

**3RD DRAFT**  
FOR DISCUSSION  
MAY 2006

# CAREGIVER BOOKLET SYMPTOM MANAGEMENT AND END OF LIFE CARE



*A guide for caregivers*



**World Health  
Organization**

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# CAREGIVER BOOKLET

**A guide for caregivers**



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Organization**

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## How to use this booklet effectively

The caregiver booklet is designed to help caregivers in the home-based care of serious long term illness. Home care is best for many people with long term illnesses, including those who are close to the end of life. All patients being cared for at home should be first assessed and treated by a health care worker, who will help caregivers provide high quality home care and ensure that medicines are taken correctly.

This booklet explains how to:

- 1. Deal with specific symptoms.*
- 2. Provide care for terminal and bedridden patients at home.*
- 3. Decide when to seek help from a health facility.*

The booklet should be given to the caregiver and its contents explained by a nurse or community health worker.

Look at the illustration and read the text, or ask someone to read it for you. If anything in the booklet is not clear, ask for further explanation from the health worker. In case of problems not explained in the booklet, seek help.



**For any of the more serious problems, marked with this sign, you should seek help from a trained health worker.**



# Chapter 1: Universal precautions

## Universal precautions

Health workers and caregivers are exposed to HIV and other blood borne illnesses such as hepatitis for example.

As a caregiver of a person who is HIV positive, you are exposed to HIV and you should take some precautions called "universal precautions".

The occupational risk of becoming HIV infected from caring for patients is very low (approximately 0,3%).

- ◇ Collect all used needles and sharps in puncture resistant container (box). Don't fill the box completely to avoid accidental puncturing by needles or sharps objects which could be near the surface. When the box/container is three-quarter full, take it to the health centre where it will be disposed properly.
- ◇ Dispose things used for cleaning (such as cotton wool or toilet paper) either by burning or throwing in pit latrines for example. If the pit latrine is full, use another one.
- ◇ Use gloves when handling body fluids.
- ◇ Clean up spills of blood or other body fluids with diluted bleach.
- ◇ Make sure any wounds or sores on your own body are covered.
- ◇ Wash your hands as much as possible to protect you and to protect the sick person: before and after care, before and after going to toilet, before preparing food, before giving food or water to the sick person.



Clean  
spills



Separate  
stained  
laundry



Cover  
wounds



Wash your  
hands



Throw away  
soiled items

## **Accidental exposure to blood and body fluids**

What to do in case of accidental exposure to blood or body fluids?

- ◇ Flush the site with large amount of running water.
- ◇ Wash with soap and water. If bleeding: allow the site to bleed a bit.
- ◇ Use of antiseptic is not recommended as it can have a caustic effect and is not recognized as being effective (however, in the absence of water, antiseptic can be used).



Seek help in case of an emergency from the health worker. He/she will know how to manage the exposure and will give you an appropriate treatment if needed.

## Skin problems

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The following skin problems occur more often in PLWHA:

- ◇ rashes
- ◇ itchy skin
- ◇ painful sores on the skin (excoriations)
- ◇ increased dryness of the skin
- ◇ slow healing of the wounds
- ◇ boils and abscesses
- ◇ papules, vesicles (with shooting pain)

As a general rule, cleaning the skin frequently with mild soap and water and keeping it dry between washing will prevent the most common problems.

Remember: Sometimes skin infections are a sign that the condition may be getting worse.

### Very Dry Skin

Avoid soap and detergent, use bath oils and skin creams (Vaseline, glycerine, vegetable or plant oils can be just as effective as the more expensive oils and creams).

### Rashes



Seek help from a trained health worker in case of:

- painful sores
- excoriations
- boils and abscesses
- vesicles (with or without shooting pain)

These could be a drug side effect or an allergic reaction especially if the patient is on ART.

## Itchy Skin

Itchy skin can be due to infections or the body's reaction to the medication the sick person is taking. This is a frequent side effect of morphine. It can be associated with a rash.

