

HOME-BASED CARE FOR PEOPLE LIVING WITH HIV/AIDS

Home Care Handbook

Supporting Primary Caregivers



REPUBLIC OF UGANDA



Pathfinder
INTERNATIONAL

**STD/AIDS Control Program
Ministry of Health, Republic of Uganda**

Pathfinder International

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LIVING WITH HIV/AIDS

HOME CARE HANDBOOK

Supporting Primary
Caregivers in Uganda

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STD/AIDS CONTROL PROGRAM
MINISTRY OF HEALTH
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PATHFINDER INTERNATIONAL

HOME CARE HANDBOOK – Supporting Primary Caregivers in Uganda

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Published by: Pathfinder International and Ministry of Health
Africa Regional Office Republic of Uganda
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Nairobi, Kenya Kampala, Uganda

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Printed by: The Regal Press Kenya Ltd
PO Box 46166
Nairobi, Kenya

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Introduction

The *Home Care Handbook* is a reference manual developed especially for facilitators of home-based care for people with living AIDS. The *Handbook* complements the Pathfinder International curriculum, *Training Home-Based Caregivers to Take Care of People Living with HIV/AIDS – A Curriculum for Training Community-Based Health Service Providers*. The curriculum was developed initially for use in community-based health services in Kenya, Uganda, and Ethiopia.

The curriculum promotes effective, compassionate care for persons living with HIV/AIDS (PLWHAs). The principles of the training can be applied

1. At home and within the community, in order to prevent disruption of normal life and to promote resolution of family problems.
2. At a clinic for medical problems where there is limited confidentiality due to lack of space.
3. For in-patient care for the very sick. No need for isolation, just follow standard guidelines for controlling infection on ward, e.g., safe and proper handling of sharp instruments and body fluids.

Home-based care as defined in the curriculum consists of selected services that are provided at home. The curriculum emphasizes the following types of care:

- Home nursing and general hygiene
- Supportive care, e.g., good nutrition
- Counseling
- Maintaining good health through:
 - Education of patients to prevent deterioration
 - Prevention and early treatment of infections especially TB
 - Prevention of malnutrition and pregnancy
- Terminal care

The key helpers in the care of AIDS patients are:

- **The patient**, providing own care, if not very sick
- **Family members**, relatives, friends and community members: these need education and counseling especially in home nursing care, psychosocial and material support, patient-caregiver interaction and positive communication, and protective wear and other clinical supplies.
- **Health workers** such as community-based health workers, traditional healers, and staff of non-government and community-based organizations.

The *Home Care Handbook* includes step-by-step guides for nursing care, care of the PLWHA's environment, nutrition services, referrals for medical services, treatment of AID-related illnesses, and other support services. It also covers information and education on responsible sexual behavior, including condom use, provides tips on physical therapy for PLWHAs, and summarizes the highlights of what to teach PLWHAs and their families to do at home. Finally, the *Handbook* describes the supportive care needed as the PLWHA is succumbing to the disease and outlines the steps to take immediately after death.

As noted, the *Handbook* was developed to serve as a reference for home-based care training. It was thus written for home-based care facilitators and assumes a level of training in and knowledge about health service delivery. Nonetheless, the *Handbook* is detailed enough to stand alone, and simple enough to be used by a wide range of people who are confronted by the need to take care of AIDS patients at home. It is hoped that use of the *Handbook* will help ease the suffering of PLWHAs, their families, and their communities.

- Mouthwash
- Glycerine/liquid paraffin or Vaseline
- Cotton wool balls
- Container for used swabs
- Tooth brush/tooth sticks
- Plastic/polythene paper and clean cloth
- Spoon, fork, or stick to use for swabs
- Another spoon, fork, or stick padded with a piece of clean cloth (for unconscious or uncooperative patients)

Steps to follow

For conscious patient

Step 1: Preparing resources, patient, and yourself

- Prepare materials you will use:
 - Pour the salt solution/mouthwash/baking soda solution into small containers.
- Wash and dry your hands.
- Explain to patient what you are going to do and role you want the patient to play.
- Place the towel/piece of cloth and plastic paper (*kavera*) across patient's chest and under the chin.
- Bring all the materials needed within easy reach of the patient.

Step 2: Cleaning the mouth

- If patient is able: provide the tooth stick/tooth brush with toothpaste (if available) and water in a cup for rinsing the mouth.
- Offer another small container to spit into while rinsing the mouth.

If patient is conscious, but too weak to do it without help

- Put on plastic bags/gloves.
- Wind some cotton wool around the spoon/fork or stick to make a swab or fold a piece of cloth to clean gently:
 - Between the lips and upper gum
 - Between the lips and lower gum
 - The roof of the mouth
 - The floor of the mouth
 - The tongue
 - The lips
- Move the swabs from the back to the front of the mouth in each area and change them and discard them as necessary.
- Gently but thoroughly brush the teeth.
- Give water to rinse the mouth.
- Apply Vaseline to the lips if they are dry.
- Leave the patient comfortable.

Step 3: Clearing the used articles

- Take the tray away, clean it, and return it with a cover to the bedside.
- Throw away used cotton in a proper way or wash the piece of cloth and hang it to dry for the next use.
- Remove the plastic bags and throw away in a proper way.
- Wash your hands with soap and water.

For unconscious patient or one who is too sick to move

Step 1: Preparing the resources, patient, and yourself

- Prepare materials to use (same as above).
- Wash and dry your hands.
- Bring all the materials near the bed.
- Put the patient in a lateral position (lying on their side).
- Place the plastic sheet and a piece of cloth/towel under the patient's head to protect the bed from getting wet.

Step 2: Cleaning the mouth

- Put on plastic bags or gloves.
- Place the padded stick/spoon in the patient's mouth to keep it open.
- Wind some cotton wool around the other spoon or stick to make a swab or fold a piece of cloth to clean gently:
 - Between the lips and upper gum
 - between the lips and lower gum
 - The roof of the mouth
 - The floor of the mouth
 - The tongue
 - The lips
- Move the swabs from the back to the front of the mouth in each area and change them and discard them as necessary.
- Gently but thoroughly brush the teeth.
- Remove the padded stick/spoon.
- Leave the patient comfortable.

Step 3: Clearing the used articles

- Follow steps as for conscious patient.

1.3 NAIL CARE

Objectives

To keep the nails clean and short in order to:

- Reduce collection of germs
- Prevent self-injury
- Raise patient's morale

Requirements and Resources for Nail Care

- Nail cutter/scissors/razor blade
- Soap
- Water in basin
- A piece of clean cloth or towel
- Nail brush
- Vaseline or lotion

Steps to Follow

Step 1: Preparing the patient

- Explain the procedure to the patient (if conscious), mentioning the advantages of caring for the nails.
- Obtain patient's permission to trim the nails.

Step 2: Cutting/trimming the nails

- Gently wash each hand with soap and water. Scrub nails with the brush.
- Rinse and dry the hands using a clean cloth.
- Trim the nails gently with the scissors or nail cutter/razor blade, taking care that you do not harm the patient.
- Apply Vaseline or lotion to both hands.
- Repeat procedure for feet and toenails.
- Leave the patient comfortable and thank the patient for cooperating.

DISPLAYING A CARING ATTITUDE

PLWHAs are emotionally very vulnerable and can be hurt easily by careless remarks and uncaring behavior. Caregivers need to take deliberate steps to help ease the pain and self-stigma AIDS patients feel. Caregivers should consider the following (see also Section 9.12):

Caring behaviors:

- Gentleness
- Appropriate smiles
- Responsiveness
- Open-ended questions
- Attentive listening
- Positive body language

Uncaring behaviors:

- Rudeness
- Shouting
- Ignoring
- Blaming language
- Negative body language

Step 3: Clearing the used articles/ materials

- Collect all the nail cuttings into a piece of paper/any container to be thrown away in a pit latrine.
- Clear all the articles used.
- Wash your hands with soap and water.

1.4 WASHING HAIR IN BED

Requirements and Resources for Washing Hair in Bed

- Patient's towel/clean cloth for drying hair
- Soap/shampoo if available
- Comb/hair brush
- Water - cold, hot
- Basin or similar container
- Stool to place the basin of water

Steps to Follow

Step 1: Preparing the patient and the materials/requirements to use

- Gather all the requirements.
- Explain to the patient (if conscious) what you are going to do and what role you want the patient to play.
- Bring all the requirements near to the bed/place where the patient is lying.

Step 2: Washing and drying the hair

- Place a short stool at the head of the bed to hold the basin of water.
- Move the patient/ask the patient to move (if conscious) to the head of the bed so that their head hangs.
- One of you supports the patient's head so that the patient does not get tired.
- Wash the patient's hair with soap/shampoo.
- Rinse the hair.
- Dry with a piece of cloth or towel.
- Move the patient/ask the patient to move back to normal position in bed.
- Comb hair and ensure that it is dry.
- Do what patient wishes: e.g., apply hair oil, plait the hair, etc.
- Straighten the patient's bed and leave the patient comfortable.

Step 3: Clearing the materials used

- Clear all the materials used.
- Pour the water used.
- Dry the cloth/patient's towel in the sun.
- Ask how the patient feels.
- Leave the patient comfortable.

1.5 TURNING PATIENT IN BED

A PLWHA who cannot move without help should be turned every 4 hours.

Objectives

- To prevent patient from developing pressure sores caused as a result of lying on the same side for a long time.

Requirements and Resources for Turning Patient in Bed

- Plastic/polythene bags to use as gloves
- 2 people to work together

Steps to Follow

Step 1: Preparing the patient

- Explain to the patient what you are going to do and why it is good to do so (if conscious).
- Explain what you want the patient to do so as to make the procedure easier.
- Strip the bed, leaving the top sheet loose so that the patient's limbs can easily be moved.

Step 2: Turning the patient in bed

- Bring one of the patient's arms and one leg across to the side the patient is to face.
- One person brings over the shoulder while the other rolls the pelvis.
- Now the 2 people join hands over the patient's hip joint and thighs and lift the patient to the center of the bed.
- Adjust the pillow under the patient's cheek and ask if the patient is comfortable.
- Put the patient's hands in a comfortable position.
- Bend the patient's legs slightly.
- Remake the bed and leave the patient comfortable.

Step 3: Clearing the articles used

- Collect the articles used to be disposed of in a proper manner.
- Wash hands with soap and water.

***Don't forget to ask if your patient is comfortable.
Smile!***

1.6 PRESSURE AREA CARE

Objectives

- To prevent the development of pressure sores around the protruding bony parts of the body in a PLWHA who is unable to move out of bed.

Requirements and Resources for Pressure Area Care

- Plastic/polythene bags to use as gloves if patient is soiled or has wounds
- 1 stool/chair
- Container of warm water
- Basin or similar container
- Plastic/polythene paper
- Soap
- Patient's own towel/clean cloth
- Body powder (if possible)
- Vaseline or lotion
- Toilet paper and a receiver
- Clean linen
- Container for soiled linen

Steps to Follow

Note: This procedure can be done at the time a bed bath is given or it can be done as you change the sheets or turn the patient.

Step 1: Preparing resources, patient, and yourself for pressure area care

- Gather all the requirements by the bed for easy reach.
- Explain the procedure to the patient (if conscious).
- Close nearby windows/draw curtains.
- Pour warm water into the basin.
- Wash and dry your hands.

Step 2: Treating the pressure sores

Note: Treat all pressure areas systematically from head to foot with the least possible disturbance to the patient, e.g., shoulder, elbow, and wrist should be attended together.

