



BUK
BILONG
MI

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ABOUT BUK BILONG MI



Tingim Laip is Papua New Guinea's largest targeted peer-led HIV prevention and care project, operating in 20 locations over 10 provinces. It is a joint National AIDS Council and Australian aid project, funded by the Australian Government and managed by Cardno Emerging Markets.

The objective of Tingim Laip is to ensure that people most at risk for and impacted by HIV in selected locations engage in safer sex by using condoms regularly, obtain regular treatment for sexually transmitted infections (STIs), know their HIV status and access treatment if living with HIV.

To achieve this, Tingim Laip works where there is a higher convergence of HIV risks. Tingim Laip engages more than 150 volunteers and staff from key populations, and supports them to implement a range of peer-led activities to increase knowledge; condom use and accessibility; STI and voluntary confidential counselling and testing (VCCT) service uptake; the number of people who know their status; support for people living with HIV; and to contribute to more supportive environments for key populations.

A key component of the project is providing support to people living with HIV (PLHIV). We assist PLHIV to access clinical and social services. We facilitate regular 'positive living' support visits as well as the formation of support groups led and managed by PLHIV. We also connect PLHIV to the PNG national umbrella body for PLHIV, Igat Hope at both the provincial and national level.

In PNG, getting people to understand the importance of being treated for HIV and taking their medication all the time remains an issue. Adherence is a serious threat to effective drug treatment for PLHIV.

This booklet, *Buk Bilong Mi* aims to provide PLHIV an easy to use resource to help them understand the progression of HIV, opportunistic infections, the different medications and the importance of taking medication as prescribed by their health care worker. *Buk Bilong Mi* aims to support PLHIV to pursue a positive living approach towards a happy, healthy and full life.

HOW TO USE BUK BILONG MI

The *Buk* has been divided into six parts:

PART 1

Part 1: My Details records personal information that is useful for your Doctor/ Health Care Provider to know when he/she is reviewing your case. If you do not feel comfortable writing in some of the information, you can leave those sections blank.

PART 2

Part 2: Appointment Reminders records your appointments and reminds you when your next visit to the clinic or doctor is scheduled. This is to ensure that you:

- ★ Always have enough medication
- ★ Remember to go to your appointments with your Doctor/ Health Care Provider
- ★ Get regular check-ups with your Doctor and that you are getting treatment for other illnesses (known as opportunistic infections) you may get

PART 3

Part 3: Marasin Reminders records your treatment history. Your Doctor/ Health Care Provider will fill in these tables:

- ★ Table 1 records your ART treatment history
- ★ Table 2 records your other treatment history (Example: for opportunistic infections)

PART 4

Part 4: Clinical Tests and Results records clinical tests you have been given by your Doctor/ Health Care Provider as well as the results

PART 5

Part 5: Monitoring Symptoms and Side Effects records any symptoms and side-effects you may have experienced

PART 6

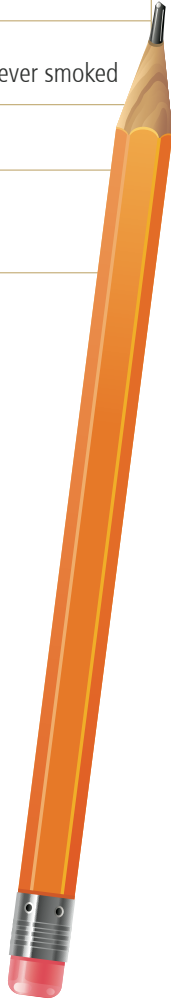
Part 6: Understanding your marasin. Living happily and healthily provides some very basic and useful information on living a happy and healthy life.

THIS IS YOUR BUK.
YOU CAN USE IT THE
WAY THAT MAKES
MOST SENSE TO YOU!!