To help get some relief:

- ❖ Cool the skin or fan it.
- ❖ Avoid heat and hot water on the skin.
- ❖ Avoid scratching, which causes more itching and sometimes infection.
- ❖ Apply lotion (Calamine)



**Do not scratch**

Tell the patient not to scratch. Tea leaves soaked in hot water are good for itching.

*Remember:* Itchy skin could be a new opportunistic infection or a side effect of ART. Consult the Patient Treatment Card.



Seek help if itchy skin does not go away in a few days, if vesicles or peeling appear or if the problem generalizes and extends to the eyes and mucosa.

## Wounds



**Wash wounds  
with clean water**

Uninfected wounds: wash with clean water. If possible apply an antiseptic. If possible, apply a local antiseptic to wounds after washing.

*Remember:* in PLHA, wounds may take more time to heal.



Seek help if wound is infected (swollen, red, painful, with pus,...) and if fever is present.

# Preventing pain in muscles and joints

The sick person may suffer stiff joints and muscle fatigue.

- ❖ Encourage the sick person to move in bed or get out of bed (if possible).
- ❖ Massage the sick person with petroleum jelly or oil.
- ❖ Encourage exercise twice daily and help with movement of ankles, knees, hips, wrists, elbows, shoulders and neck .



- ❖ Hold the limb above and below the joint while moving it. Support as much of its weight as you can.



- ❖ Bend, straighten and move the joints gently and slowly as far as they normally go.
- ❖ Exercise the wrists: Bend wrists gently and slowly without causing pain. Apply pressure gradually. Repeat the exercise several times.
- ❖ Exercise the elbows: Gently lift the forearm up and down. Repeat the exercise several times.
- ❖ Exercise the shoulders: Gently lift the arm up and bring the hand above and behind the head. Move the arm from side to side. Repeat the exercise several times.
- ❖ Exercise the knees: Gently bring the knee up and to the side. Repeat the exercise several times.

In all cases, let the sick person do as much as he or she can do.

## Prevent bedsores

- ❖ If possible, help the bedridden patient sit up in a chair from time to time.
- ❖ Lift the sick person to change position in bed. Do not drag the sick person, as this breaks the skin.
- ❖ Encourage the sick person to move his or her body in bed whenever possible.
- ❖ Look for damaged skin (change of color) on the back, shoulders and hips everyday.
- ❖ Put extra soft material, such as a soft cotton towel, under the sick person.
- ❖ Keep the bed clothes clean and remove all wet clothes and wet bedsheets.



In case of bedsores:

Report to a trained healthworker and seek advice on treating the sores.



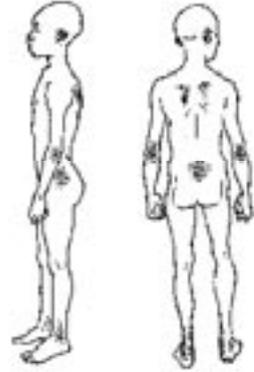
**Change the position of the sick person in bed every 2 hours**

# How to care for bedsores

In the case of bedsores, report to the health worker for advice on care. For small and superficial sores, proceed as follows below.

To soothe the pain of bedsores and speed up the healing process:

- ❖ For small sores, clean gently with salty water and allow to dry.
- ❖ For bedsores that are not deep, leave the wound open to the air.
- ❖ For pain, give pain killers such as paracetamol or aspirin regularly.
- ❖ Keep changing position in order to avoid prolonged contact on sores.