- Examine pressure areas to check if pressure sores are developing, if not continue to next point.
- Place the plastic paper or towel under the part to be treated first.
- With soapy hand gently massage each area in a circular movement and for long enough to stimulate good circulation of blood (count to 10 as you do each part).

- Using a wet face cloth rinse each part and pat it dry with the patient's towel/cloth.
- Apply a little powder before continuing to the next area. If the skin is very dry, and to protect the skin of an incontinent patient, apply a little Vaseline.
- Ask how the patient feels (if conscious).

Step 3: Clearing the materials used

- Change or straighten the underlying bed clothes as necessary.
- Remake the bed and leave the patient comfortable.
- Clean and store the equipment.
- Remove plastic paper bags; wash and dry your hands.

Step 4: Follow up

- Report verbally to your trainer or supervisor if the patient's skin is discolored, excessively moist, blistered, or broken. These conditions indicate that the patient may need hospital care.
- Share this information with patient and relatives.
- Remember to turn the patient every 2–4 hours to change position and relieve pressure.

1.7 CARE OF PRESSURE SORES

Objectives

- To prevent the sores from becoming worse or infected.
- To promote healing.
- To reduce the suffering of the patient.

Requirements and Resources for Pressure-Sore Care

- Plastic/polythene bags to use as gloves
- 1 stool/chair
- Container of warm water
- Basin or similar container
- Plastic/polythene paper
- Face cloth/small piece of cloth
- Soap
- Patient's own towel/clean cloth
- Materials for home treatment, as shown in the box on page 7

Steps to Follow

Step 1: Preparing resources, patient, and yourself

- Collect all the items to be used and place them near the bed.
- Wash and dry hands.
- Explain to the patient (if conscious) what you are going to do.
- Ensure privacy.
- Put on plastic bags/gloves.
- Pour warm water into the basin and make it soapy with a mild soap.
- Place plastic paper or cloth under the part where the pressure sore is and expose the sore.

Step 2: Dressing the sore

- Dip the small piece of cloth into the soapy water and clean the sore.
- Wash around the edge of the sore first, then wash from the center out to the edges until it looks clean. If possible use separate pieces of cloth for each wiping.
- If the wound has pus or blood in it, cover after cleaning with a clean piece of cloth or a strip of cloth (torn as a bandage); leave it loose and change it every day. If the sore is dry, leave it open to the air.
- Raise the area with the sore as often as possible to relieve it from pressure of the bedding (this can be done by changing the patient's position in bed).

Step 3: Clearing the materials used for dressing the sore

- Remove all items used and straighten the bed.
- Remove plastic bags/gloves; wash and dry your hands.
- Leave the patient comfortable.
- Wash the soiled cloth and bandage in soap and water and put them in the sun to dry. Boil them for a short time if possible before hanging to dry.
- If the cloth and bandages will not be used again, burn them or throw in a pit latrine.

1.8 GENERAL CARE OF WOUNDS AND SORES

Objectives

- To promote healing and prevent the sore/wound from becoming worse.

Requirements and Resources

Same as those for Care of Pressure Sores

Steps to Follow

Step 1: Preparing resources, patient, and yourself

Follow Step 1 as in pressure sore care.

Step 2: Dressing the wound or sore

- Dip the small piece of cloth into the soapy water; squeeze out some of the soapy water, but leave the cloth wet.
- Use the wet cloth to clean around the edges of the wound/sore first, wiping in only one direction.
- Clean the wound/sore from the center out to the edges until it becomes clean (if possible use separate pieces of cloth for each wiping).
- For wounds that have pus or blood (infected): put a warm compress (a small piece of cloth soaked in warm water and rinsed out) on the wound at least 3 times a day for about 20 minutes.
- If the wound looks gray or rotten, rinse it with salty water. (It would be better to use hydrogen peroxide if available, or the home treatments suggested in the box below, e.g., pawpaw, honey and sugar.)
- Try to pick off the gray parts with the piece of cloth.
- After cleaning, cover the area with a clean piece of cloth or a strip of cloth cut like a bandage. Leave it loose and change it daily.
- If the wound is dry, leave it open to the air. It will heal more quickly this way.
- If the sore is on the leg, keep the leg raised above the head level as often as possible.

Note: For further treatment: If the wound is very bad and you cannot manage, inform your trainer or supervisor or contact the health worker at the health unit/refer the patient for further care.

For closed wounds that are not infected (abscesses and boils)

- Check the patient for all the areas that may be swollen and note the following:
 - Swelling that is raised and patient feels pain
 - Swelling at the groin, armpits, on buttocks, back, and upper leg
- Apply warm compress right away for 20 minutes 3–4 times a day. This may make pus come out. Keep applying it daily until pus stops coming.

- Cover the lump with a piece of cloth that is loosely tied. If the lump becomes too large and painful, refer/contact a health worker trained to drain abscesses.

Step 3: Clearing the materials used

- Follow step 3 in the procedure for treatment of pressure sores.

HOME TREATMENTS FOR PRESSURE SORES

Some home treatments have been shown to work very well in treating the sores:

Pawpaw (papaya): This fruit contains chemicals that help make the old flesh in a pressure sore soft and easy to remove.

- Soak a piece of cloth in the "milk" that comes from the trunk or green fruit of a pawpaw plant.
- Pack this into the sore.
- Repeat it 2 or 3 times as necessary.

Honey and sugar: This mixture will kill germs, help to prevent infection, and speed healing.

- Mix honey and sugar into a thick paste.
- Press this deep into the sore and cover with a clean cloth. (Molasses or thin pieces of raw sugar can also be used.)
- Clean out and refill the sore at least 2 times a day. If the honey or sugar becomes too filled with liquid from the sore, it will feed germs rather than kill them.

1.9 HANDLING BODY FLUIDS

Note well:

- Body fluids may contain HIV and other harmful germs. PLWHAs and their families need to handle body fluids with great care.
- The caregiver may find body fluids in bedding, bandages, clothing, sanitary pads or cotton wool, or other material. Body fluids may also be on surfaces as a result of spills or accidents.

In general, remember:

- Always wear gloves or plastic bags to prevent direct contact with body fluids. Remember to protect your feet when cleaning body fluids spilled on floors.
- Any materials that you want to keep and re-use should be cleaned and decontaminated according to the procedures given below. These include clothing, bedding, towels, cloths for bandages.
- Any materials that you can't or won't re-use should be burned, buried, or thrown into a pit latrine. These include cotton wool, bandages, sanitary pads, disposable diapers, etc. To make handling them safer, wrap in newspaper or plastic bag. Try to use newspapers if you must bury or throw into a pit latrine; the paper will eventually rot, but the plastic bag will not.
- Fresh blood or pus from wounds or blood from childbirth pose the greatest danger to the caregiver. Be especially careful when handling blood or pus.

Objectives

- To prevent contamination/infection spread by body fluids:
 - Blood
 - Pus
 - Stool and urine
 - Sputum and vomit

Requirements and Resources

This will depend on the specific body fluids. Generally the following are necessary for disposal of body fluids:

- Plastic bags/gloves
- Container to place items soiled with the body fluid
- Soap
- Clean water
- Jik 1:6 (see page 9)

1.9.1 BLOOD FROM WOUNDS AND MENSTRUAL BLOOD**Requirements and Resources for Handling Blood from Wounds and Bleeding and Menstrual Blood**

- Plastic/polythene bags to use as gloves

- Container for soiled clothes/bedding with cold Jik 1:6 solution (if available)
- Water
- Clean cloth/bandage/pads/cotton wool
- Soap

Blood from wounds**Steps**

- Put on gloves or plastic bags.
- Stop bleeding by applying pressure on the injured part.
- Cover the wound with clean cloth or bandage.
- Soak clothes or bandages soiled with blood for 20 minutes in cold Jik 1:6 solution.
- Wash them with water and soap; rinse well.
- Dry clothes in the sun on a wire for hanging clothes.

Note: Wrap contaminated wastes in newspaper, if available, for disposal in a pit latrine.

Menstrual blood**Steps**

- Put on gloves/plastic bags.
- Change the pads or cloths.
- Wrap the used pads or cloths in newspaper or plastic bag.
- Burn the pads or throw them into a pit latrine.

1.9.2 BLOOD FROM GIVING BIRTH**Requirements and Resources for Handling Blood from Giving Birth**

- Plastic/polythene bags to use as gloves
- Receiver/container for blood and placenta (afterbirth)
- Container with cold Jik 1:6 solution (if available)
- Soap

Steps

- Put on gloves/plastic bag.
- Soak soiled cloths for 20 minutes in cold Jik 1:6 solution.
- Wash the soiled cloths with soap and hot water.
- Dry cloths in the sun.
- Throw blood clots and placenta (afterbirth) into pit latrine or bury in the

ground deep enough to prevent easy removal by animals, e.g., dogs.

- Soak the container used for the placenta

MAKING JIK 1:6 SOLUTION FOR DISINFECTION

Jik is the brand name for a chlorine bleach (for laundry and other cleaning) that is manufactured in Kenya and is widely available quite cheaply. The bleach can be mixed with water to make a solution that kills HIV and other germs. To mix the solution you will need:

- Jik (3.5% sodium hypochlorite)
- Clean water
- A container for measuring
- Container for the bleach solution e.g., bucket or basin
- A stick or large spoon for stirring

Steps to follow

Step 1: Preparing the requirements

- Gather all the requirements.
- Ensure that they are clean.
- Wash hands with soap and water and dry them.

Step 2: Mixing the solution

- Place the container for measuring bleach on a flat surface (so that it gives an equal measurement) and pour in bleach to the amount needed.
- Empty into the bigger container, e.g., bucket/basin, etc.
- Use same measure for the amount of water needed.
- Use 1 part Jik to 6 parts water
- Stir to combine.

Step 3: Clearing materials used

- Clear all the materials used.
- Wash hands with soap and clean water.

Note: Generally mix only what you will need at one time. If any is left over, keep it covered.

in Jik 1:6 solution for 10 minutes or boil in water.

- Wash, rinse, and dry the container.
- Avoid direct contact with blood when cleaning the mother.

1.9.3 PUS

Requirements and Resources for Handling Pus

- Plastic/polythene bags to use as gloves
- Newspapers or plastic bag for soiled bandages
- Bandages/clean cloths
- Soap
- Container for Jik 1:6 solution, *or*
- Large pot for boiling
- Container for clean water
- Box of matches

Steps

- Put on gloves/plastic bags.
- Remove the soiled bandages or cloth used to cover the wound.
- Wrap soiled bandages or throw into a pit latrine.
- If cloths were used, soak them in Jik 1:6 solution for 20 minutes.
- Place the cloths in a large pot of water and boil for 20 minutes.

Then:

- Scrub and wash the cloths in soapy water.
- Rinse the cloths.
- Dry cloths in the sun.
- Soak receiver/container for 10 minutes in Jik 1:6 solution.
- Wash the containers in soapy water.
- Rinse and dry the containers.

1.9.4 STOOL, URINE, VOMIT, AND SPUTUM

Stool and urine should be thrown down the pit latrine immediately.

