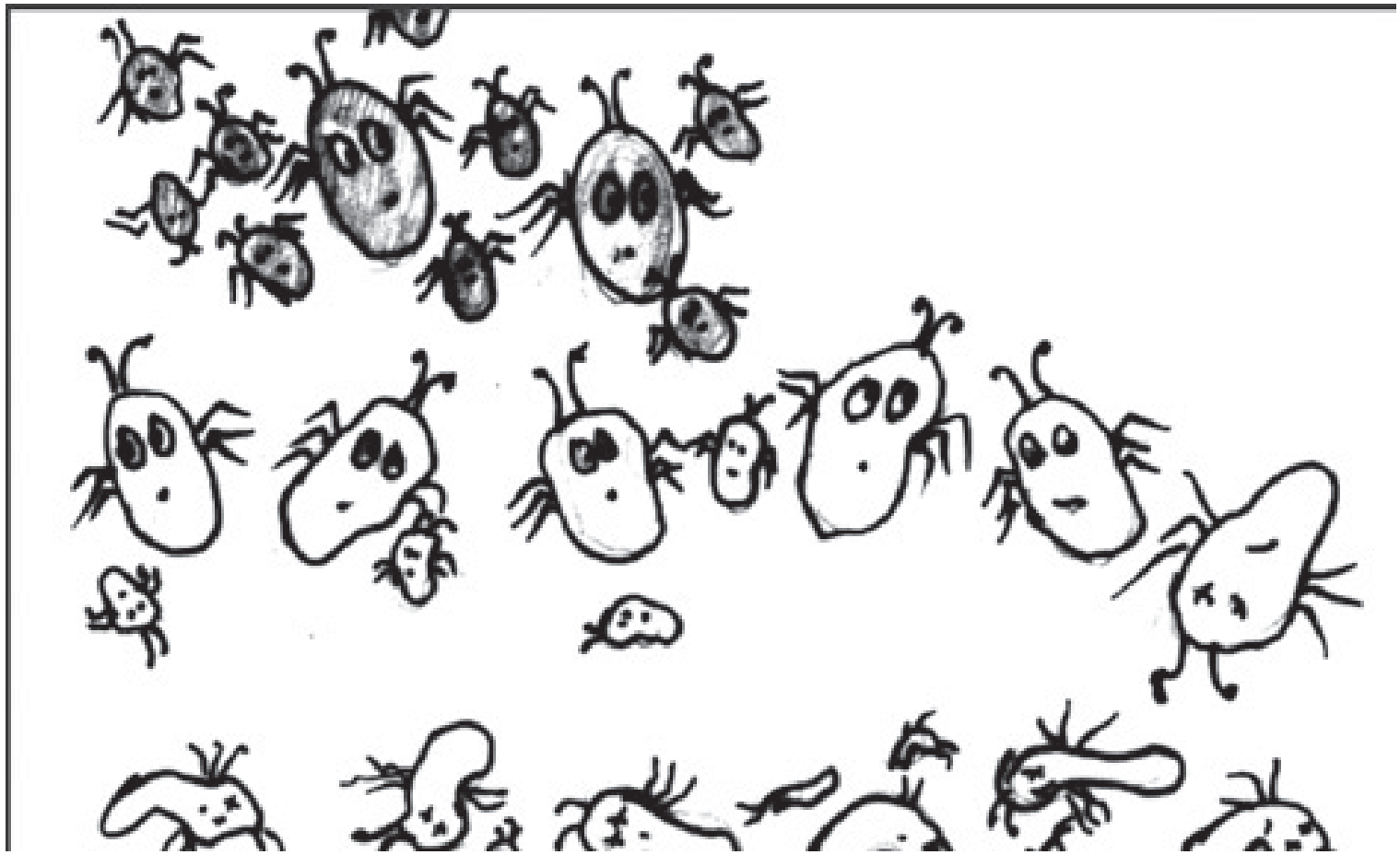
The second day, we spray again. We are trying to kill the weak bugs and any new bugs – the bug families of those bugs that weren't killed on the first day.

5.

More bugs die, especially those that were already made weak. But some are still well enough to multiply and some are strong enough to multiply quickly.

If we remember to spray just the right amount every day, we can keep up with the multiplying bugs. As fast as they multiply, the spray will kill them, even though it can never kill all of them.