Points on the body where the patient is likely to get bedsores



Seek help from a trained health worker :

- if sores are infected (red, swollen, pus...)
- if the pain increases
- if passing little urine
- for appropriate drugs and dressing material



Applying ripe pawpaw flesh to the bed sore may help

## Mouth ulcers and pain on swallowing

In case of mouth ulcers it is recommended to:

- ◇ Avoid extremely hot or cold or spicy foods.
- ◇ Use a soft tooth brush or stick to remove debris.
- ◇ Rinse the mouth with diluted salt water (a finger pinch of salt in a glass of water) after eating and at bedtime.
- ◇ If available, mix 2 tablets of aspirin in water and rinse the mouth up to four times a day.



**Mix two aspirin tablets in a glass of water and rinse the mouth with the solution.**

- ◇ Eat soft foods, such as cold milk, porridge, boiled potatoes or honey, depending on what the sick person feels is helpful.

*Remember:* difficulty in swallowing and white patches can be a sign that the patient's condition is getting worse.



Seek help from a trained health worker if:

- pain or difficulty in swallowing
- white patches that can be scraped off

## Nausea and vomiting

If the patient or sick person feels like vomiting:

- ❖ Seek locally-available foods that cause less nausea.
- ❖ Give small quantities of boiled potatoes, cassava or gonja, or drinks such as water, juice or tea.
- ❖ Advise to drink slowly and more frequently.



Drink slowly and more often

To reduce nausea :

- ❖ If due to ARV drugs, advise to take pills with food (except for DDI or IDV).
- ❖ Licking ash from wood is a safe and effective remedy for nausea.



Some ARV drugs can be taken with food

Remember: Vomiting and nausea can be side effects of medications, including ART (common with ZDV). Look at the **Patient Treatment Card**.



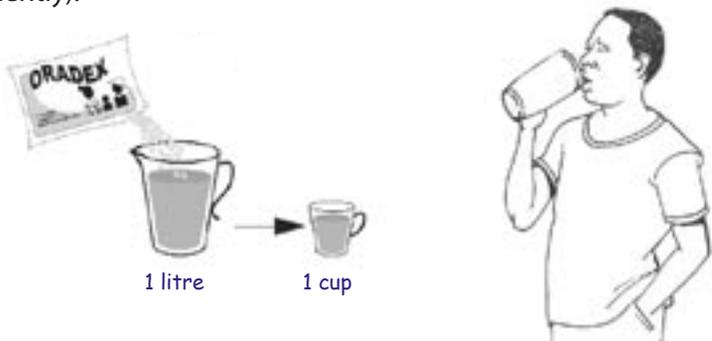
Seek help from a trained health worker if:

- nausea for more than 2 weeks
- dry tongue
- vomiting for more than 1 day
- passing little urine
- abdominal pain or yellow eyes

## Diarrhoea

To help:

- ◇ The person should drink frequently and in small amounts (water, rice soup, other soups, porridges) but should not eat raw food.
- ◇ Ensure the sick person is drinking the above fluids as much as possible.
- ◇ Very sweet drinks, alcohol and coffee should be avoided.
- ◇ Mix Oral Rehydration Solution (ORS) and drink frequently.
- ◇ Encourage the patient to continue eating (small amounts frequently).



Care for the rectal area:

- ◇ After passing stool, clean rectal area with toilet paper or soft tissue paper.
- ◇ Wash the rectal area when necessary, with soap and water.
- ◇ If pain when passing stool, apply petroleum jelly around the rectal area.

*Remember:* Diarrhoea could be the sign of a new opportunistic infection. Also it can be due to ARV. In this case, it usually improves in a few weeks.



Seek help from a trained health worker for any of the following:

- blood in the stool
- diarrhoea lasting for more than 5 days
- if you become even weaker
- if there is broken skin around the rectal area.

## Cough and difficulty breathing

For simple cough, local soothing remedies such as honey and lemon can help.



Make a lemon tea sweetened with honey.

- ◇ Make the sick person a lemon tea sweetened with honey.
- ◇ Use local remedies, for example, steam with menthol or eucalyptus leaves.



- ◇ Help the sick person to adopt a position that eases breathing. Usually sitting is best.
- ◇ Use extra pillows for back support.