MY DETAILS

PART 1

Date of Birth	
Date Diagnosed	
Clinic	
Doctor	
ART Registration No	
Smoking Status	<input type="checkbox"/> Smoker <input type="checkbox"/> Ex-smoker <input type="checkbox"/> Never smoked
Allergies	
Reaction to Medication	



PART 2

APPOINTMENT REMINDERS

- ★ Column 1: The date of your next appointment
- ★ Column 2: The type of service you are going to receive
- ★ Column 3: If you missed an appointment, explain why you missed it

Date of next appointment	Type of service- E.g. Drug refill, review, etc.	If missed an appointment, explain why you missed it

It is very important that you attend your medical appointments. Getting medical check-ups, including picking up your medicines, helps you to stay on your treatment - this is VERY IMPORTANT for controlling HIV, the virus that weakens the *banis blong bodi* and leads to people getting sick. You can:

- ★ Check this table regularly so you don't forget
- ★ Set the date on your mobile phone so it automatically reminds you
- ★ Ask a friend or relative who knows about your status to help remind you of your visit dates

MARASIN REMINDERS

PART 3

TABLE 1- ART TREATMENT RECORD

Your Doctor/ Health Care Provider should fill this in for you.

ART Treatment	Date Prescribed	Comments/Problems/Questions

In order for ART to fight HIV in the body, it is very important that you take this medicine at the right time and the right amount each day. Many people in PNG have died because they did not take their medication EVERY DAY. If you forget to take your ART:

- ★ Take it as soon as you remember
- ★ Carry on with your usual dose
- ★ DO NOT take a DOUBLE dose to make up for a missed dose

REMEMBER: When you take your medicine every day, all of the time it can stop the virus from making you feel sick, and reduce the chances of you getting sick.

TABLE 2- OTHER TREATMENT HISTORY

Your Doctor/ Health care provider should fill this in for you.

Other Infection/ Illness	Date the illness started	Is it ongoing (Yes or No)	Treatment

It is easier for someone who is living with HIV to get sick with other illnesses. This is because their immune system is weak and can't fight off new infections as easily. It will also take longer to recover from these illnesses, compared to someone who does not have HIV. Some of the most common illnesses include TB, Malaria, and pneumonia. These are often referred to as OPPORTUNISTIC INFECTIONS. There are treatments available, for these illnesses so it is important that you regularly visit your doctor or nurse and follow their guidance on what medicines to take.

CLINICAL TESTS AND RESULTS

PART 4

Your Doctor/ Health Care Provider will complete this record for you. They will also explain the results to you, and if there is anything you need to do to follow-up. The most common tests that you should receive on a regular basis are:

- ★ Blood Pressure & Cholesterol - to check risk to the heart
- ★ Blood Glucose - to check for diabetes
- ★ Full Blood Count/Haemoglobin (Hb)- to check for anaemia
- ★ Liver, Kidney and Pancreas function - check for damage to these organs; and specific tests for infections e.g. hepatitis/TB.

Blood Pressure		Blood Glucose		Haemoglobin	
Date	Result	Date	Result	Date	Result

OTHER TESTS

Date	Test	Results	Comments/ Follow-up Treatment

MAKE SURE YOU ASK THE DOCTOR/ HEALTH CARE PROVIDER IF THERE IS ANYTHING YOU NEED TO DO TO IMPROVE YOUR HEALTH!!

SIDE EFFECTS

The table below summarises some of the feelings and side effects associated with HIV and taking ART. This table will be useful when you are filling in the table in Section 4: Monitoring symptoms and side effects.