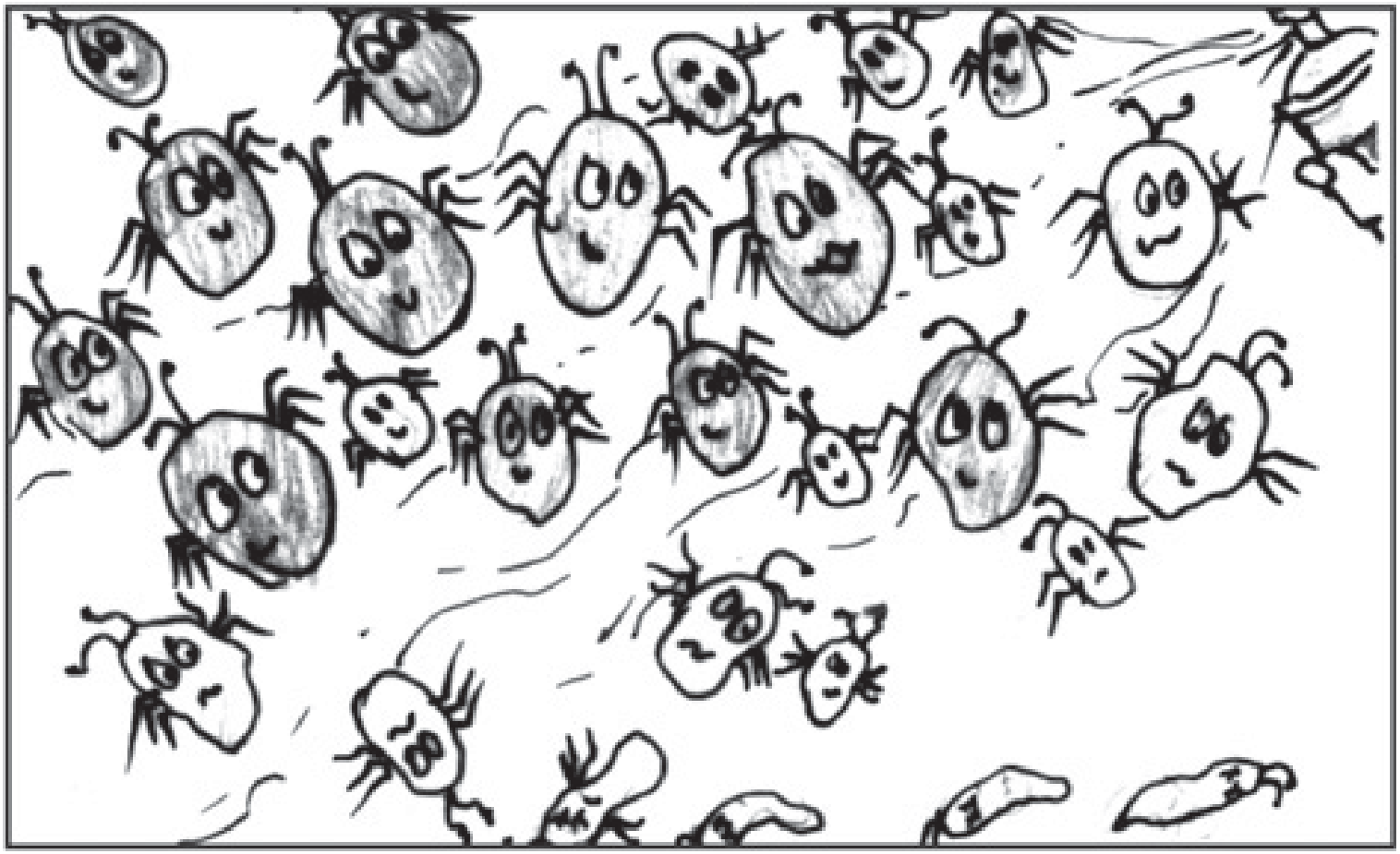
6.



Even the weaker ones now look stronger and are multiplying. Their babies may be more like the very strong bugs.

This day, we forget to spray – and the bugs that were sick start to feel better. Not only do they feel better, they reproduce more quickly.

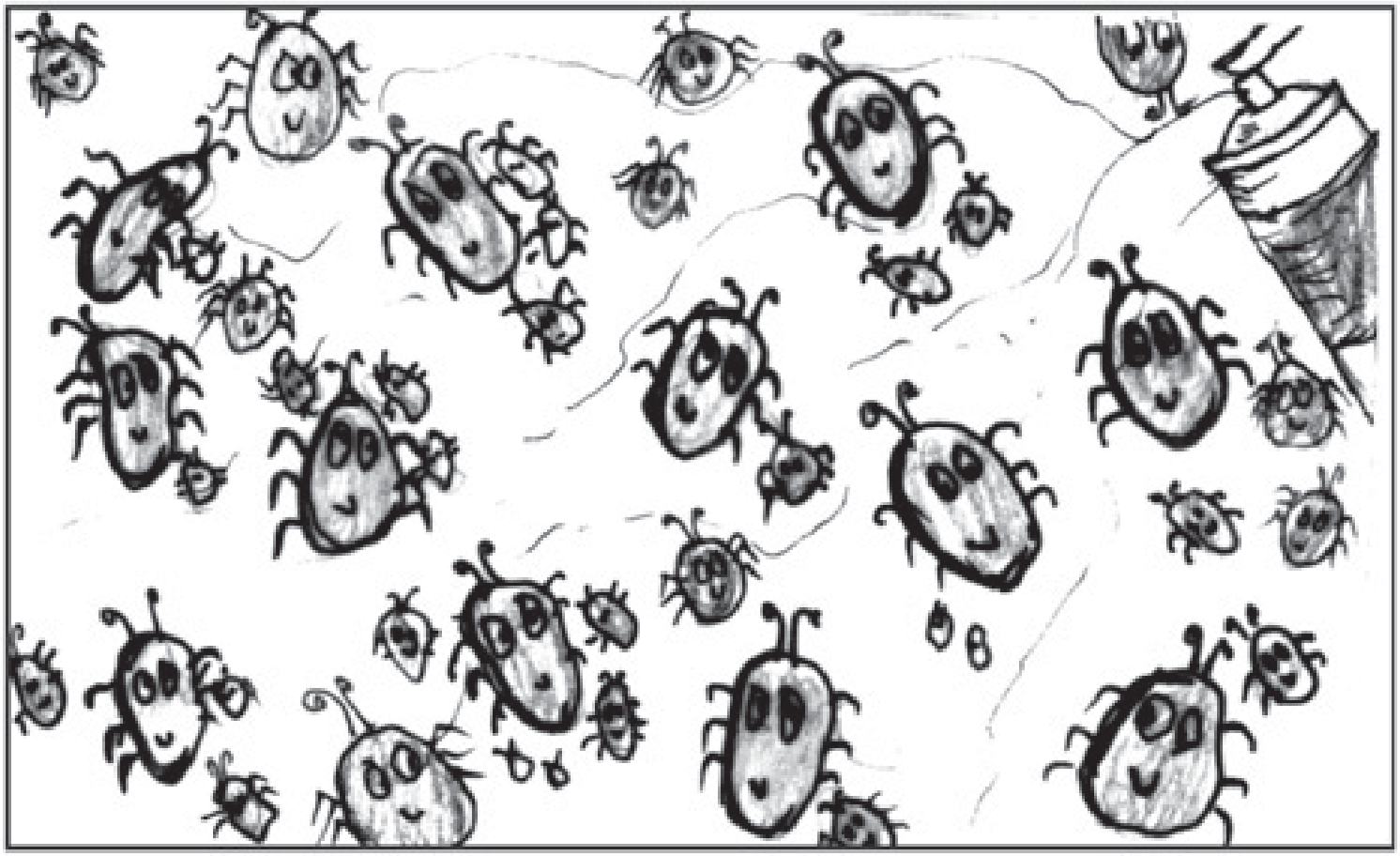
7.