- ◇ Open windows to allow in fresh air.
- ◇ Encourage the patient to drink water frequently.
- ◇ Tap or slap the sick person's back and chest to loosen sputum and make it easier to cough.

Safe handling and disposal of sputum:

- ◇ Handle the sick person's sputum with care to avoid spreading infection.
- ◇ Provide a tin with ash in it for the sputum, then cover it.
- ◇ Empty the container in a pit latrine and wash the container with detergent or clean with boiled water.



Use a tin with ash in it for the sputum and then cover.

Remember: Cough or difficulty breathing could be the sign of a new opportunistic infection. If on ART it could be immune reconstitution syndrome.



Seek care from a trained health worker for the symptoms below (if on ART seek care urgently) :

- fast breathing/chest pain.
- fever and night sweats
- blood in sputum
- symptoms lasting for more than two weeks

## Fever

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A fever (high body temperature) is not a disease in itself but a sign that something is wrong in the body and can indicate one of many different illnesses.

In PLHA, fever often comes and goes.

### How to lower a fever

- ❖ Remove any unnecessary clothing and blankets.
- ❖ Cool the skin by taking a bath or pouring water over parts of the body.
- ❖ Provide plenty of drinking water to prevent dehydration due to the loss of liquid caused by the fever.
- ❖ Give paracetamol 500 mg tablets: 2 tablets every 4 hours but not more than 8 tablets per day.

*Remember:* if on ART, fever can be a sign of immune reconstitution syndrome or a new OI.



Seek help from a trained health worker if:

- suspicion of malaria (history of fever, no new rashes, no other apparent causes)
- fever persists for more than 7 days
- fever is accompanied by cough, weight loss, stiff neck, yellow eyes, diarrhoea
- the sick person is pregnant or recently had a baby

# Headache

For minor headaches:

- ◇ It could be a tension headache that is common when fever is present.
- ◇ A massage of the scalp can help.
- ◇ Help the sick person to rest and relax.
- ◇ Give paracetamol (Panadol) 2 tablets (500 mg per tablet) every 4 hours, and aspirin (500mg per tablet) or ibuprofen (400 mg per tablet) at night.
- ◇ Paracetamol (500 mg tablets): do not give more than 8 tablets per day.

				
				
2 paracetamol (500 mg tablet) <b>Early Morning</b>	2 paracetamol (500 mg tablet) <b>Mid Morning</b>	2 paracetamol (500 mg tablet) <b>Mid Afternoon</b>	2 paracetamol (500 mg tablet) <b>Evening</b>	2 aspirin (500 mg tablet) <b>Night</b>

Remember: Headache could be a sign of a new opportunistic infection.



Seek care from a trained health worker if:

- headache persists more than 24 hours, despite taking pain killers or medication
- visual defects, vomiting present
- slurred speech
- pain in the neck and/or stiff neck
- weakness in one side of the body
- change in behaviour or attention

# Managing pain

Pain is common and can be relieved.

Determine the **CAUSE** of pain :

- ◇ Where is the pain?
- ◇ What makes the pain better or worse? Describe the pain.
- ◇ Is there a psychological or spiritual component?

Determine the **TYPE** of pain :

- ◇ Is it common pain such as bone or muscle pain or
- ◇ Is it commonspecial pains such as shooting nerve pain, zoster, colic or muscle spasms?

## Grade the pain with **FACES**

(especially with children)

**or**

## with your **HAND**

(0 is no pain, 1 finger is very mild pain and

5 fingers means the worst possible pain)

<b>FACES</b> scale						
<b>HAND</b> scale	 0 no hurt	 1 hurts little bit	 2 hurts little more	 3 hurts even more	 4 hurts whole lot	 5 hurts worst

## Additional methods for pain control

Additional methods for pain control can be combined with pain medications.