Requirements and Resources for Handling Stool, Urine, Vomit, and Sputum

- Plastic/polythene bags to use as gloves
- Toilet paper/soft paper
- 3 containers with lids
 - 1 container for urine
 - 1 container for stool
 - 1 container for sputum and vomit (with Jik 1:6 solution)
- Piece of cloth/napkin

- Brush
- Container with clean water

Steps

- Prepare plastic containers with Jik 1:6 solution to decontaminate the body waste.
- Put the plastic container by PLWHA's bedside or underneath for use.
- Always cover containers used to collect body wastes.
- Explain to the PLWHA how to use the containers.
- Put on the gloves/plastic bags to empty the containers preferably in a pit latrine or bury the contents.
- Soak the plastic containers for 10 minutes in soapy water with Jik 1:6 solution.
- Scrub container using Jik 1:6 solution.
- Rinse in clean water.
- Prepare containers for re-use.

1.9.5 BODY FLUIDS ON SURFACES

If body fluids spill on the floor, seats or objects, they should be cleaned up immediately and the surfaces decontaminated.

Requirements and Resources for Cleaning Body Fluids on Surfaces

- Jik 1:6 solution
- Plastic/polythene bags to use as gloves
- Soap
- Water
- Clean rags or cloths for wiping

Steps

- Pour Jik 1:6 solution on the spilled body fluid and leave for 10 minutes, or pour on hot ash.
- Put on gloves/plastic bags.
- Clean up body fluids with soap and water.
- Leave the surface dry.
- Burn cleaning rags, or decontaminate and wash as for handling soiled bedding, Section 2.3.

1.10 MEDICAL TREATMENT

In some settings home-based caregivers may be taught to provide a limited range of medical services as well as nursing care. Medical treatment provided may include:

- **Putting up IV drips in the home:** The caregiver is taught to:
 - Observe when the bottle is almost empty and how to stop it.
 - Replace empty bottle with a full one.
 - Keep the patient's arm in proper position.
 - Notice when the fluids go into tissue.
 - Remove the drip once finished.
- **Giving instructions on taking medication:** The caregiver/PLWHA is taught:
 - The instructions for taking medication and how to follow them.
 - The dose the patient is supposed to take.
 - The signs and symptoms of side effects when patient reacts to the drug, and when and where or whom to call for medical help.
 - When to and not to use local remedies.
- **Preparing a home-made oral rehydration solution:** The caregiver/PLWHA is taught to mix together
 - 1 liter boiled water
 - 2 tablespoons sugar
 - ¼ teaspoon salt

→ Mixture should not be saltier than tears.

The medical teams should supervise use of medical drugs as recommended (see tables 1 and 2 in Chapter 5, Treatment of AIDS-Related Conditions).

2. Care for the PLWHA's Environment

This chapter considers the "environment" as the PLWHA's immediate surroundings—bed, home, and compound. The chapter discusses how to make a bed and handle soiled bedding, and gives pointers on keeping the house and compound clean. The idea is to ensure that the PLWHA's living quarters are as clean, safe, and pleasant as possible in order to support physical and emotional health.

2.1 HOW TO MAKE A BED

Objectives

To keep the bed neat and tidy so as to:

- Maintain cleanliness, prevent spread of infection, and boost morale.

Requirements and Resources

- 1 stool/chair
- 2 clean sheets
- 2 blankets
- Gloves/polythene bags
- Pillow (something to raise the head) and pillow case (if available)
- 1 bed cover (if available)
- Plastic (see note below)
- Small sheet (see note below)

Steps to Follow

Step 1: Preparing the resources

- Wash hands and dry them.
- Gather all the materials needed.

Step 2: Making the bed

- Place a stool/chair at the foot of the bed.
- Place clean sheets on the chair/stool.
- Remove bedding that is on the bed. If bedding is soiled, protect hands with gloves or polythene bags.
- Remove the pillow from the bed and put on the chair.
- Spread the first clean sheet on the mattress and tuck edges of the sheet under mattress all around, making envelopes at the corners.
- Spread second sheet over the first sheet.

- Spread the blanket over the top sheet and tuck bottom edges of both under the mattress, making envelope corners.
- Fold the top edge of the sheet back over the edge of the blanket.
- Tuck the edges in.
- Place the pillow in the pillowcase (if available) and return it to the bed.
- Spread the bed cover (if available) neatly over all.

Note: If the patient is incontinent (that is, has lost control of passing urine or stool) put a draw sheet (a small sheet or *lesu*) on the bed. The draw sheet can often be changed without having to remove the rest of the bedding. It may also be helpful to tie a small piece of cloth around the patient as a napkin.

To use a draw sheet for someone who has lost control of urine and/or feces:

- Spread plastic sheet across bed at the middle. Cover plastic sheet with the small sheet and tuck in the edges of both.
- Proceed with the rest of the steps for making the bed.

Step 3: Clearing the used articles used

- Remove the stool/chair at the foot of the bed.
- Remove plastic bags and wash hands.

2.2 CHANGING SOILED BEDDING

Objectives

- To prevent the growth of germs.
- To provide a state of comfort to the patient.
- To maintain dryness of pressure areas so as to prevent pressure sores.

If the patient is soiled, bathe the patient before putting the clean sheets on the bed.

Requirements and Resources for Changing Bedding

- Plastic/polythene bags to use as gloves—if the patient is soiled
- Stool/chair

- Clean sheets/clothing
- Container for soiled bedding, e.g., a basin

Steps to Follow

To change the bottom sheet/cloth from side to side

These steps are used to change the bottom sheet of someone who is unconscious or too weak to move out of bed.

Step 1: Preparing resources, patient, and yourself

- Gather all the materials needed.
- Explain to the patient (if conscious) what is going to be done and screen for privacy.
- Place the two chairs at the bottom of the bed.
- Prepare the bottom sheet to be replaced (and the draw sheet if patient has lost control of urine or stool).
- Put on plastic bags (if the patient is soiled).

Step 2: Changing the bottom sheet

- Gently loosen the bed clothes over the patient and remove them onto the chair.

Note: Be sure to leave the patient covered with one blanket or one sheet.

- Loosen the bottom sheet and the draw sheet. Also loosen the plastic paper if there is one.
- Remove all but one pillow onto the chairs, unless the patient is breathless. If the patient is having trouble breathing, leave the pillows in place.
- After explaining what you are going to do (if conscious) gently roll the patient to one side with support from another caregiver. Remove the wet or soiled sheet/*lesu* by rolling it towards the side where the patient is lying.
- Place sheet in a container for dirty clothes.
- Place the prepared sheet and roll it to replace the soiled one, making sure that it does not become dirty.
- Straighten and tuck in sides, top, and bottom.
- Roll the patient to the opposite side and repeat the same way as the first side of the bottom sheet.
- Change the top sheet if it is wet or soiled.
- Make a pleat or fold at the bottom end of the sheet to allow space for free movement of the patient's feet.

- Put back the blanket and tuck it.
- Replace the pillows (after changing the pillow case/s where necessary) and adjust them to meet the needs of the patient.
- Leave the bed tidy and the patient comfortable.
- Change the draw sheet (cloth/*lesu*) in the same way you changed the bottom sheet.

Step 3: Clearing away the soiled bedding

- Remove all the used materials.
- Remove stool from the foot of the bed.
- Remove plastic bags (if they were worn).
- Wash and dry your hands.

For changing the sheet from top to bottom

These steps are used to change the sheets of someone who is able to move.

Step 1: Preparing resources, patient, and yourself

- Follow steps above.

Step 2: Changing the sheet

- Explain to patient what to do to assist you to change the sheet.
- Ask the patient to move to the bottom of the bed.
- Place the prepared sheet at the top of the bed, tuck it in, and roll it towards the area where the patient is seated. Tuck the sides as well.
- Ask the patient to move back to the top of the bed. Complete rolling, straightening, and tucking in the sheet at the bottom of the bed.
- Change the top sheet if it is wet or soiled.
- Make a pleat or fold at the bottom end of the sheet to allow space for free movement of the patient's feet.
- Put back the blanket.
- Replace the pillows (after changing the pillow case/s where necessary) and adjust them to meet the needs of the patient.
- Leave the bed tidy and the patient comfortable.

Step 3: Clearing away the materials used

- Remove the used materials.
- Remove the stool/chair from the foot of the bed.
- Remove plastic bags (if they were worn).
- Wash hands with soap and clean water.

2.3 HANDLING SOILED CLOTHES OR BEDDING

Objectives

- To make soiled clothes or bedding safe to touch by the caregivers or any other person who comes in contact with these articles.

Requirements and Resources for Handling Soiled Clothes or Bedding

- Plastic/polythene bags to use as gloves.
- Container with Jik 1:6 solution for decontamination, or hot water.
- Wooden stick
- Basin
- Soap
- Iron if available

Steps to Follow

Step 1: Preparing materials to use

- Have all the requirements ready.
- Keep clothes stained with blood, diarrhea, or other body fluids separate from all other clothes.
- Mix enough Jik 1:6 solution to soak soiled clothes/bedding.

Step 2: Handling the clothes

- Put on the plastic bags/gloves or use a big leaf to handle the dirty clothes/bedding.
- Hold onto the unstained part and rinse off any body fluids or stool particles with water. Be especially careful if there are large amounts of blood or stool. Dispose of this water in a pit latrine.
- Soak the clothes/bedding in soapy water. Use hot water if possible. Use the wooden stick to turn the clothes especially if the water is hot.
- Rinse the clothes/bedding in clean water.
- Boil in a large container (if possible, otherwise, skip this step).
- Rinse in clean water.

Note: Using Jik 1:6 solution is helpful because it destroys the HIV and other germs. It may not be possible to have it always, but if you can afford to, follow the steps in the box on page 9.

- Soak the clothes in the Jik 1:6 solution for 20 minutes.

Step 3: Washing the clothes

- Wash the clothes thoroughly with soap and water, ensuring that all the stains are cleaned out.
- Rinse clothes well in clean water.

Step 4: Drying the clothes

- Hang the clothes to dry, preferably in the sun.
- Press with a hot iron (if possible).
- Fold to keep ready for use.

2.4 GENERAL HOUSE CLEANING

Since family members are in close contact with each other, it is very easy to spread germs and illness to the whole family. It is even more important to keep the house clean when there is a sick person because sickness reduces the body's ability to protect itself from even ordinary illnesses.

Objectives

A clean house will help:

- To maintain good hygiene so as to prevent infection and the spread of infection.
- To make the house pleasant to live in.

Steps to Follow

There will be less illness if these steps are followed:

- Keep house clean. Special cleaning materials are not necessary. Caregivers should use the same materials that they use for usual daily cleaning.
- Wear plastic bags/gloves when cleaning items that have been in contact with the AIDS patient's body fluids.
- Sweep (and mop) the floors and beneath the furniture every day.
- Smear floors in mud houses with cow-dung soil to keep them from being dusty.
- Fill the cracks and holes in the floor or walls where cockroaches, bed bugs, scorpions, and other insects can hide.
- Wash cooking and eating pots and utensils with soap (or clean ash) and clean water before and after using them. If possible dry them in the sun (sunlight kills many germs that cause illness).
- Keep the cooking place clean and tidy so as to chase away flies.
- Throw away leftover food in a proper way.
- Always keep all foods covered.

- Hang or spread bedding in the sun to kill parasites and bed bugs.
- Do not spit on the floor when you cough or sneeze; cover your mouth with your arm, or with a piece of cloth/handkerchief. If possible, wash your hands.
- Clean bath place frequently and clean the grass and excess water from it.
- Clean pit latrine daily using ash and smear the floor with cow-dung/soil so that it is not dusty.
- Always keep the pit covered and smoke frequently to keep away the smell and flies.
- If the pit latrine has a concrete floor, scrub the floor frequently using ash or soap (if possible).

2.5 CLEANING THE COMPOUND

Weeds, rubbish, and leftover food in the compound can attract rats, flies, mosquitoes, and other pests that carry germs. The compound around the home should be kept clear of all weeds and rubbish.