Look at the different bugs. Some are dead and others look sick, but the grey ones don't look too worried.

When these bugs reproduce, some of their babies are even stronger. The spray doesn't kill them; they are becoming immune to it. The spray isn't going to work as well now.

8.



Now the bugs don't look worried or sick even though the spray is being used.

The immune bugs quickly have immune baby bugs, which grow up to have more immune baby bugs.

So now, though some bug families can be killed by the spray, the bug families that can't be killed are growing very quickly. There are more and more of these immune bugs.

The same thing can happen with HIV germs and ARV medicines. If we forget to take some of our medicine, the HIV can multiply and change. It can become immune to the medicine. Since there is more and more of this kind of HIV, it kills more and more of the blood cells in our immune system.

Our immune system can't protect us and we get sick. If we don't get different medicine that can kill the HIV, we can die of AIDS.

ART drug side-effects

Headache

Dry mouth

Tingling or pain

Anaemia

Tiredness & dizziness

Skin rashes

ART drug side-effects

Skin turning yellow

Diarrhoea

Nausea & vomiting

Nightmares

Source: Adapted from FHI. *Art adherence training workshop: Trainer's manual.* FHI China, 2006

ART drug side-effects

Headache

ART drug side-effects

What you can do at home:

Rub the base of your head gently with your thumbs

Rest in a quiet, dark room with your eyes closed

Place a cold cloth over your eyes and forehead

Avoid drinks with caffeine, such as strong tea or coffee

Take two paracetamol tablets every four hours

You need to see a doctor if:

Your vision becomes blurry or unfocused

You have frequent or very painful headaches and pain relievers do not stop the pain

You have a fever or are vomiting

ART drug side-effects

Dry mouth

ART drug side-effects

What you can do at home:

Rinse your mouth with clean warm, salty water

Drink lots of clean and boiled water

Avoid sweets

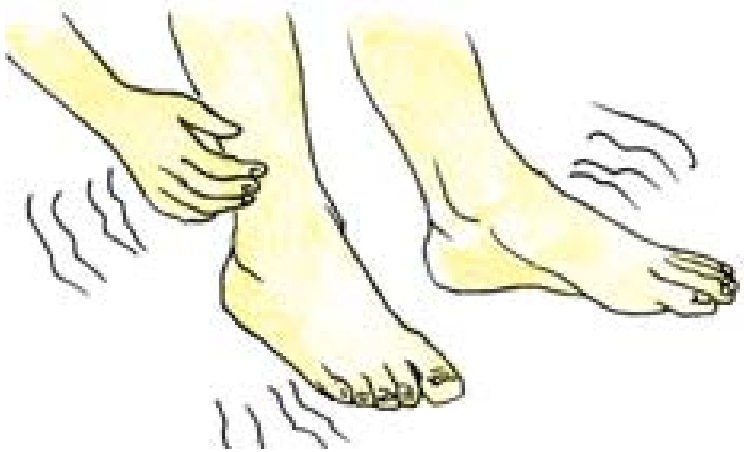
Avoid drinks with caffeine such as strong tea or coffee

You need to see a doctor if:

Your mouth is very dry and the dryness is not going away

You have trouble swallowing food

ART drug side-effects



Tingling or pain in hands or feet

ART drug side-effects

What you can do at home:

Wear loose-fitting shoes and socks

Keep feet covered in bed

Walk a little, but not too much

Soak feet in warm water and massage with cloth

You need to see a doctor if:

The tingling does not go away or gets worse

You have too much pain to walk

You cannot use your hands properly

ART drug side-effects

Anaemia

ART drug side-effects

What you can do at home:

Eat fish, chicken, and meat

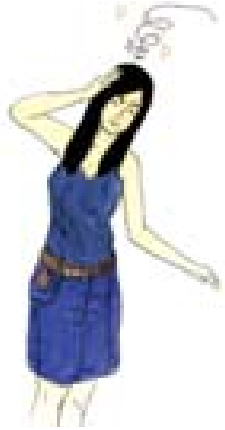
Eat spinach, asparagus, dark leafy greens, and beans

Take iron tablets

You need to see a doctor if:

You have been tired for 3-4 weeks and are feeling more and more tired

You feel unsteady and dizzy



ART drug side-effects

Tiredness and dizziness

ART drug side-effects

What you can do at home:

Get up and go to sleep at the same time every day

Get a little exercise

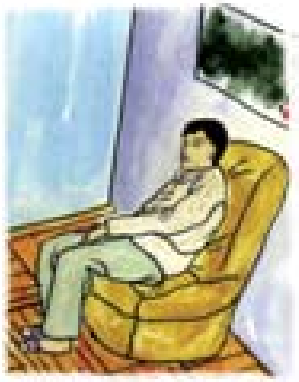
Balance your diet with fruit and vegetables