You can try:

- ◇ Emotional support.
- ◇ Physical methods (touch, stroking, massage, rocking, vibration, ice or heat, deep breathing).
- ◇ Cognitive methods (distractions such as a radio, music, or imagining a pleasant scene).
- ◇ Prayer (with respect to everyone's practice and beliefs).
- ◇ Traditional remedies which are helpful and not harmful.

### Pain killers:

- ◇ All pain killers must be taken after meals or a snack.
- ◇ For mild pain in adults: Use paracetamol (Panadol) 500 mg tablets. Take 2 tablets every 4 hours, and aspirin or ibuprofen at night (see p. 16).



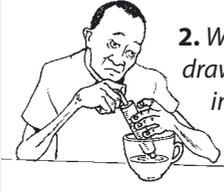
Seek help from a trained health worker for more severe pain:

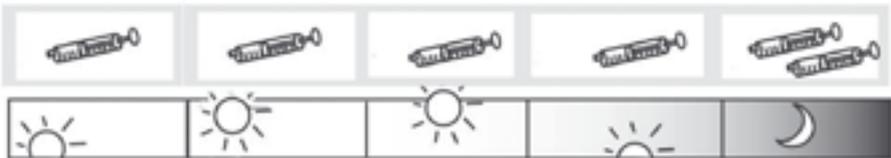
- pain control is possible
- stronger drugs like morphine can be prescribed
- if the sick person has been prescribed oral morphine, see p. 19

# Oral morphine

Oral morphine is a strong pain killer.

If oral morphine has been prescribed, follow these directions:

 <p><b>1.</b> Pour morphine into a small cup.</p>	 <p><b>2.</b> Without the needle, draw some morphine into the syringe.</p>
 <p><b>3.</b> Push the morphine into mouth.</p>	 <p><b>4.</b> Pour the remaining morphine into the bottle.</p>



Oral morphine should be taken by mouth at regular times, approximately every 4 hours.

Use a clock, the sun or the moon, a radio or another system to help you or the sick person remember.

**Managing the side effects of oral morphine:**

- ❖ Nausea usually goes away after a few days of starting oral morphine and does not usually come back.
- ❖ Constipation always occurs. Always give preventive local remedies such as dried papaya seeds or a laxative such as senna at night.
- ❖ Morphine will help reduce diarrhoea. Never give a laxative if the sick person is taking oral morphine and has diarrhoea.



Inform your health health worker if:

- the pain is getting worse
- the sick person took an extra dose of oral morphine
- drowsiness comes back
- you reduced the dose

**If the pain is getting better, the dose may be decreased.  
Do not stop morphine suddenly.**

## Trouble sleeping

- ❖ Make sure the sick person is in a quiet environment so they can sleep well.
- ❖ Provide a comforting drink at night. Strong tea, coffee or other stimulating beverages should be avoided late in the evening.
- ❖ If pain is present, give a double dose of analgesic before going to sleep (but remember, do not give more than 8 paracetamol 500 mg tablets per day).



Remember: if on ART, this may be due to efavirenz.



Seek help from a trained health worker if:

- anxiety and nightmares are associated with pain
- if on ART and these symptoms last for more than 2 weeks from the start of ARVs.

## Worries and fears

Encourage the sick person to talk to a person he/she can trust (family member, friend, yourself, ...).

- ❖ A massage or soft music may help the sick person to relax.



Seek help from a trained health worker if the sick person is feeling abnormally sad, cannot sleep, or if he/she is experiencing a lack of interest or has suicidal thoughts.

## The sick person who is confused

The sick person may be confused, showing forgetfulness, lack of concentration, trouble speaking or thinking, frequently changing moods, unacceptable behaviour such as going naked and using bad language.



Unacceptable behaviour

*Remember:* This could be a side effect of ART. As a caregiver, look at the patient treatment card and seek advice from a trained health worker.



Remove dangerous objects

- ❖ As far as possible, keep the patient in a familiar environment, with objects always in the same place that are easy to reach and see. Keep a regular pattern in the day's activities.