Objectives

Keep the compound clean in order to:

- Maintain a clean environment and so minimize the spread of disease.
- Make the compound a pleasant place in which to live.

Steps to Follow

- In rural areas, burn weeds and other rubbish and compost kitchen wastes or feed them to livestock. Keep cows and goats as far from the living house quarters as possible.
- If allowed in town areas, burn rubbish. If not, put the rubbish in bags for collection (if this is done) or take to a dump site.
- If dogs and cats come into the house, watch for fleas and ticks and keep these under control. Fleas and ticks carry many germs that can make anyone sick and PLWHAs get sicker than other people do.
- Clear away standing water that might attract mosquitoes.
- If allowed in town areas, either throw HIV contaminated wastes into a pit latrine or bury them. If not allowed, wrap them in a plastic bag, tie the bag and fasten securely, then take to the place for disposal. Use tin containers to burn this rubbish within the compound.
- Get rid of body wastes like feces in a safe way. Teach children how to use a latrine or bury deep their feces away from the water sources. If children or animals pass stool in the compound, clean it up at once.



3. Nutrition Services

Good nutrition is extremely important for PLWHAs. A well balanced diet will help the PLWHA to stay healthy longer by providing the nutrients the body needs to fight disease.

Objectives

The objective of nutrition services to PLWHAs is to provide a balanced diet that:

- Repairs worn out body cells
- Provides energy to the body
- Protects the body against infections
- Stimulates the appetite
- Improves well-being of the body and the spirit

3.1 PREPARING THE FOOD

Definition

Food preparation in this context means making nutritionally balanced meals in a form that is appealing, appetizing (presentation, smell, taste), and culturally acceptable.

Requirements and Resources for Food Preparation

- Food from the 3 food groups:
 - **Energy giving foods:** maize, sorghum, cassava, rice, millet, potatoes
 - **Protective foods:** papayas, oranges, mangoes, bananas, green vegetables, pumpkins, cabbages, carrots
 - **Body building foods:** meat, fish, eggs, milk, beans
- Clean cooking utensils
- Clean water for utensils
- Fuel for cooking

Steps to Follow

Step 1: Selecting the food

- Find out what the patient's favorite food is. (Ask the patient.)
- Select locally available foods ensuring that the 3 food groups are covered.

Step 2: Preparing the food

- Wash hands before and after handling food; be especially careful in cleaning and

handling food because PLWHAs get sicker than others do if the food is contaminated.

- Wash utensils thoroughly.
- Wash food before preparation.
- Wash raw vegetables and fruits before serving.
- Thoroughly wash and properly cook all animal products.
- Avoid overcooking vegetables, as certain vitamins are destroyed by heat.
- Cover the food while it is being cooked.
- Cook the food until it is properly cooked and soft enough for the sick person.
- Keep the food covered to protect it from flies and other insects and also from cooling.

3.2 SERVING FOOD AND FEEDING THE PATIENT

Objective

- To serve food in a way that encourages the patient to enjoy the food.

Requirements and Resources for Food Service

- Boiled water for drinking
- Cup and eating utensils
- Food nicely set out and in small amounts
- Feeding towel/cloth
- Chair/stool

Steps to Follow

Step 1: Getting ready to serve food

- Prepare all the requirements needed and ensure all are clean, e.g., plates, spoons, cups.
- Wash hands and dry them.
- If it is necessary to wash the food, do so.

Step 2: Serving the food

- Serve food in small amounts and set it out nicely on the plate in an attractive way that may encourage the patient to eat.
- Ensure that you serve the food when it is still hot/warm.

Step 3: Feeding the patient

- Support the patient in sitting position.

- Allow the patient to feed self to the extent possible, but assist where needed, e.g., getting the food into the spoon or getting the spoon to the mouth.
- Scoop out small amounts of food at a time so that the patient can chew easily.
- Encourage the patient to chew the food very well.
- Give small amounts of a drink to ease the swallowing of food.
- Commend the patient for any efforts taken to eat the food.
- When the patient has finished, give water/juice to drink and also to rinse the mouth.

- Wipe any food droppings from the patient's mouth.
- Leave the patient comfortable.

Note: Remember to:

- Feed the patient frequently, at least 5 times a day or more.
- Change types of meals according to the patient's requests and needs.

FOOD GROUPS			
Body-Building Foods (Proteins)	Protective Foods		Energy-Giving Foods (Starches)
	Greens/Vegetables	Fruits	
<ul style="list-style-type: none"> • Beef, goat meat, lamb, chicken, pork • Fish • Eggs • Grasshoppers (<i>Ensenene</i>) • White ants (<i>Enswa</i>) • Groundnuts • Milk • Green grams • Beans • Peas (cow, garden, and pigeon peas) • Sim-sim (sesame) 	<ul style="list-style-type: none"> • Cabbages • <i>Doodo/omubwiga</i> • Carrots • <i>Enswiiga</i> • <i>Obugorra/Nakati</i> • Tomatoes • Cassava leaves • Pumpkin leaves • <i>Bbuga</i> • Eggplant (<i>Biringanya</i>) • Bitter tomatoes (<i>Entula/Enjagi</i>) • Bamboo shoots • Cauliflower • Cucumber • Sour vegetables (<i>Malakwanga</i>) • <i>Sukuma wiki</i> (kale) 	<ul style="list-style-type: none"> • Pineapples • Mangoes • Oranges • Pawpaws (papaya) • Ripe bananas • Lemons • Jack fruit (<i>Fene</i>) • Passion fruit • Watermelons • <i>Empafu</i> • Gooseberries • Guavas • Avocados 	<ul style="list-style-type: none"> • <i>Matooke</i> • Maize meal (<i>Posho</i>) • Cassava • Rice • Bread • Potatoes • Sorghum • <i>Chapati</i> • Millet • Yams • Plantain • Pasta (spaghetti, noodles)

4. Referrals for Medical Services

PLWHAs often have health problems that cannot be treated at home. In this case they must seek the advice and care of medical practitioners. The home-based caregiver needs to be able to recognize such conditions and provide referrals for medical treatment.

Medical treatment is treatment prescribed by a trained health clinician. Health care workers should teach caregivers that they must explain to the sick people that the appearance of certain symptoms and signs means that they need to seek advice and help from a health care worker (preferably the health care worker they usually see, who may be working in the community, at the clinic, health center, or hospital). It is much better for the sick person to go to the same place and be attended to by the same health care worker repeatedly during the process of treating AIDS symptoms, than to keep changing or shopping around. Meeting more health care workers does not mean increasing the chances of having good health.

Objectives

- Maintains continuity of medical care.
- Provides linkage between clinic and PLWHA.
- Provides support for PLWHA.

Requirements and Resources for Referral for Medical Treatment

- Referral forms
- Information about the referral place

Steps to Follow

Step 1: Preparing for referral

- Identify the PLWHA requiring referral for medical treatment or other reasons.
- Decide where to refer. You can also make advance arrangements for the PLWHA at the referral place, i.e., inform them of the person you are referring, reasons for referral, and condition of the person.
- Explain to PLWHA and/or relatives in a caring manner:
 - The reasons for referral
 - Where the referral place is, cost of going there, what PLWHA/relatives might find there, working days, time, costs
 - Any other requirements needed

- Explain the time, date, and travel arrangements.
- Ensure that:
 - The caregiver has made the patient ready for travel, e.g., cleaned up, dressed, etc.
 - The caregiver has all the requirements, e.g., utensils, bedding, money
- Assist the caregiver to make transport arrangements.
- Allow PLWHA to air concerns and respond appropriately.

Step 2: Conducting the referral

- Fill the referral forms or write a referral letter.
- Decide if the PLWHA needs an escort. If necessary you can get personally involved in escorting the patient.
- Request the PLWHA/caregiver to give you feedback after referral.

Step 3: Following up the referral

- Take appropriate action during the follow-up (depending on the PLWHA or caregiver).
- Allow the caregiver and/or PLWHA to ask questions and express their concerns.
- Respond to them in a caring manner.
- Document the results of the follow-up (as required by the organization).
- Thank the PLWHA and caregiver then bid them farewell.

HOME CARE KIT

Caregivers and care facilitators should try to have the following materials available:

- Razor blades
- Cotton wool
- Plastic bags/gloves to protect the hands
- Soap
- Wash cloths
- First aid supplies
- Aspirin/paracetamol
- Toweling to use as diapers/napkins for incontinent patients
- Plastic sheeting
- Cloth that can be used for linen
- Calamine or other anti-itching lotion
- Vaseline

5. Treatment of AIDS-Related Conditions

This section describes some of the medications used to treat conditions that PLWHAs often have. It is the responsibility of the health care worker prescribing or distributing medicines to give full instructions on how and when they should be used. It is your responsibility as a home-based care facilitator to follow up with the PLWHA to see that instructions are being followed. If you have questions about any medication, ask the health care worker yourself.

5.1 ANTIBIOTICS - A GENERAL GUIDE

Almost every person with AIDS will be given an antibiotic at some point to fight an infection.

When used correctly antibiotics are extremely useful and important medicines. They fight certain infections and diseases caused by bacteria. Well-known antibiotics are **penicillin, tetracycline, cotrimoxazole** and **chloramphenicol**. The **sulfonamides** have a similar effect and are also considered here. It should be noted that medicines containing sulfonamides can cause severe allergic reactions in people with AIDS, such as unusual itching or widespread rashes.

Different antibiotics work in different ways against specific infections. All antibiotics have dangers in their use, but some are far more dangerous than others. Great care must be taken in the choice and use of antibiotics. People should never take an antibiotic unless it has been prescribed by a health care worker for a specific reason. Leftover antibiotics should not be used to treat a new infection.

People must continue to use the antibiotics they have been prescribed for the full length of time they are told. Some illnesses, like tuberculosis, need to be treated for many months or years after the person feels better.

If the antibiotic causes a skin rash, itching, difficulty in breathing, or any other reaction, people should stop using it and immediately contact a health care worker. If these reactions do occur, people should always mention this to the health care worker who

prescribes medicine for them. People should be encouraged to remember the name of any medicine they have a bad reaction to so that they can tell a health care worker in the future.

The antibiotic should only be used at the recommended dose—no more, no less. The dose depends on the illness and on the age or weight of the sick person. Increasing or decreasing the dose can be harmful, or can make the medicine useless.

Antibiotics can kill bacteria. However, not all bacteria are harmful and antibiotics often kill good bacteria along with the harmful ones. People with AIDS who are given antibiotics often develop fungal infections of the mouth, skin, or vagina. This is because the antibiotics kill the bacteria that help keep the fungus under control in the body. Similarly, certain antibiotics may lead to diarrhea—the antibiotics kill some of the bacteria necessary for digestion, upsetting the natural balance of bacteria in the intestines.

When antibiotics are used incorrectly, they become less effective. When attacked many times by the same antibiotic, bacteria become stronger and are no longer killed by it. They become resistant to the antibiotic. For this reason, certain diseases like tuberculosis can become more difficult to treat over time if the antibiotics for them are not used in the right way.

5.2 MEDICINES FOR FEVER

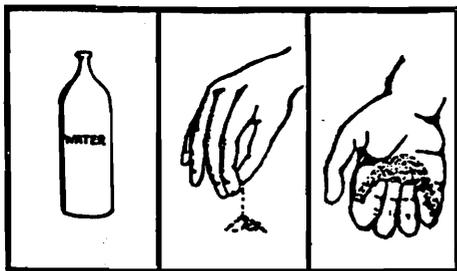
These include aspirin and paracetamol.