Avoid alcohol, tobacco, and drugs

Cook simple food when you are too tired to cook

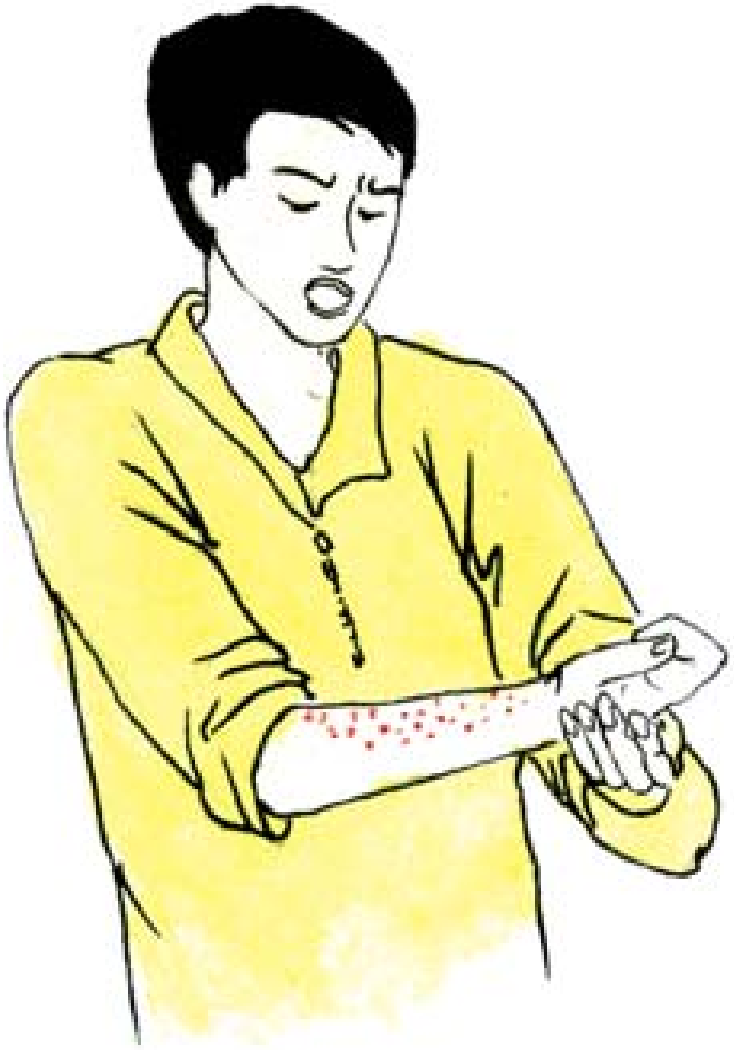
You need to see a doctor if:

You feel too tired to move or eat



You cannot swallow or eat enough to keep strong

ART drug side-effects



Skin rashes

ART drug side-effects

What you can do at home:

Wash often with unscented soap and water

Keep the skin clean and dry

Use lotion to relieve itching

Avoid the sun

Drink plenty of water to keep skin hydrated

You need to see a doctor if:

You have a fever

You have pain in your mouth or throat, or red eyes

Skin rash persists for a long period

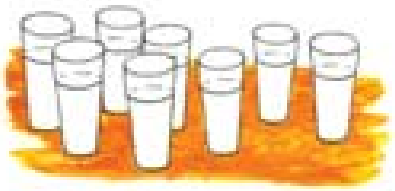
The rash blisters

ART drug side-effects

Skin turning yellow

ART drug side-effects

What you can do at home:



Drink plenty of clean boiled water

Get plenty of rest

Avoid food high in fat

You need to see a doctor if:

The yellowness is increasing

You have a fever

You are weak, have no appetite, and have some abdominal discomfort

You have swelling of hands, legs, or abdomen

ART drug side-effects

Diarrhoea

ART drug side-effects

What you can do at home:

Eat less but more often during the day

Eat easy-to-swallow foods, such as rice, bananas, and biscuits

Drink plenty of clean boiled water

Take oral rehydration solution (ORS) when needed

Avoid spicy and fried foods

You need to see a doctor if:

There is blood in the stool

You have diarrhoea more than four times a day

You also have a fever

You are thirsty but cannot eat or drink properly

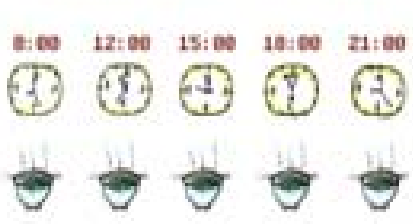
ART drug side-effects

Nausea and vomiting

ART drug side-effects

What you can do at home:

Ask doctor if you can take ART drugs with food



Eat less but more often during the day

Drink clean boiled water, weak tea, or ORS until vomiting stops

Avoid spicy and fried foods

You need to see a doctor if:

You have sharp pains in your stomach

You have a fever

There is blood in the vomit

Vomiting lasts for more than one day

You are thirsty but cannot eat or drink properly

ART drug side-effects

Nightmares

ART drug side-effects

What you can do at home:

Try to do something that makes you happy and calms before you go to sleep

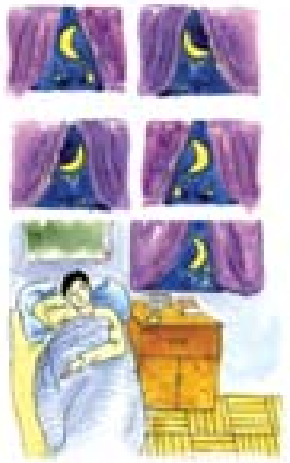
Avoid alcohol and drugs, as these will make things worse

Avoid fatty foods or heavy meals before sleeping

Talk with others about your feelings

You need to see a doctor if:

You haven't been able to sleep for several nights



You dream about terrible things, such as suicide

Practical problem solving for managing common barriers to adherence[1]

Patients may not take their medications for several reasons. Problem solving relates to finding out why medications are missed and addressing those reasons. The table below lists some of the common reasons patients cite for missing doses, the possible barriers, and suggestions for problem solving.

Patients' reasons for missing doses	Possible barriers	Problem solving
Forgot to take pills	• Travelling • Addicted to alcohol/drugs • Depressive / Has psychiatric illness • Living alone and sick • Homeless, no family support	• Plan before travel, take extra pills • Use reminder cues • Address addiction (alcohol and drugs)
Pills do not help; felt better so did not continue	• Inadequate knowledge • Incorrect beliefs and attitudes	• Enhance counselling • Provide scientific information and examples • Enlist family support
Family said no to medications	• Inadequate knowledge • Incorrect beliefs and attitudes	• Counsel family • Provide scientific information and examples
Instructions were unclear; did not understand how to take medications	• Low literacy • Depression / Psychiatric illness • Alcohol intake / Active drug use • Insufficient time to counsel	• Use literacy materials • Use dummy pills and repeat instructions • Ask patient to repeat instructions • Enlist family support • Treat depression • Address addiction (alcohol and drugs)
Unable to care for self	• Living alone • Unemployed • Has AIDS dementia / mental illness	• Use PLHA support groups • Register with the home-based care programme • Link with FBO food donation programmes • Enlist family support • Identify a friend who can help
Did not want others to see patient taking medications	• Stigma at place of work • Non-disclosure in the family	• Provide counselling support for disclosure • Identify a friend who can help
Fear of toxicity	• Insufficient preparation • Inadequate knowledge	• Provide scientific information on what to expect and how to manage it • Counsel on risks of non adherence

[1] Source: Adapted by K. Casey from Population Council/Family Health International *Adherence to Antiretroviral Therapy in Adults: A guide for trainers*, Population Council India, 2004. pp. 194–195.