Seek help from a trained health worker if the confusion is increasing or the behaviour is getting worse.

### End of life care

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- ◇ Be aware that the sick person may go through a range of reactions from anger and fear to sadness and acceptance.
- ◇ Learn to listen, showing that you understand and feel what the sick person is going through.
- ◇ Try to allow the sick person to express his/her feelings and frustrations freely. Try not to over react to the person's emotions. Try and find out if there is something special she/he needs and if you can help.
- ◇ Be sensitive! The sick person may be thinking about losing family and friends soon, and may want to talk about this.
- ◇ Listen to the concerns of the sick person, counsel and give emotional support when needed.
- ◇ Encourage other family and community caregivers to do the same.
- ◇ Discuss worrying issues such as custody and support of children, school fees and funeral costs; try and arrange and prepare everything according to the sick person's wishes.
- ◇ Arrange for spiritual support if asked (respect the will and faith of the person, even when converted).



Pray together if requested

## Preparing for death

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Be compassionate, and be willing to talk about the concerns of the patient.

Provide physical contact, such as holding hands.

Provide care:

- ◇ Talk with the health worker about stopping some medicines.
- ◇ Keep giving pain killers. Make sure pain is controlled even if sick person is unconscious.
- ◇ Treat fever.
- ◇ Control symptoms to relieve suffering with diarrhoea medicine or antibiotics.
- ◇ Continue TB treatment to avoid spreading the disease to family members.
- ◇ Moisten lips, mouth and eyes.
- ◇ Keep the sick person clean and dry.
- ◇ Give skin care and turn the patient every 2 hours or more frequently.
- ◇ Eating little is OK when near death.
- ◇ Call a religious leader if the sick person asks.

## Taking care of children whose parent is near the end of life

- ❖ Children need to talk about the loss of their parents. If you don't talk to them, they may suffer more later.
- ❖ Allow time to talk about the disease and death with the children.
- ❖ Talk in a simple and direct way so that they can understand.
- ❖ Let them express their feelings and ask questions.



Children who have a parent who is near the end of life

- ❖ Help children feel that they will still be loved and cared for, even after their parent dies.
- ❖ Pay attention to the children's behaviour and their feelings in the following weeks and months.
- ❖ Do not take children away from their dying parent as they need to be close to each other.

## Taking care of a child near the end of life

- ❖ Be willing to talk to the child and answer questions.
- ❖ Help the child feel loved and not alone.
- ❖ Ensure that family members are around to play when the child is able.
- ❖ Involve the parents, brothers/sisters, or the other family members, or a person that the child trusts to take care of the child and to talk to him/her.

## Grieving after the loss of a loved one

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Mourning and grief after the death of a loved one is normal. Mourning is the natural process of accepting a major loss.

- ◇ It may last months or years.
- ◇ It is very important that you express grief. Feeling sadness is a part of continuing to live.

It is possible to live with grief and it is natural to experience grief when a loved one dies. There are many ways to cope with grief.

You might want to:

- ◇ Seek out caring people.
- ◇ Express your feelings.
- ◇ Take care of your health.
- ◇ Accept that life is for the living.
- ◇ Hold off on major life changes.
- ◇ Be patient.
- ◇ Seek help when necessary.

Try and look to the future:

With support, patience and effort, you will survive grief. The pain will lessen with time, leaving you with important memories of the person you have lost.

# Chapter 4: Caregiver burn out

## Caregiver burn out

Working as a caregiver is not easy and requires a lot of attention, time and energy. You should pay attention to yourself and take care of your own health, and adopting appropriate behaviour.

At times the sick person might direct strong emotions (such as anger and blame) towards you. Often they do not mean to hurt you and are just generally frustrated with their own situation.

Try to allow the sick person to express his/her feelings and frustrations freely. Try not to over react to the person's emotions. Try to find out if there is something they need and how you can help.