Feelings & Sicknesses associated with living with	Some side effects of taking ART
★ Lack of appetite, night sweats, fatigue, weight loss, fever	★ Lack of appetite, night sweats, fatigue
★ Nausea & vomiting	★ Nausea & vomiting
★ Diarrhea	★ Diarrhea
★ Mouth ulcers, dry mouth	★ Mouth ulcers
★ Peripheral Neuropathy (pins and needles in your fingers and toes, hands and feet, arms and legs)	★ Peripheral neuropathy (pins and needles in your fingers and toes, hands and feet, arms and legs)
★ Itchiness, rash, skin sores	★ Skin problems/rash
★ Pain, sore joints and muscles	★ Muscle pain
★ Sleeping problems, depression, anxiety, worry	★ Headache
★ Sinusitis (headache, pressure around nose, forehead and head)	★ Anaemia
★ Cough, difficulty breathing, chest pain	★ Blood sugar changes
★ Swollen glands	★ Cholesterol problems
★ Difficulty or painful swallowing	★ Lipodystrophy (body shape changes)
★ Visual problems	★ Liver problems
★ Impotence, vaginitis (discharge, itching, pain in the vagina)	★ Kidney problems
	★ Menstrual problems

PART 5

MONITORING SYMPTOMS AND SIDE EFFECTS

If you are experiencing any feelings or sickness related to living with HIV (including side effects from drugs), please record them in the table below. Having a record of these, what they are, when they happen, how long they last for - will help you and your Doctor/ Health Care Provider identify causes of these unwanted feelings of illness, and try to prevent or reduce them in the future.

Feelings/illness associated with HIV or ART side effects				
Date	Describe the feeling/side effect	When did it start?	How are you dealing with it?	Doctor/Health Care Provider comments

WHAT DOES IT MEAN TO LIVE POSITIVELY?

People living with HIV, can live full and active lives. They can have families, be employed and pursue careers, contribute to their communities and enjoy social activities and hobbies. Living with HIV, does not mean that they have to be sick. If people living with HIV look after themselves, eat well and take their medicines regularly as guided by your Doctor, they can have a healthy and active life.

There are many things people living with HIV can do to stay healthy. These include:

- ★ Getting 8 hours of sleep each night. Like anyone, your body needs to rest every night. Getting enough sleep will help keep you healthy, and have plenty of energy.
- ★ Relax. It is important that you make time to relax and not keep a schedule that will cause stress and strain. Listen to music, read books or catch up with friends and family members.
- ★ Spending time with your family - this is a great way to relax and ease tension.



- ★ Continuing to work for as long as you can. Pursuing your career, will keep you busy doing something you enjoy. You will continue to earn a wage so that you can support yourself and your family and build savings for the future. You will continue to contribute to your community.
- ★ Working in the garden, around the house and the village helps keep you fit and healthy- any form of physical exercise is good for you, regardless of whether you are living with HIV or not.

Why is nutritious food and clean water important?

- ★ Food helps maintain a strong and healthy body. It helps you have energy to work and move around. It also helps fight sicknesses.
- ★ Healthy food includes *kaukau*, fresh fish and meat, green vegetables, and fresh fruits.
- ★ Even if you do not feel hungry, you should try to eat regular healthy meals. You may find that eating smaller amounts, several times a day is easier than eating three large meals.
- ★ Eating your meals with other people
- ★ friends and family
- ★ It may help you to eat regularly. If you find it difficult to eat solid food, you can mash or blend your food into liquid form, so it is easy to swallow.
- ★ Drink at least 2 litres of clean (boiled) water every day.

UNDERSTANDING YOUR MARASIN

PART 6

THE MEDICINE THAT YOU ARE TAKING

What does ART mean?

- ★ ART stands for anti-retroviral therapy. This is the medicine for HIV.
- ★ For most people it is usually a combination of three drugs that are taken together.
- ★ The different ART medicines attack HIV in different ways. One of the drugs slows the rate at which the virus multiplies in the body. Another drug helps reduce the damage HIV does to the immune system.

What do I need to know about ART?

- ★ ART keeps the virus under control, but it does not get rid of it.
- ★ ART has to be taken for the rest of your life.
- ★ ART must be taken at very specific times, every day. Good adherence helps ART fight the virus effectively.
- ★ ART works differently for different people.
- ★ ART is NOT a cure for HIV.

When should I start taking ART?