What can I do to have a healthy and safe pregnancy?

Receive antenatal care from qualified health staff.
Have a check up at least three times during your pergnancy.

You will be able to discuss any worries/problems with the health staff. You will receive a vaccination against tetanus. You will be able to make a plan for feeding your baby safely.

You will be given iron tablets to prevent anaemia.

Consider telling the health staff that you are HIV-positive. They will be able to give you appropriate care and advice. It will be easier to discuss problems with them. They will also understand your special needs.

Adapted from: FHI. *Self Care Series Book 4: Staying Healthy for Mothers Living with HIV*. Thailand, 2004

What should I eat to stay healthy during my pregnancy?

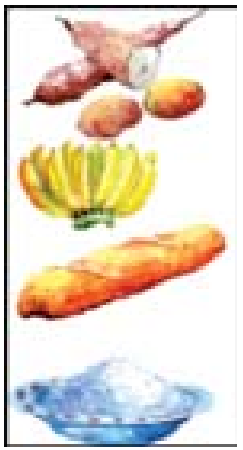
Pregnant women need extra food to stay healthy and to help their baby grow strong and healthy inside the uterus. According to WHO, you need at least 10% extra energy giving foods when you are pregnant and HIV positive. Nutritious eating can help you stay healthy and strengthen your immune system. All pregnant women need daily iron and folic acid supplements to prevent anaemia and birth defects.

1. "GROW" FOODS

"Grow" foods include all kinds of meat, fish, eggs, and some kinds of beans, especially soybeans.

2. "GLOW" FOODS

"Glow" foods have vitamins to help the body work well. Most fruits and vegetables contain vitamins. Dark green leafy vegetables contain many kinds of vitamins



3. "GO" FOODS

"Go" foods provide energy. Rice, sugar, bread, and all foods made from these things are "go" foods. Fats are also "go" foods. Adding fat or oil to rice or food is an easy way to add energy.

Adapted from: FHI. *Self Care Series Book 4: Staying Healthy for Mothers Living with HIV*. Thailand, 2004

Other helpful things you can do during pregnancy

Get plenty of rest. If possible, avoid heavy work such as carrying water.

Keep clean by bathing daily and wearing clean clothes.

Seek immediate advice from a qualified medical person if:

- You have any bleeding from the vagina.
- You have a headache with swelling of legs and hands.
- Your baby is not moving.
- You have fever or chills.

Avoid smoking, alcohol, and sleeping pills. They are harmful to you and your baby. They will also reduce your appetite.

Adapted from: FHI. *Self Care Series Book 4: Staying Healthy for Mothers Living with HIV*. Thailand, 2004

What treatment is available to reduce the risk of HIV?

A special drug treatment that can reduce the risk of HIV transmission to infants is available. This treatment cannot completely stop HIV transmission, but it can reduce the risk. This drug is given by mouth to the mother during labour and later to the baby.

Where can I receive treatment to reduce the risk of HIV transmission to my baby?
To receive treatment to reduce the risk of transmission to your baby, you will need to have a confirmed HIV test. You and your partner can be referred to a specialist HIV treatment service.

What will happen when I attend a centre that offers voluntary counselling and testing?
At the centre, you will receive counselling before testing and again after you receive your results. If you are HIV-negative, you will learn how you and your partner can prevent future HIV infection and protect your baby. If you are HIV-positive, you will learn about treatment and care to reduce the risk of transmitting HIV to your baby.

Adapted from: FHI. *Self Care Series Book 4: Staying Healthy for Mothers Living with HIV*. Thailand, 2004

Where is the best place to deliver my baby?

The best place to deliver your baby is in a health facility with a trained medical person.

What should I do during labour and delivery?

If possible, deliver in a centre that provides the special drug that will reduce the risk of HIV transmission to infants. Consider telling the medical staff that you are HIV-positive. They can help you to have a normal delivery and protect you and your baby from complications.

If you do not deliver in a centre that provides the special drug, deliver at a health centre or referral hospital that has trained midwives and doctors.

Adapted from: FHI. *Self Care Series Book 4: Staying Healthy for Mothers Living with HIV*. Thailand, 2004

What is the best way to feed my baby if I am HIV-positive?

Breast-feeding carries some risk of infecting your baby with HIV. In HIV-positive women who breast-feed for two years there is a risk that one out of seven babies will be infected. If these women were to breast-feed for only 6-12 months the number of babies infected would be reduced. Breast-feeding for a shorter period can reduce the number of babies infected.

Here are some things to think about before you decide how to feed your baby:

- Is it difficult for you to gain access to affordable, good-quality health-care?
- Is it difficult to obtain clean drinking water in your community?
- Is the cost of milk formula too high for you to buy it for 12 months?
- Are diarrhoea and chest infections common problems for babies in your community?

If you answer YES to any of these questions, then exclusive breast-feeding for the first six months of your baby's life is the best and safest way to feed your baby. It reduces the risk of HIV infection and the risk of diarrhoea and malnutrition.

WHO and UNICEF recommend exclusive breast-feeding for the first six months. Breast milk contains everything your baby needs for the first six months.

Adapted from: FHI. *Self Care Series Book 4: Staying Healthy for Mothers Living with HIV*. Thailand, 2004

What is the best way to feed my baby if I am HIV-positive?

You and your partner should consider the following:

- Do you have money to buy substitute feeding for at least 12 months?*
- Do you have clean water available and the time and fuel needed to boil water for mixing formula and for cleaning the cups, etc.? (You will need to do this 5-6 times a day).
- Can you afford to buy a large saucepan, a kettle, plastic cups, liquid washing soap, and a special brush for cleaning the utensils?
- Will you be able to prepare milk at least 7-8 times a day?
- Do you have access to affordable and good quality health-care if your baby has any health problems?

*Counsellors are advised to calculate the local cost for 12 months.

If you answer YES to all the five points above, then you can feed your baby infant formula.