The caregiver's role can be very demanding, so caregivers may have times when they are tired, angry and disinterested in caring for the sick person. These are normal reactions and you should not feel guilty but you should try to find a way to manage them and avoid **burn out**.

The burn out is caregiver exhaustion.

The signs which can help you to recognize burn out:

- ◇ Irritability
- ◇ Fatigue
- ◇ Poor sleeping
- ◇ Poor concentration
- ◇ Avoiding the patient and other people
- ◇ Emotional numbness, lack of joy
- ◇ Alcohol or drug abuse

The caregiver's role can be very demanding



Be aware and pay attention to these signs for you and for the other caregivers and family member. Most of the time the individuals facing burn-out is unaware of it because they are so involved in their activities.

**To prevent and respond to burn out:**

- ◇ Define for yourself what is meaningful and valued in care giving.
- ◇ Change approach to care giving: divide tasks into manageable parts (small acts of care); ask others to help; encourage self-care by the patient.
- ◇ Be aware of what causes stress and avoid it.
- ◇ Share your problems and feelings with other caregivers, family members and friends.
- ◇ Be aware that you can't do everything yourself and that you can need help.
- ◇ Try to take regular breaks from caring for the sick person. Try to do something refreshing and relieving, and manage time for activities which are not related to caregiving.
- ◇ Do something outside the patient home, such as joining social gatherings, visiting friends or joining activity groups.
- ◇ Take time to rest. Try to find somebody who can replace you for periods of time.
- ◇ Use relaxations techniques.
- ◇ Take care of your own health.

## Now you are on ART

d4T-3TC-NVP		
stavudine	lamivudine	nevirapine



Week 1-2	Week 3-on
Morning: d4T-3TC-NVP (combined tablet)	Morning: Combined tablet
Evening: d4T and 3TC (2 separate tablets)	Evening: Combined tablet



### Remember that

- If you miss doses (even 3 doses in a month) **DRUG RESISTANCE** can develop. This is bad for you and your community. (These drugs will stop working.)
- Drugs must be taken twice daily, **and miss no doses**. This is very important to maintain blood levels so ART can work.
- If you forget a dose, do not take a double dose.
- If you stop you will become ill within months or year.
- Drugs **MUST NOT** be shared with family and friends.
- If you find it difficult taking your pills twice daily, **DISCUSS** with health workers. **ASK** for support from your treatment supporter, family or friends.



It is common to have side effects. They usually go away in 2-3 weeks.

If you have:	Do the following:
Nausea →	Take the pill with food.
Diarrhoea →	Keep drinking and eating.

If nausea or diarrhoea persist or get worse, or you have any of the following, report to the health worker **AT THE NEXT VISIT**.

- Tingling, numb or painful feet or legs or hands.
- Arms, legs, buttock, and cheeks become **THIN**.
- Breasts, belly, back of neck become **FAT**.

### SEEK CARE URGENTLY if:

- Severe abdominal pain
- Yellow eyes
- Skin rash
- Fatigue **AND** shortness of breath



## Now you are on ART

ZDV - 3TC - NVP		
zidovudine	lamivudine	nevirapine



Week 1-2	Week 3-on
Morning: ZDV-3TC-NVP (combined tablet)	Morning: Combined tablet
Evening: ZDV and 3TC (2 separate tablets)	Evening: Combined tablet

### Remember that

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It is common to have side effects. They usually go away in 2 weeks. If you have them, do the following

If you have:	Do the following:
Nausea →	Take the pill with food.
Diarrhoea →	Keep drinking and eating.
Muscle pain, fatigue →	These will go away.