5.3 MEDICINES FOR DIARRHEA

Treatment of acute diarrhea

Oral rehydration salts (ORS). For diarrhea with no blood in the stools, no specific medicines are needed. An oral rehydration solution is the best means of preventing dehydration resulting from diarrhea. Powdered oral rehydration salts are available from the pharmacy or clinic. The solution may also be mixed at home as shown in the box below.

HOMEMADE ORAL REHYDRATION SOLUTION



Add 4 thumb-and-finger pinches of salt and 2 4-finger-handfuls of sugar to 1 liter of water.
→ Mixture should be no saltier than tears.

Antibiotics are effective against only some of the diarrhea-causing organisms. When they are effective their benefit should be seen after 2 days and the medicine should be continued as prescribed. If not effective, the person should be advised to seek additional care. Prolonged or frequent use of antibiotics may increase the resistance of some disease-causing organisms to antibiotics. Also, antibiotics are costly, and should only be used when most effective. Therefore, antibiotics should not be used routinely for diarrhea. They may be appropriate for the treatment of dysentery, cholera, and some infections common in people with AIDS, but this should be determined by a health care worker.

Treatment of persistent diarrhea

Relieving the symptoms of persistent diarrhea, especially in people with AIDS, can be a difficult task. The diarrhea does not usually have a known cause. When diarrhea interferes with normal activity, or is very emotionally burdensome, a health care worker may prescribe specific medicines. In addition to ORS, the medicines most commonly used are: **adsorbents**, such as **kaolin**, **pectin**, and **activated charcoal**.

5.4 MEDICINES FOR SKIN PROBLEMS

General

Calamine lotion may be rubbed on the skin to soothe itching or irritation. It should never be taken by mouth.

Bacterial infections

Gentian violet comes as a ready-made solution or as dark blue crystals that should be

mixed with clean water to make a solution. To use the crystals, dissolve 1 teaspoonful in half a liter of water. This medicine helps fight certain skin infections, and has many uses.

Potassium permanganate comes as dark red crystals. It makes a good antiseptic (bacteria-killing) solution for soaking infected sores. Add a pinch of the crystals to 1 liter of clean water or 1 teaspoonful of crystals in a 4–5 liter bucket of water for soaking infected sores.

Hydrogen peroxide comes as a liquid. It should be kept in a dark bottle, as the light destroys its effect. This medicine helps to clean deeply infected wounds on the skin.

Oral yeast infections (thrush)

Before using home remedies or medicines prescribed by a health care worker, a person should try cleaning the mouth with a soft toothbrush and then rinsing with salt water or lemon juice. Next, people can use **gentian violet** or **potassium permanganate**.

The medicines most commonly prescribed by a health care worker for treatment of oral fungal infections are **antifungal agents** such as **nystatin** or **clotrimazole**. A solution or suspension should be held in the mouth for at least 1 minute and then swallowed. Lozenges should be sucked in the mouth until dissolved. It may be necessary to take these medicines 3 or 4 times a day.

In some people, the thrush involves not only the mouth but the entire esophagus, causing pain on swallowing and a burning sensation in the chest. Treatment for this can be provided by a health care worker and includes **antifungal medicines** such as **ketoconazole**, which is taken by mouth every 12 hours for 14 days.

Vaginal yeast infections

Antifungal agents (creams or suppositories) may be prescribed to cure vaginal yeast infections. These should be used once or twice a day for 5–7 days. It may help to line underclothes with some cotton cloth since the medicine will drain from the vagina.

5.5 MEDICINES FOR NUTRITION PROBLEMS

Vitamin and mineral supplements come in many forms, but tablets are usually cheapest

and work well. Injections of vitamins are rarely necessary, are a waste of money, cause unnecessary pain, and sometimes cause abscesses. Tonics and elixirs often do not contain the most important vitamins and are usually too expensive for the good they do. A well balanced diet of carefully cooked, nutritious food is the best source of vitamins and minerals. If vitamin and mineral tablets are needed, it is necessary to make sure the tablets do contain the important vitamins and minerals that are required. In addition, pregnant women need extra amounts of iron and folic acid.

With standard "multivitamin" tablets (tablets that contain several different vitamins), one tablet each day is usually enough. Vitamins should be taken with, or soon after, meals.

5.6 MEDICINES FOR NAUSEA AND VOMITING

Round-the-clock treatment with medicines for nausea and vomiting (**anti-emetics**, e.g., stemetil, phenergan, plasil, largactil) may become necessary if these symptoms become a big problem. They should only be taken on the advice of a health care worker. Some have serious side effects, for example:

- Nervous system effects with trembling or inability to control the movements of the neck or eyes.
- Fatigue, sleep problems, and possibly depression; people taking anti-emetics should therefore not drive or operate machinery.

5.7 MEDICINES FOR PAIN

People with AIDS usually have pain that gets worse as their disease progresses. The World Health Organization recommends a three-stage approach to pain management: paracetamol in the early stages (aspirin may also be used by some patients); codeine phosphate for more severe pain; and oral morphine sulphate when the pain is very bad.

Paracetamol is recommended for pain and fever. It does not cause stomach problems, such as ulcers, so it can be used instead of aspirin if such problems are experienced. Paracetamol, rather than aspirin, should be given to children.

Paracetamol is readily available from chemists, pharmacies, or village health workers. It usually comes in tablets of 500mg and should be given at least every 8 hours (or 2 to 3 times per day) as follows:

- Adults: 1 or 2 tablets (500–1000mg)
- Children 8–12 years: 1 tablet (500mg)
- Children 3–7 years: one-half tablet (250mg)
- Children 6 months–2 years: one-fourth tablet (125mg)
- Babies under 6 months: one-eighth tablet (62mg)

Aspirin can also be used to reduce pain, to lower fever, and to reduce inflammation. It may also help to calm a cough and reduce itching. Aspirin usually comes in tablets of 300–500mg and should be given to adults at least every 8 hours (or 2 to 3 times per day). For someone suffering from severe joint pains a higher dose may be recommended.

Aspirin should **not** be used by people who have indigestion or heartburn because it can make these problems much worse. In some people, aspirin can be taken with milk, some bicarbonate of soda, a lot of water, or with meals. If ringing in the ears is experienced, this is a sign that the amount of aspirin that is being taken should be lowered. Aspirin must be kept out of reach of children as large amounts can poison them.

Codeine phosphate and oral **morphine sulphate** may be prescribed by a health care worker for severe pain. In these forms these drugs are not addictive, but they may have troublesome side effects. These include nausea, drowsiness, constipation, depression, fatigue, and itching. Make sure that people are advised to take extra fluids to prevent constipation if they are taking such medicine. Make sure they follow the directions carefully and do not drive or operate machinery.

5.8 MEDICINES FOR TUBERCULOSIS

Almost all countries in the world have guidelines or standard treatment protocols for the treatment of tuberculosis. Follow your country's standard treatments. This section describes the most common medicines used in the treatment of tuberculosis. At least 2 medicines to treat tuberculosis should always be given at the same time.

Streptomycin is given by injection. It is an important medicine for treating tuberculosis; however, it should *always* be used in combination with other medicines. In some places it is being used less often because there are other medicines that can be used in its place and because there is a risk of HIV and hepatitis transmission if the needles or syringes used to inject the medicine are not sterilized adequately.

The dose depends on the age and weight of the sick person and the severity of the tuberculosis. Treatment regimes vary depending on the national policies. In some places 1 injection is given each day for 2 months, in others injections may be given 2 or 3 times a week for 2 months.

Great care must be taken not to give more than the correct dose. Too much streptomycin for too long may cause ringing in the ears or dizziness, particularly in people aged 50 years or more. If either of these symptoms occurs, patients people should return immediately to the health care worker who prescribed the medicine.

Streptomycin is not suitable for use in pregnant women because it can cause hearing and kidney problems in the unborn baby. It is also unsuitable for children since they develop the side effects more often and do not tolerate the painful injections well.

Isoniazid comes in tablet form and should be taken before the morning meal. Tablets should be stored out of direct sunlight.

Isoniazid occasionally causes liver problems. If this happens people notice itching and the white part of their eyes will turn yellow. They should return immediately to the health care worker who prescribed this medicine. In rare cases, the medicine causes anemia, nerve pains in the hands and feet, muscle twitching, or even fits. These side effects can usually be prevented by taking a tablet of **vitamin B6** (pyridoxine) each day.

Ethambutol comes in tablet form. It is usually given once a day for 2 to 12 months. It may cause eye problems if taken in large doses for a long time. If people notice that their eyesight seems worse, with blurring of vision or color blindness, they should go to the health care worker who prescribed this medicine. Ethambutol is not advised for use in children less than 6 years old.

Thiacetazone often comes in tablet form and is always given in a combined form, usually mixed with isoniazid in a tablet called "thiazina." Side effects occur fairly frequently and include reddening of the eyes, unusual itching, widespread rashes, vomiting, dizziness, and loss of appetite. In people with AIDS these reactions can be very severe.

Table 1: List of drugs at community-based health care level

Pain including headache and fever:

Aspirin tablets 300mg
Paracetamol (Panodol) tablets 500mg
Paracetamol pediatric syrup 120mg/5ml

Anti-allergics

Chlorpheniramine maleate injection 10mg/ml
Chlorpheniramine maleate syrup 2mg/5ml
Chlopheniramine maleate tablets 4mg

Anthelmethics

Mebenazole suspension 100mg/5ml
Mebendazole tablets 100mg

Antibacterials

Penicillin V syrup 125mg/5ml
Penicillin V tablets 250mg

Antimalarials

Chloroquine phosphate syrup 50mg base/5ml
Chloroquine phosphate tablets 155mg base
Sulfadoxine 500mg + Pyrimethamine 25mg tablets

Antimalarials may vary from country to country depending on the resistance of the malaria parasite.

For skin conditions

Benzyl benzoate lotion 25%
Compound benzoic acid 6%, salicylic acid 3%
Gentian violet crystals/powder 10gms
Hydrocortisone skin ointment 1% 500gm

For heartburn

Compound magnesium trillicate tablets
Oral rehydration powder

For eye conditions

Tetracycline eye ointment 1%

Vitamins/minerals

Vitamins - single and multivitamin tablets
Ferrous sulphate compound tablets

If people who are taking this medicine begin to have these problems they should stop taking the medicine and return immediately to the health care worker who prescribed it. In many countries this medicine is no longer used for people with AIDS because the side effects occur so frequently in such people.

Thiacetazone is usually given once a day, for between 6 months and 1 year.

Rifampicin comes as single tablets of 150–300mg or in a combined form mixed with isoniazid, as tablets that contain 150–300mg of rifampicin and 100–150mg of isoniazid.

Rifampicin should be taken on an empty stomach, at least 30 minutes before the morning meal, since food interferes with the absorption of the medicine. It should be stored out of direct sunlight in a dry place.

Rifampicin can be used during pregnancy.

Side effects are not very common. This medicine may cause liver problems, which can cause the white part of the eye to turn yellow. If this happens, the person should return immediately to the health care worker who prescribed the medicine.

Rifampicin is likely to stain urine, tears, saliva, feces, and other body fluids an orange color. If people notice this discoloration, they should **not** stop taking the medicine as it is a normal reaction and is completely harmless. Sometimes the medicine may cause flushing, itching, rash, fever, or flu-like symptoms. If people have any of these problems they should discuss them with their health care worker.