If you decide to feed the baby infant formula, never mix with breast-feeding. Practice strict hygiene. Ask an experienced health worker to demonstrate how to prepare the formula in a clean and correct way. A cup is preferable to a bottle as it is easier to keep clean and free of germs.

Adapted from: FHI. *Self Care Series Book 4: Staying Healthy for Mothers Living with HIV*. Thailand, 2004

How do I exclusively breast-feed?

Good attachment

Breast-feed within the first hour of birth so that the baby gets the full benefit of colostrum and other nutrients that protect the baby against infections.

Give nothing but breast milk for the first six months of life. Do not give any water, tea, milk formula, rice water, tinned sweet milk, juices, or sugared water.

Poor attachment

Make sure the baby is attached properly to the breast while feeding. The baby should be in a comfortable position with his/her body straight and head facing your breast, and held close. His/Her mouth needs to be wide open and to cover most of the brown area around the nipple. His/Her chin should touch the breast.

Use a condom when having sex. This will help prevent re-infection with HIV or other STIs and thus reduce the chance of transmission to your baby.

Adapted from: FHI. *Self Care Series Book 4: Staying Healthy for Mothers Living with HIV*. Thailand, 2004

What does exclusive breast-feeding mean?

Exclusive breast-feeding means giving your baby nothing but breast milk from the moment he/she is born. NO WATER, NO TEA, NO MILK FORMULA, NO FRUIT JUICES, NO HONEY, NO SUGAR, NO RICE WATER, AND NO DUMMIES. (But medicines prescribed by a qualified medical person can be given.)

AVOID MIXED FEEDING.

Mixed feeding carries the highest risk of HIV transmission because any fluid or food other than breast milk can damage the lining of the baby's stomach and intestines, making it easier for the HIV virus to enter.

Important:

Exclusive breast-feeding for the first six months is one of the best ways to make sure your baby stays healthy. It helps reduce the risk of HIV transmission to the infant. Also, infants who are not breast-fed are more likely to die in the first six months of life from diseases such as diarrhoea and chest infections.

Mixed feeding is giving a baby breast milk and also other fluids or foods such as milk formula, sugared water, rice water, flavoured milk, or fruit juices.

Adapted from: FHI. *Self Care Series Book 4: Staying Healthy for Mothers Living with HIV*. Thailand, 2004

What if I am worried about breast-feeding my baby?

If you feel worried about breast-feeding your baby, then consider these three options. Do not make a decision until you consider all the options carefully. Discuss the options with an experienced health worker who knows how to prevent transmission of HIV to infants.

You can express your breast milk and heat it until it boils. Then cool it and feed your baby this breast milk in a cup. (Heating breast milk until it boils kills HIV in the breast milk.)

Another woman could exclusively breast-feed your baby.
This woman needs to have an HIV test.

You could feed your baby infant milk formula.

Adapted from: FHI. *Self Care Series Book 4: Staying Healthy for Mothers Living with HIV*. Thailand, 2004

What do I need to consider if I would like another woman to exclusively breast-feed my baby?

You and your partner will need to consider the following:

- The woman selected should be counselled, tested, and shown to be HIV-negative. She will need to have another HIV blood test in three months.
- If the woman is sexually active, she and her partner will need to be counselled about always using a condom for sex, so that she does not become infected while breast-feeding your baby.
- The woman should be available for as long as you need her. Your baby should be exclusively breast-fed for six months. The woman should agree to exclusively breast-feed your baby and know what this means.
- The woman breast-feeding your baby has a small risk of getting HIV from your baby while breast-feeding. She should receive counselling from an experienced counsellor.

You will need help from an experienced health worker to organize this. You will also need to have a good relationship with the other woman. A relative living in the same house or nearby would be best.

You need to stay as close to your baby as possible and provide all other care so your baby will also bond with you.

Adapted from: FHI. *Self Care Series Book 4: Staying Healthy for Mothers Living with HIV*. Thailand, 2004

How should I care for my baby?

Your baby needs:

Lots of love.

The best way to provide love is to keep the baby close to you. If you are breast-feeding, do it as soon as possible after delivery, so that your baby can receive the special fluid called colostrum and other nutrients that will protect and nourish him or her

Frequent feeding

If you are breast-feeding, feed your baby often. Do not give him or her anything other than breast milk. It has everything your baby needs to stay healthy.

Seek medical care immediately if your baby has:

- Fever
- Poor sucking/feeding
- Pus from the cord
- Difficulty breathing
- Yellow skin and eyes

Immediately after delivery, your baby should be dried with a clean cloth and put naked on your chest. This will keep your baby warm and happy. Cover yourself and your baby with a warm cloth. Always keep your baby close to you. Bathe your baby daily. It is not necessary to use soap on a newborn baby's skin.

Adapted from: FHI. *Self Care Series Book 4: Staying Healthy for Mothers Living with HIV*. Thailand, 2004

Assessment of drug and alcohol use

Instructions:
This assessment should be completed as part of the post diagnosis and ongoing counselling follow-up. It will also help clients think about the impact of drug and alcohol use on their lives.

- Explain to the client that you wish to understand his or her use of drugs and alcohol to see how it may affect his or her health and quality of life.
- Reassure the client of confidentiality.
- After the assessment, determine the client's willingness to change (see chapter 3 of *HIV Counselling Handbook*) and develop interventions that are appropriate for the client's readiness for change. You may wish to use some tools found in the handbook to help you assess the client's readiness for change and engage in "motivational interviewing".
- Do not pressure the client to enter detoxification or rehabilitation.
- Offer the client information on transmission reduction strategies.

Client Number: **Date:** _ _ _/ _ _ _ _/_ _ _ _

HIV status:

Untested ❑ HIV positive ❑

HIV negative ❑ If positive, date of original HIV diagnosis:

Age when you first used drugs or alcohol:

Type of drug you used the first time:

Does your regular partner use also? Yes❑ No❑ NA[1] ❑

Reasons you started to use drugs (circle as many as applicable):

Relieve physical pain	❑	Succumb to peer pressure	❑
Satisfy curiosity	❑	Have pleasure	❑
Enhance sex	❑	Suppress psychological symptoms (hearing voices or seeing things)	❑
Escape from problems	❑	Cannot remember why	❑

Your progression of drug use (no. 1 being the type of drug you used first):

Solvents ❑
Alcohol ❑
Marijuana ❑
Heroin ❑
Stimulants ❑
Analgesics ❑
Tranquilizers ❑
Opium ❑
Others ❑ (Specify :_____)

[1] Not applicable, i.e., no partner.