If nausea or diarrhoea persist or get worse, report to the health worker **AT THE NEXT VISIT.**

### SEEK CARE URGENTLY if:

- Yellow eyes
- Skin rash
- Pale or do not have enough blood
- Fatigue AND shortness of breath



## Now you are on ART

ZDV - 3TC - EFV		
zidovudine	lamivudine	efavirenz



Week 1-2
Morning: ZDV-3TC (2 separate tablets)
Evening: ZDV-3TC-EFV (3 separate tablets)

### Remember that

- If you miss doses (even 3 doses in a month) **DRUG RESISTANCE** can develop. This is bad for you and your community. (These drugs will stop working.)
- Drugs must be taken twice daily, **and miss no doses.**
- This is very important to maintain blood levels so ART can work.
- If you forget a dose, do not take a double dose.
- If you stop you will become ill within months or year.
- Drugs **MUST NOT** be shared with family and friends.
- **If you find it difficult taking your pills twice daily, DISCUSS with health workers. ASK for support from your treatment supporter, family or friends.**



It is common to have side effects. They usually go away in 2 weeks. If you have them, do the following

If you have:	Do the following:
Nausea →	Take the pill with food.
Diarrhoea →	Keep drinking and eating.
EFV can cause brain effects such as sleepiness, dizziness, bad dreams, or problems with sleep or memory →	These side effects usually go away. Taking the efavirenz at night is important.
Muscle pain, fatigue →	These will go away

If nausea or diarrhoea persist or brain effects get worse, report to the health worker **AT THE NEXT VISIT.**



### SEEK CARE URGENTLY if:

- Bizzare thoughts/confusion
- Yellow eyes
- Pale or do not have enough blood
- Skin rash



## Now you are on ART



<b>Week 1-2</b>
Morning: d4T - 3TC (2 separate tablets)
Evening: d4T - 3TC - EFV (3 separate tablets)

d4T - 3TC - EFV		
stavudine	lamivudine	efavirenz

Remember that

- If you miss doses (even 3 doses in a month) **DRUG RESISTANCE** can develop. This is bad for you and your community. (These drugs will stop working.)
- Drugs must be taken twice daily, **and miss no doses.**
- This is very important to maintain blood levels so ART can work.
- If you forget a dose, do not take a double dose.
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It is common to have side effects. They usually go away in 2 weeks. If you have them, do the following

If you have:	Do the following:
Nausea →	Take the pill with food.
Diarrhoea →	Keep drinking and eating.
EFV can cause brain effects such as sleepiness, dizziness, bad dreams, or problems with sleep or memory →	These side effects usually go away. Taking the efavirenz at night is important.

If nausea or diarrhoea persist or get worse, or you have any of the following, report to the health worker **AT THE NEXT VISIT.**

- Tingling, numb or painful feet or legs or hands.
- Arms, legs, buttock, and cheeks become THIN.
- Breasts, belly, back of neck become FAT.



**SEEK CARE URGENTLY if:**

- Bizzare thoughts/confusion
- Yellow eyes
- Severe abdominal pain
- Fatigue AND shortness of breath
- Skin rash



## ART does not cure HIV: SAFER SEX is still essential when on ART



Abstinence from sex is the safest method from getting or transmitting HIV.

If you wish to have a child, talk to the health worker before getting pregnant in order to decrease the possibility of passing on HIV.



Continue to protect yourself and others. Use a condom each time you have sex. Always be mindful of your partner.

Safer sex protects you from another HIV strain. If you get re-infected again with a different strain of HIV, your immune system gets weaker.



If you do not desire a child, talk to health workers about FAMILY PLANNING and use a second mode of contraception in addition to condoms (DUAL PROTECTION).

## HIV CAN BE PASSED ON TO AN UNBORN CHILD IN ANY OF THE FOLLOWING STAGES



Pregnancy .....



Delivery .....



Breast-feeding

**Some ART medicines are safer during pregnancy than others**

### USE PMTCT

Some ART medicines are safer to use while you are pregnant. Talk to your health worker about which ART medicines to use. Tell your health worker right away if you are pregnant or want to have a baby.



**World Health  
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