Pyrazinamide comes in tablet form and should be taken in the morning with or without food.

Pyrazinamide is safe to take during pregnancy.

The most common side effect of this medicine is joints pains. These pains tend to occur in the shoulders and are relieved by mild pain medicines. The pain usually goes away within a short period of time. This medicine may also cause liver problems, which make the white part of the eye turn yellow. If this happens the patient should return to the health center or hospital immediately.



Table 2: Symptomatic care of AIDS related illnesses

Symptoms	Care	Medicines and supplies
Oral discomfort Difficulty swallowing	For thrush (whitish coating of the tongue, mouth, and throat): Rinse mouth with salt water For poor nutrition: Soft diet For Kaposi's sarcoma (KS): Refer for treatment, if condition is not terminal For general hygiene: Rinse mouth with salty water	Gentian violet rinses, nystatin or ketoconazole Multi vitamins
Cough/difficulty in breathing/chest pain	Physical therapy and treatment for TB, other pulmonary infections or KS; followed by emotional support	Cotrimoxazole (septrin) or penicillin Cough mixture, codeine
Diarrhea	Treatment for treatable infections; skin care; dietary changes; ORS/fluid replacement	Cotrimoxazole (septrin) or metronidazole (flagyl) for empirical treatment
Weight loss	Nutritional support; skin care	
Vomiting	ORS/fluid replacement; oral care	Antiemetic (medicines to stop vomiting), e.g., stemetil, plasil, avomine
Pain	Instruction to family in providing comfort measures; For abdominal pain: Dietary changes	Aspirin/paracetamol, antacids; for severe pain health worker may prescribe codeine phosphate or oral morphine sulphate
Immobility/weakness	Family education to provide: Assistance with daily activities, skin care, nutritional support	Crutches or wheelchair, walking stick, walking with support from HBC giver
Fever/night sweats	Treatment for infection, followed by comfort measures (cool baths, fluids)	Aspirin/paracetamol
Rash/skin lesions	Treat infections, followed by cleansing, application of salt water soaks and dressings for discharging wounds	Prescribed skin ointment, antihistamine (Piriton), aspirin/paracetamol
Edema	Elevate affected limbs; cool compresses; pain relief; skin care	Prescribed medicines (diuretic)
Urinary infection/pain when passing urine/blood in urine/swelling in the groin	Treatments, comfort measures, patient education	Prescribed medicines (antibiotics), aspirin/paracetamol
Depression/anxiety	Provide emotional and spiritual support; ensure patient receives counseling and pastoral care services	Prescribed medicine
Lack of sleep	Emotional support	Prescribed medicine
Confusion, headache, paralysis, loss of vision, personality changes	Treatment of treatable infections, in hospital or clinic, if treatment is available; followed by safety precautions, pain relief, family education, emotional support	Prescribed medicine
Drug reactions: skin rashes, diarrhea, loss of vision	Symptomatic care as above	Discontinue all medication and refer for review and/or change of treatment

Source: Adapted from Lamptey et al. (1990).

6. Other Support Services

People who have AIDS or people who are in contact with someone with AIDS are often afraid that the negative feelings toward PLWHAs will be too strong to bear. These feelings cannot and should not be avoided. They are normal reactions to crisis. Family, friends, neighbors, community-based health workers—anyone who cares—can help another person cope with these feelings by listening and talking to the person about these feelings.

Neighbors can help a family that is affected by AIDS. Women's clubs and youth and religious groups can also mobilize to assist, as can local political and social organizations. Mobilizing these and other community members to provide support for home-based care is an important task of the home-care facilitator.

Support services also serve a preventive function. Just talking openly and honestly about HIV/AIDS can have a great impact on reducing stigma and motivating people to adopt safer behaviors.

6.1 DEFINITION AND PURPOSE

Support services are those given to PLWHAs to help meet social, spiritual, emotional, economic, and medical needs. Support services help to:

- Assure quality of care
- Reduce anxiety
- Provide sense of belonging
- Improve relationship between PLWHA and caregiver
- Meet material needs

6.2 INSTITUTION-BASED SUPPORT TEAMS/PERSONS

These are health workers from AIDS support organizations, e.g., TASO, who go to the homes of PLWHAs and provide them with medical care. These teams include doctors, nurses, midwives, clinical officers, social workers, and counselors. Support services provided by these teams include:

- Medical care for AIDS-related conditions
- Family education on HIV/AIDS
- Voluntary HIV testing

- Supportive counseling
- Material support
- Training of home-based caregivers

6.3 LINKING PLWHAS TO SUPPORT SERVICES

To ensure that PLWHAs have access to needed support services, community health workers should:

- Assist PLWHAs and their families to identify the support that is needed.
- Identify groups/agencies/individuals that can provide the support.
- Inform the PLWHA about the existence of the agencies/individuals and the services they provide.
- Introduce the identified groups/individuals to the PLWHAs and their homes.
- Help the PLWHAs to evaluate the groups/individuals who provide the support.
- Allow PLWHAs to choose the agency/individuals to meet own needs.
- Help plan for transportation if needed, or help set up home visits.
- Follow up to assure coordination of services.

6.4 COMMUNITY MOBILIZATION

Community mobilization is the process of gearing the community into action. This is important for several reasons: It helps to counter the stigma AIDS patients and their families face, so that they can live without fear or discrimination. It involves the PLWHAs themselves and helps them to "live positively." It can increase community awareness and thus helps prevent the further spread of HIV. And, it brings the community together in the care of PLWHAs, AIDS orphans, and others.

Community-based health care occurs when community members take on the responsibility of initiating and sustaining their own health care. It implies the use of locally available resources and the community's full participation and involvement in decision making for the planning, organizing, implementing, monitoring, and evaluating of these services.

Key mobilizers for HBC activities who can influence the introduction of HBC services are:

- Local Council leaders
- Religious leaders
- Organized groups, e.g., women, youth, religious
- Related community health workers
- Traditional healers
- School teachers

Some of the ways of mobilizing the community for HBC services are:

- Meetings with key persons, existing committees, and community groups
- Home visits to talk to individuals and groups
- Announcements through mosques, churches, temples, schools
- Group community talks

Usually when initiating home-based care (or other community-wide) services, it is more effective to work from the "top down." That is, ensure that you have the leadership in the community involved in the process from the very beginning. Try to take these steps:

Step 1: Planning and organizing yourself for community mobilization

- Know about and be a believer in home-based care so that you can explain it very well to the people (community).
- Know the community leadership and those who can influence the acceptance and implementation of HBC services.
- Prepare yourself psychologically, emotionally, and physically for involvement/commitment to work with PLWHAs. These are people who are terminally ill.
- Identify resources and prepare them for community mobilization according to the rationale and objectives of HBC services. Make other arrangements such as the venue (according to the plan or process you have decided on, which can be home visits, community gatherings, or church/mosque/temple meetings).
- Send out information to the relevant persons involved, e.g., to the community leadership (LC1), church/imam leaders, depending on where you have decided to begin mobilization.
- Confirm appointment dates and time; be on time without making people wait.

Step 2: Entering the community to mobilize the people

Because the facilitator is already known and has been working in this community, this may not be a complicated step. Depending on the mode, venue, and type of group or individuals you have decided to mobilize, it is important to note the following: Remember to show respect to the community/individuals and be willing to acknowledge and deal with the different feelings about home-based care services.

Step 3: Conducting community mobilization sessions

- Greet the group/individuals according to the culture.
- Find out what they know about home-based care for PLWHAs. Do not assume that they do not know anything; they have experiences that can be useful for the program.
- Give correct and complete information about HBC services.
- Allow the group/individuals to express fears, make contributions, and suggest approaches. Together with them come to agreements that are practical.

Step 4: Monitoring the community response and making reinforcements for action

- Watch out for sign of acceptance of home-based care for PLWHAs, for example:
 - Community asking for more information about HBC
 - Community taking interest in supporting the activities or PLWHAs
 - People volunteering to act or willing to work with the community health workers
 - People voluntarily seeking assistance to take care of PLWHA
- Acknowledge the positive responses and find out more about the reasons for negative responses in order to clarify issues and further enlighten those concerned.
- Give feedback to the relevant persons concerned.

6.5 NETWORKING

A network is any group of individuals or organizations that on a voluntary basis exchanges information or undertakes joint activities in a way that strengthens and extends the individual capacity of each member. Networking and coordination are a process that promotes information exchange, builds

alliances, and facilitates the creation of complementary and reinforcing programs.

Networking has many benefits. It:

- Promotes unity and harmony
- Provides a learning atmosphere
- Improves ability to address complex problems
- Promotes peer support
- Reduces duplication of efforts/resources
- Help reduce the isolation of individual groups working alone

The formation of networks pertaining to HIV/AIDS has become a necessity.

Comprehensive HIV/AIDS care should be accessible at several points along a continuum ranging from medical and social facilities, through to community-based services and home care. At the level of continuity of care for PLWHAs, an efficient referral network is essential. Referrals may be to and from voluntary testing and counseling centers, hospitals or clinics, community-based services, and home care programs. At an institutional level, networks provide for the sharing of experiences on what works and what doesn't, and help organizations learn from each other.

The following approaches to networking are suggested:

- Establish AIDS networking bodies at different levels: national, regional, district, subdistrict, parish, village. Involve all institutions and NGOs dealing with care and support of PLWHAs.
- Facilitate the exchange of information and experiences to avoid duplication of effort.
- Establish a strong referral system to and from hospitals, HIV/AIDS counseling centers, and home-based care providers.
- Ensure the availability of essential drugs to treat common HIV-related infections.

At the community level, HBC facilitators and community-based health workers are an important link in national networks. The recording and exchange of information about their activities, and the results of those activities, is an important part of their functions. They should try to share information about their experiences as often as they can, including at formal meetings.

PLWHA SUPPORT ORGANIZATIONS

AIDS Information Center
P.O. Box 11300, Kampala
Musajja Lumbwa Road, Plot 1321, Block 12
Mengo, Kisenyi
Tel: 271433/347603
Email: aidsinfo@IMUL.COM

Ministry of Health, AIDS Control Program
P.O. Box 7272, Kampala
Lourdel Road, Plot 4 Wandegeya
Tel: 231563/9 Fax: (256) 41 231571

Nsambya Community Based Health Care
P.O. Box 7146, Kampala
Tel. 267377 Fax: (256) 41 269969
Email: nhhp@INFOCOM.CO.UG

The AIDS Support Organization (TASO)
P.O. Box 10443, Kampala
Tel. 566703/4/5 Fax: (256) 41 567637

Uganda AIDS Commission
P.O. Box 10779, Kampala
Sentema Road, Plot 213 Mengo
Tel: 273538/273231/258538
Fax: (256) 41 258173
Email: uacnadac@IMUL.COM

Uganda Protestant Medical Bureau
P.O. Box 4127, Kampala
Balintuma Road, Plot 877 Mengo
Tel: 271776 Fax: (256) 41 34143
Email: upmb@swiftuganda.com

Uganda Women's Effort to Save Orphans
(UWESO)
P.O. Box 8419, Kampala
Off Kira Road, Tagore Crescent, Plot 2
Kamwokya
Tel: 41 532394/5 Fax: (256) 41 532396
Email: UWESO@IMUL.COM

7. Information and Education about Responsible Sexual Behavior

The purpose of providing information and education about sexual behavior is to:

- Prevent the further spread of the disease.
- Reduce the potential for re-infection.
- Improve and maintain sexual relationship
- Raise awareness.
- Provide opportunities to make informed decisions.