Drugs you are now using (check all that apply):

Solvents ❑
Alcohol ❑
Marijuana ❑
Heroin ❑
Stimulants ❑
Analgesics ❑
Tranquilizers ❑
Opium ❑
Others ❑(specify which:_____)

Your present drug of choice (most often used) (check all that apply):

Solvents ❑
Alcohol ❑
Marijuana ❑
Heroin ❑
Stimulants ❑
Analgesics ❑
Tranquilizers ❑
Opium ❑
Others ❑(specify which:_____)

Your method of drug use (check all that apply):

Swallowed ❑
Smoked ❑
Inhaled ❑
Sniffed ❑
Injected ❑
Others ❑ (specify which:_____)

Length of time you have been using your drug of choice: ____years_____ months

Amount you spend daily on drug use:

Injecting drug use

Have you injected drugs in the last three months?	Yes❑	No❑
How often each day (times per day) do you inject drugs ?	Yes❑	No❑
Do you share syringes/needles?	Yes❑	No❑
Do you clean the syringes/needles?	Yes❑	No❑
Cleaning method:		
Does somebody else help you inject drugs?	Yes❑	No❑

Information related to drug treatment

Have you ever sought treatment for drug use?	Yes❑	No❑

If yes, when and where were you treated?

Centre name Location Month(s) and year(s) of treatment Duration of treatment

Have you ever been refused treatment? Yes❑ No❑
If yes, why?

Drug-related crime (remind client about confidentiality)

Have you ever been arrested for drug/alcohol use? Yes❑ No❑
If yes, how many times?

Do you still have an ongoing court case or hearing? Yes❑ No❑

Have you ever been jailed for drug/alcohol use? Yes❑ No❑
If yes, how many times?
When were you last in jail for drug or alcohol use?

Dependency assessment ("drug" is used here to refer to drugs or alcohol)

Do you find yourself needing more and more of the drug to feel good than you used to? Yes❑ No❑

Do you have withdrawal symptoms if you cannot get the drug or enough of it? Yes❑ No❑

Do you take another drug or alcohol to relieve withdrawal symptoms? Yes❑ No❑

Would you say that you have difficulties controlling your drug use (amount, frequency, etc.)? Yes❑ No❑

Do you feel a strong desire to use the drug or even feel you must have it? Yes❑ No❑

Could you stop using it if you chose to, without too much difficulty? Yes❑ No❑

Are you neglecting things you used to enjoy because you take drugs? Yes❑ No❑

Are you spending more time looking to get drugs, using them, and recovering from their effects? Yes❑ No❑

Even though you see that the drug is harming your health or mood, do you still use it? Yes❑ No❑

Counsellor's use only
Drug dependency assessment (ICD-10 diagnostic guidelines)
A definite diagnosis of dependence should usually be made only if three or more of the following were present together at some time during the previous year:

- Evidence of tolerance, such that increased doses of the psychoactive substance are required to achieve effects originally produced by lower doses
- A physiological withdrawal state after substance use stops or is reduced:
  - as evidenced by the characteristic withdrawal syndrome for the substance, or
  - use of the same (or a closely related) substance to relieve or avoid the withdrawal symptoms
- A strong desire or compulsion to take the substance
- Difficulties controlling substance-taking behaviour (onset, level of use, or termination)
- Progressive neglect of other pleasures or interests because of psychoactive substance use:
  - more time needed to obtain or take the substance or to recover from its effects
- Persistent substance use despite clear evidence of harmful consequences:
  - including depressive mood states after periods of heavy substance use, or drug-related impairment of cognitive functioning

Notes:

Counsellor's Name: **Signature:** **Date:**

Activities for processing children's grief

Many children who are grieving the death of someone, or who have witnessed traumatic loss, such as that which happened in recent tragedies like tsunamis or earthquakes, feel emotion at many levels, not the least of which is physical. Activities that allow children and teens to express their feelings provide them with a healthy and effective outlet for the many emotions they are experiencing. These activities can also bring parents and children together, at a time when the support of the family is supremely important.

For children of any age:

Scream box

Equipment: Cereal box, paper towel tube, tape, paper, scissors
- Stuff a cereal box with crumpled paper.
- Close the cereal box and cut a hole in the top for the paper towel tube.
- Tape the paper towel tube to the hole in the cereal box.
- Decorate the box whichever way you want.
- Scream into the box!!!

Mad box

Equipment: Box of any size, tape, paper
- Fill the box with paper—pictures cut from a magazine or slips of paper on which you have written down the things that make you mad.
- Tape the box shut.
- Use a plastic bat or bataka, or jump on the box until it's in shreds.
- Burn or recycle the remnants!

Worry beads

Equipment: Sculpey clay, toothpick, old cookie sheet
- Create beads from clay; use a toothpick to make a hole through each one.
- String the clay beads after baking in the oven according to package directions.

Clay sculpting

Equipment: Clay or Playdough, water for softening clay
- Mold the clay into different shapes.
- The feel of the clay can be soothing. Children can release anger by throwing clay onto a hard surface.

Paper chain

Equipment: plain white or construction paper, safety scissors, pen or markers
- Cut the paper into thin horizontal strips about 3½ inches long.
- Write on each strip the name of someone who cares about you.
- Make as many strips as you need.
- Form each strip into a loop, link the loops, and staple or tape the ends.
- Repeat until you have a chain of the names of all the people who care about you.
- Hang your chain in a place where it will remind you of all the people who care about you.

Other drawing activities

- Make a picture of grief and sadness.
- Make a picture of what happened.
- Draw an outline of the body and ask the child to colour in where he or she feels sad.
- Make a picture of a best memory.
- Make up a memory box full of pieces of happy memory items (e.g., a piece of clothing the deceased wore on a day you enjoyed together).
- Make a memory collage (a mix of drawing and magazine clippings, photos, etc.).