- ★ Before your CD4 count is below 600. A Doctor/ Health Care Provider can test your blood to measure your CD4 count for you.
- ★ Before you get sick.
- ★ When you know you are ready to make the commitment to take ART for the rest of your life.

Can pregnant women take ART medicine?

- ★ Pregnant women who have HIV can reduce the chances of passing HIV to their babies by taking HIV medicine. This should only be done under close guidance from a Doctor who is certified in prescribing ART.

Can children take HIV medicine?

- ★ Yes, children can also take HIV medicine but in different amounts from adults. This should only be done under close guidance from a Doctor who is certified in prescribing ART.

Can ART be taken together with medicines for tuberculosis (TB)?

- ★ There are some ART medicines that you should not take with TB medicines.
- ★ Make sure you talk to your Doctor about taking TB and ART treatments at the same time.

Can I take other medicines such as herbal remedies?

- ★ ART should always be taken under close guidance from a Doctor who is certified in prescribing ART.
- ★ Only ART is effective in attacking the virus
- ★ no other medicines or herbal remedies have the same impact on HIV.
- ★ Some other medicines and herbal remedies may help to reduce some of the side effects or other illnesses associated with HIV.
- ★ If you want to take some of these other medicines and herbal remedies, please talk with your Doctor about the benefits and risks of taking these medicines. Your Doctor should be able to tell you what the medicines will do, and what they won't do. Agree to a treatment plan with your Doctor.

ADHERENCE

What does it mean?

- ★ For ART to fight HIV in the body, it is very important that it is taken at the right time each day, and that the correct combination of medicines are taken. Taking your medicines correctly each day is called ADHERENCE.

What happens if I forget to take my medicine?

- ★ Take your medicine as soon as you remember.
- ★ Carry on with your usual dose.
- ★ DO NOT take a DOUBLE dose to make up for a missed dose.
- ★ When you don't take your medicine all the time on a regular basis, HIV can stop the medicine from becoming effective.

What is resistance?

- ★ Resistance is when ART can no longer fight HIV in your body. Resistance happens when someone living with HIV doesn't take their medication all the time, at the right time and right amount. If a person living with HIV becomes resistant to ART, the ART medicine will no longer work, and it will be easier for them to get sick.

Can I change medicine?

Your Doctor may advise a change of medicine if:

- ★ The HIV medicine is not working.
- ★ Side effects are too difficult to manage.
- ★ The HIV viral load is not being controlled.
- ★ Resistance occurs.

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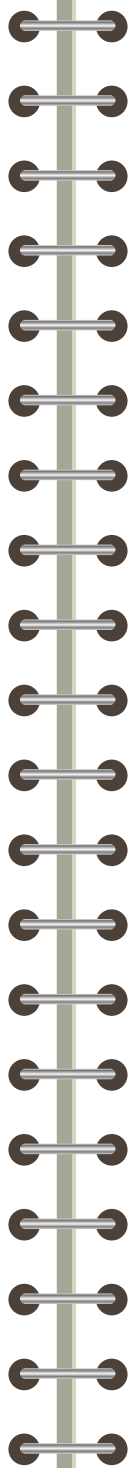
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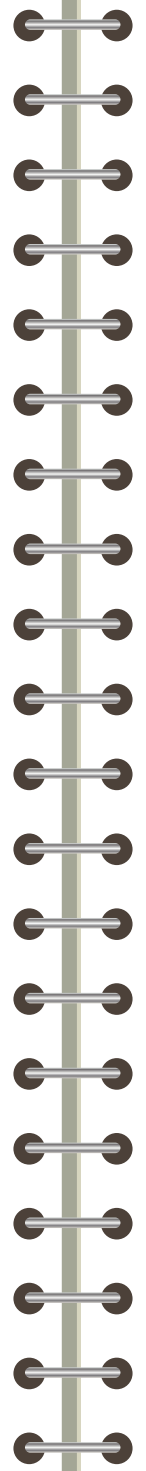
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