7.1 INITIATING PLWHA ON CONDOM USE

Properly and consistently used, condoms can provide protection against transmission of HIV and other STIs. It is important that PLWHAs know how to use condoms properly.

Objectives

- To enable the PLWHA to use condoms to prevent the spread of and/or re-infection with STDs/HIV.
- To enable PLWHA to take care of used condoms properly.

Requirements and Resources for Initiating PLWHA on Use of Condoms

- Condoms
- Penis model (or banana or soda bottle)
- Tissue paper

7.1.1 What to Discuss with PLWHA

How to Use Condoms Properly

- Condoms are effective if they are used properly every time you have sexual intercourse.
- When properly used, a condom can provide protection against transmission of HIV and other STIs such as gonorrhea or syphilis. It is important that PLWHAs, HBC givers, and everyone in the community know how to use condoms properly.
- Be sure you have a condom before you need it.
- Put on a condom only when the penis is erect.

Tips to Help Prevent Condoms from Breaking or Leaking

- If lubricant is needed, use a water-based one (like KY jelly, or glycerin). Do not use a lubricant made with oil, like Vaseline, which can cause condoms to break more easily.
- Store condoms in a cool, dark, dry place, if possible. Heat, light, and humidity can damage condoms.
- If you have a choice, choose a pre-lubricated condom that comes in a square wrapper and is packaged so that light does not reach it.
- Open the wrapper carefully so that the condom does not tear.
- Do not use condoms that are sticky, brittle, discolored, or damaged in any way.

7.1.2 How to Use Condoms

Step 1: Finding out the PLWHA's knowledge about condoms

- Ask PLWHA what they know about condoms and how they are used.
- Thank the PLWHA for the many tips mentioned about the condom.
- Remind PLWHA of the information not mentioned.

Step 2: Demonstrating condom use

- Open a condom packet and take the condom out.
- Place the condom on the tip of an erect penis (if you are not circumcised, pull the foreskin of the penis back before putting on the condom) while pressing its teat to allow a small empty space to hold semen; this prevents the condom from breaking easily. (Show while using a penis model.)

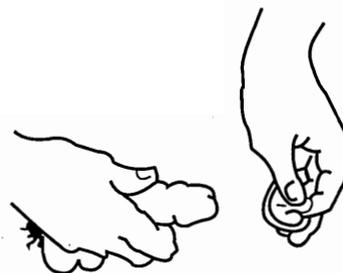


Figure: Put a condom on an erect penis

- Unroll the condom up to the end of the penis.

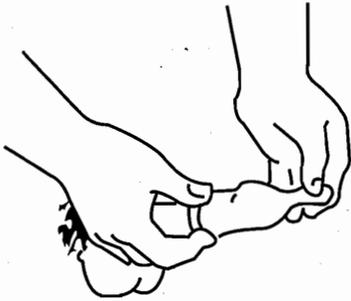


Figure: Unroll the condom to the end of the penis; leave a teat at the top.

- Tell the PLWHA that immediately the man finishes the sexual act, he holds on to the condom and removes the penis from the vagina.



Figure: Remove the condom after the sexual act.

- Tell the PLWHA that the penis must be removed from the vagina while still erect to ensure that the condom does not slip off. It should also be done carefully without spilling the semen.
- Tell PLWHA to tie a knot at the upper part of the condom so that the semen does not spill.

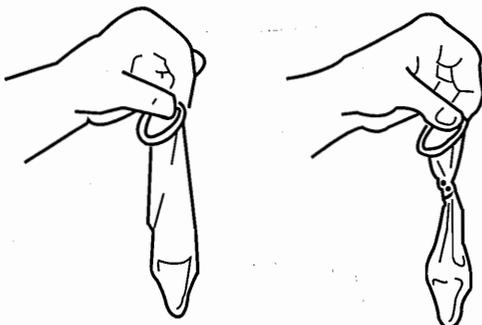


Figure: Tie a knot to avoid spilling the semen.

RELATIONSHIP BETWEEN STDs AND HIV INFECTION

There is a direct relationship between STDs and HIV:

- The behavior that puts a person at risk of contracting STDs (e.g., substance abuse because it impairs judgement about sexual behavior, multiple partners, non systematic use of condoms) puts the same person at risk of contracting HIV infection.
- A person who has a weakened immune system due to HIV infection has a higher risk of contracting STDs.
- STDs with open/broken skin (e.g., sores, ulcerations, or inflamed/red and tender skin) make it easier for HIV to be transmitted from one person to the other.
- Persons who are HIV+ have reduced immunity, which makes it difficult to treat STDs effectively.

- Remind the PLWHA to put a new and unused condom on the penis for every act of sexual intercourse.
- If the condom tears during sex, withdraw the penis immediately and put on a new condom.

Step 3: Taking care of used condom

- Ask the PLWHA to wrap the used condom with a piece of paper or cloth.
- Ask PLWHA to throw it in the pit latrine or burn it.

Step 4: Keeping unused condoms

- Keep the condoms in a place that is neither hot nor wet.
- Put/place condoms where children cannot reach them.

Step 5: Checking understanding about taking care of used condoms

- Allow the PLWHA to ask questions and answer them well.
- Ask PLWHA to repeat for you what you have discussed on how the condom is:
 - used
 - kept
 - taken care of after use

- Tell PLWHA that you have now seen that they know how the condom is used.
- Remind PLWHA of what may not have been mentioned.

Step 6: Completing the discussion

- Provide the PLWHA with condoms (according to your role as a CBHW).
- Tell PLWHA where and how to get more.
- Tell the PLWHA thank you.

7.2 OTHER SAFER SEX PRACTICES

Penetrative sex always carries some risk. This is why it is wise for PLWHAs not to have any penetrative sex at all. However, if PLWHAs and their partners decide to have penetrative sex, they should be sure to use protection. Condoms are effective in preventing pregnancies and infections from HIV/AIDS and other STDs because they help prevent contact with sexual body fluids (semen, vaginal fluids, and blood).

What is "safer sex"? Safer sex is any sexual practice that reduces the risk of passing (transmitting) HIV from one person to another. The best protection is obtained by choosing sexual activities that do not allow semen, fluid from the vagina, or blood to enter the mouth, anus, or vagina of the partner, or to touch the skin of the partner where there is an open cut or sore.

Safer sex practices include:

- Staying in a mutually faithful relationship where both partners are uninfected.
- Masturbation, massage, rubbing, dry kissing, and hugging.
- Using a condom for all types of sexual intercourse (anal, vaginal, and oral).
- Avoiding certain practices that increase the possibility of HIV transmission, for example "dry" sex, which may lead to breaks in the skin.
- Avoiding sex when either partner has open sores or any sexually transmitted diseases

(STD). If either partner has an STD they should seek medical treatment immediately.

- Oral sex—this may be an acceptable alternative for some people. Oral sex should be avoided if there are sores present in the mouth or on the genitals.

Couples should talk about sex and learn to please each other. This can allow for the negotiation of safer sex and make the intercourse more pleasurable for both and less likely to cause discomfort or minor damage to the genitals.

PLWHAS - HELP STOP IT NOW

Help prevent the spread of HIV by:

- Totally abstaining from sex
- Having only one sexual partner whose only partner is you ("zero grazing")
- Avoiding sex with casual partners
- Using condoms properly and systematically (one condom per sexual act and use of condom even during foreplay)

7.3 PREGNANCY AND AIDS

Health care workers should advise women with AIDS that:

- Pregnancy makes the condition worse by further suppressing their immunity.
- Some 40% of babies born to mothers with AIDS are infected during pregnancy or breastfeeding.
- A baby needs healthy parents to bring it up through its life.

The safest sex is NO sex!

8. Physical Therapy

Gainful exercise for PLWHAs is very good and brings a feeling of being useful. Many PLWHAs become sicker, wasted, and frustrated if they are not helped to exercise their bodies and limbs.

Physical therapy includes exercise or massage that helps to:

- Improve blood circulation
- Improve digestion
- Prevent stiffness of joints
- Prevent muscle wasting
- Prevent secondary infection, e.g., inhalation pneumonia from lack of exercise
- Relax the patient

People who are in bed because of AIDS have difficulty moving their arms and legs enough to keep their joints flexible. When this happens, and an arm or leg is kept bent for a long time, some of the muscles become shorter and the limb cannot fully straighten, or short muscles may hold the joint straight so that it cannot bend. This is called a *contracture*. Sometimes contractures cause pain.

8.1 CONDUCTING PHYSICAL THERAPY

To prevent contractures and keep muscles strong, AIDS patients need help to exercise their arms and legs every day. Try to make sure that every part of their body is moved. If they have had contractures for many months, it will be difficult to completely straighten their joints. But these exercises will prevent the contractures from getting worse and can make the joints a little less stiff and keep the muscles strong.

Physical therapy can be done both for PLWHAs who are still capable of lifting themselves and for those who are no longer capable.

Objectives

- To exercise the body and limbs to improve blood circulation and prevent stiffness of the joints and muscle wasting.

Requirements and Resources for Physical Therapy

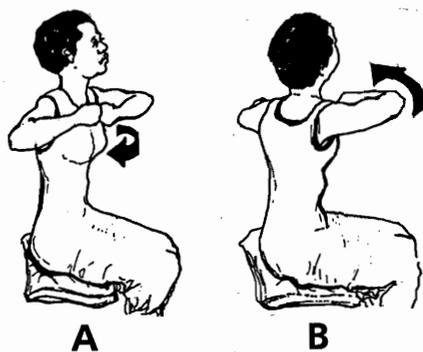
- Plastic/polythene bags to use as gloves (to prevent contact with body fluids)
- Vaseline/lotion in case massage is needed

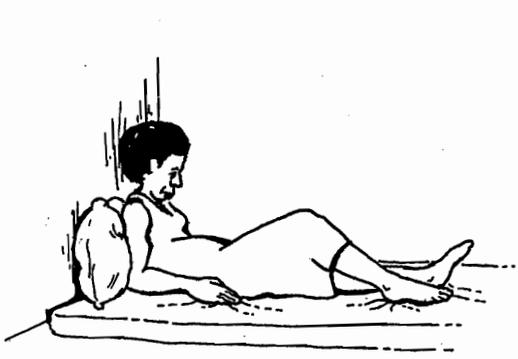
Steps to Follow

- Assess PLWHA for the need for exercises/massage.
- Explain the exercises/massage and the benefits to the PLWHA if conscious.
- Perform the exercise/massage.
- Ensure that the exercise/massage is not painful and does not make the patient tired.
- Teach a PLWHA who is still capable of lifting or moving self the routine of the exercise/ massage, and how long it should take.
- Teach family members of PLWHAs who are not able to move out of bed about the benefits of the exercise, including when it should be done and how long it should take.
- Demonstrate to the caregivers how the exercises are done (according to the patient's need and condition).
- Allow them to ask questions and do return demonstration.
- After the exercise/massage, thank the patient and the caregivers.

8.2 EXAMPLES OF SIMPLE EXERCISES

Examples of exercises that prevent some contractures and help keep the muscles strong are shown in the following diagrams.