My special one

Your name is…….. You were born on……..in

……..and died on……..

in……..

How you died:

How I learned you had died:

What I did with others to remember you:

Something I really want to forget:

Something I really want to remember:

Helping children struggling with a loss

Equipment: Small, safe space, old phone books

- Sit with the child or children in a circle and talk openly about how you experienced guilt feelings when someone died.
- Ask if the children have had feelings like that and then have each person say "It's not your fault" to the person next to them.
- Tear up the phone books while saying "It's not my fault!", letting the momentum build as you tear up more books!
- Cool down by stuffing the paper (your guilt) into trash bags or by sitting in a quiet place and discussing the children's feelings.

For young children:

Fly like a lion

Equipment: Table, bean bags or gym mats for a soft landing, loud voices, careful supervision

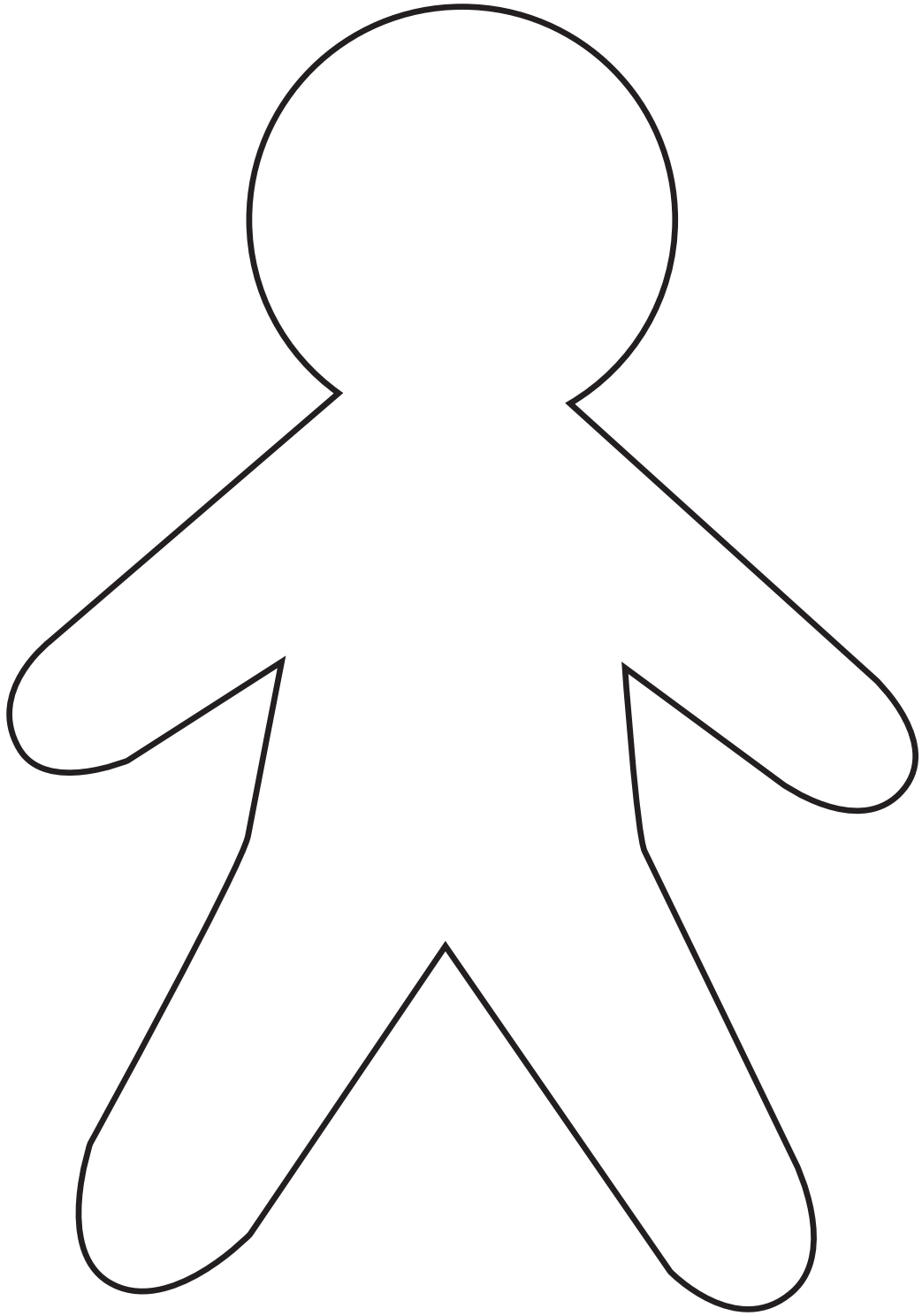
- Talk to the child about power and strength. Discuss people and animals who are powerful and what that means for them.
- Let the child climb onto the table and jump off it onto a soft landing space. Encourage him or her to jump like a powerful animal, with powerful noises.
- Recognize that this is a great way for children to take back some of the power they may feel they lost during an illness or death, as well as a way to reach and express deep feelings.

For teens:

Here are some statements that help teens write about their feelings during a time of loss. Provide a notebook and ask the teen to select a statement and to complete the statement, draw a picture, or make a collage related to the statement.

- "Sometimes I find myself imagining that if these things were different, your death might not have happened."
- "I wish you could tell me what your death was like, what really happened. I think you'd say…"
- "I can physically feel the pain of your death, and this is where and how I feel it in my body. Here is a drawing of what my pain looks like…."
- "This is what I would write on your tombstone so that everyone who would read it would have an idea of the kind of person you were."
- "I often wear a mask to hide what I am really feeling. I do this because…"
- "Late at night, when the world is asleep, I lie awake thinking about…"
- "Our friends got together and did something special in your memory…."
- "Music helps release feelings. Here are some songs/lyrics that mean a lot to me."
- "Here is a poem that I wrote (or is special)…."
- "I think about the meaning of life, why people die when they do…."
- "This is what helps me find meaning in my pain over your death…."

MARK OR COLOR IN WHERE YOU FEEL SAD



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