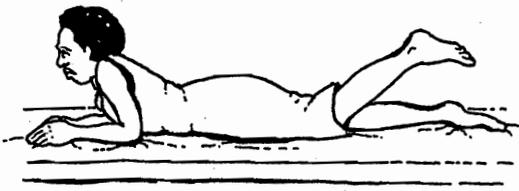




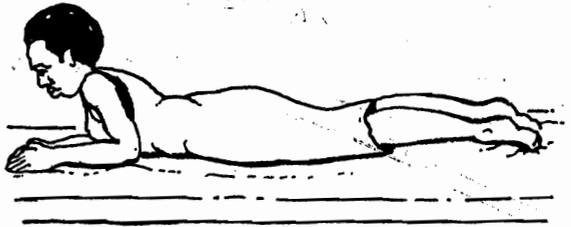
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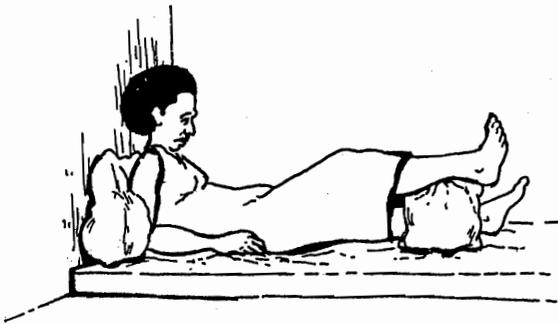
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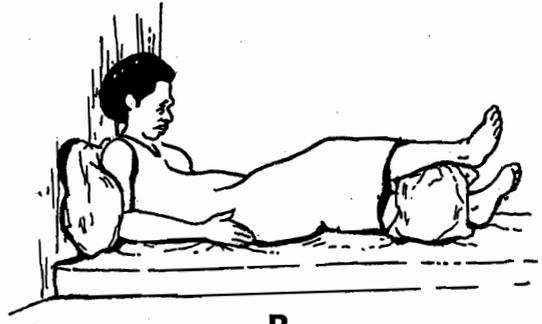
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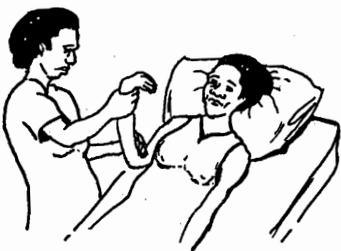
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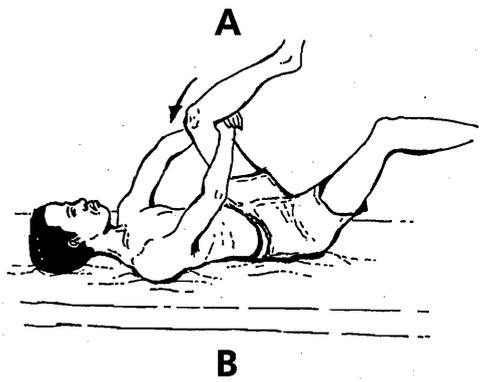
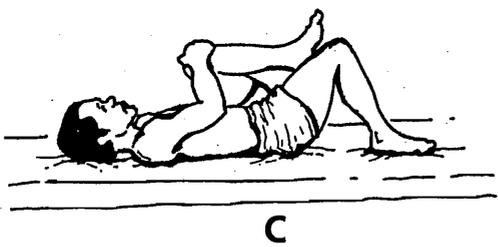
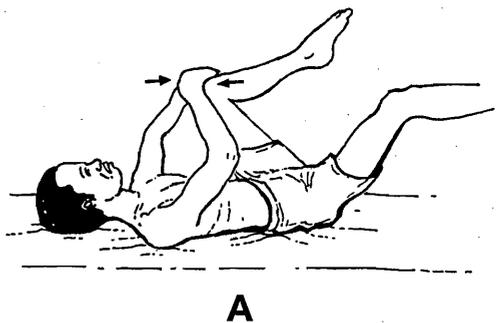
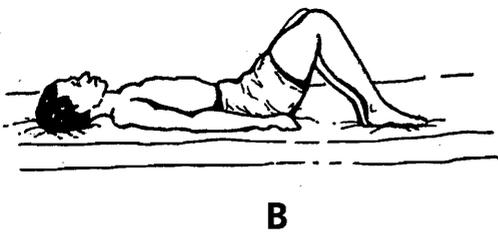
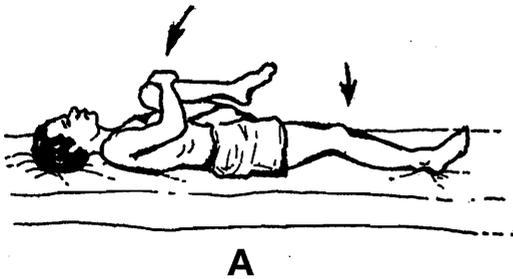
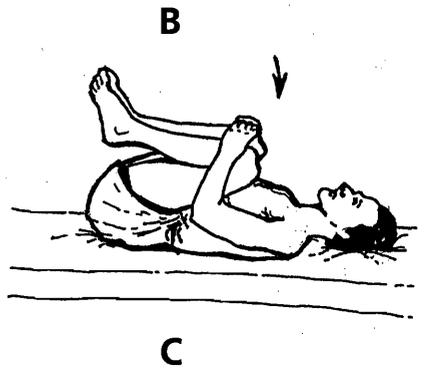
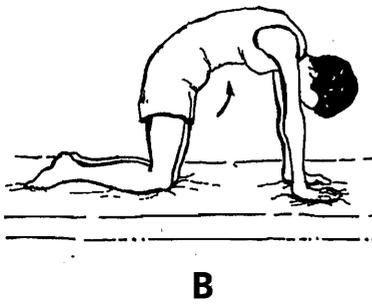
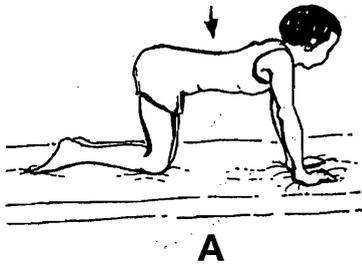
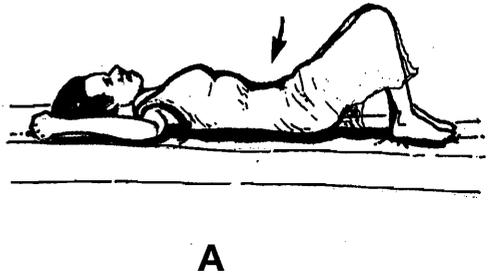
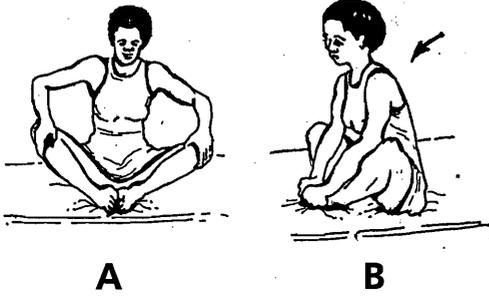
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9. Summary of Things to Teach People to Do at Home

This chapter briefly summarizes some of the basic things caregivers and PLWHAs themselves should know about handling various problems that arise in the care of AIDS patients.

9.1 HYGIENE

Good personal and environmental hygiene helps prevent the spread of germs that make people sick. (Refer to Chapters 1 and 2.)

What to Teach the Person and the Family

- Always wash hands before cooking or eating.
- Always wash hands after defecating.
- Wash dishes in hot water with soap.
- Wash linens and clothes with soap and hot water.
- Cover the mouth when coughing, then wash hands.
- Always spit into a container, not on the ground.
- Always wash the hands after touching blood.
- Dispose of garbage in covered containers, or bury or burn it.

9.2 NUTRITION

Good nutrition is essential to keep PLWHAs healthy as long as possible. Refer to Chapter 3 for details of nutrition and food service.

What to Teach the Person and the Family

- Eat small amounts often, including complete nutrition if possible: fruits, vegetables, grains and beans, and if possible, eggs, milk, meat, or fish.
- Choose foods that the person likes.

What to Teach the Family

- Keep the person away from cooking smells.
- Prepare small amounts of favorite food often. Watch for dehydration. (*See treatment for dehydration under Section 9.8, Chronic Diarrhea.*)

9.3 SKIN PROBLEMS

What to Teach the Person and the Family

If the person has diarrhea, wash the skin with warm soap and water after each bowel movement and keep the skin clean and dry.

For open sores, wash with soap and water, keep the area dry, and apply gentian violet solution. Dressings can be made of cloth strips that have been washed and dried in the sun. Dressings soiled with pus or blood should be handled as in Section 1.9, Handling Body Fluids.

For rashes, apply local remedies or calamine lotion.

Herpes zoster causes a large area of open sores on one side of the body; this can be very painful. For adults, take 2 aspirin or paracetamol every 4 hours. Local remedies may also be helpful. If the pain is very bad or the sores become infected, encourage the person to go to a health care facility for stronger pain medicine and for dressings and medicines for the open sores.

9.4 TIREDNESS, WEAKNESS

What to Teach the Person and the Family

- Rest as needed. Learn to accept help from others.
- Find ways to make activities easier. For example, sit rather than stand to wash.

What to Teach the Family

If needed, help the person with personal care such as washing, going to the toilet or latrine, getting in and out of bed, eating. If the person cannot get out of bed at all, gently move the arms and legs several times a day. (See Section 1.6 on Pressure Area Care and Chapter 8 on Physical Therapy.)

9.5 SORE MOUTH AND THROAT

What to Teach the Person and the Family

- Rinse the mouth with warm water mixed with a pinch of salt.
- For white patches, suck a lemon to ease sores on the lips and mouth.
- Eat soft foods as able.
- Apply gentian violet solution to sores on lips and mouth.
- Use any local remedies that are soothing.

9.6 PAIN

What to Teach the Person and the Family

- For adults, take 2 aspirin or paracetamol tablets every 4 hours. (*Take small amounts of food before taking aspirin.*)
- Use any local remedies that ease the pain.
- If lying in bed, change position in bed frequently.
- For swelling, raise legs or swollen body parts on pillows.

What to Teach the Family

- Rub and gently massage sore muscles. Use oils.
- Talk with the person. Provide distraction to help the person forget the pain.
- Help the person to change positions and to raise the legs or swollen body parts.

9.7 FEVERS

What to Teach the Person and the Family

- Wash the body in cool water or wipe the skin with wet cloths.
- For adults, take 2 tablets of aspirin or paracetamol every 4 hours. (*With aspirin, take small amounts of food first.*)
- Drink more than usual: water, tea, broth, or juice.
- Use any local remedies that reduce the fever.

Fevers may be caused by infections such as malaria and tuberculosis that can be treated effectively by modern medicine. Encourage the person to go to a health care facility if a new or especially high fever develops.

What to Teach the Family

- Offer water and other drinks frequently.
- If the person is weak, help the person to turn from side to side in bed, or to sit up and move about.
- Help keep the person clean and dry.
- Watch for dehydration. (*See treatment for dehydration under Section 9.8 Chronic Diarrhea.*)

9.8 CHRONIC DIARRHEA

People with AIDS may have diarrhea that does not go away.

What to Teach the Person and the Family

- Drink much more than usual: lots of water, tea, broth, or juice.
- Continue eating solid foods, including porridge and fruit such as bananas.
- Wash and dry the skin around anus and buttocks after every bowel movement.

What to Teach the Family

- Encourage and serve lots of water, soup, and juice frequently. Give oral rehydration solution.
- Watch for danger signs of dehydration: the tongue is dry, the eyes are sunken, and skin goes back slowly when pinched.

Note: If the person cannot drink, and dehydration becomes worse, encourage the family to quickly take the person to the nearest health facility.

9.9 COUGH, DIFFICULTY BREATHING

What to Teach the Person and the Family

- For adults, take 2 tablets of aspirin or paracetamol every 4 hours. (*With aspirin, take small amounts of food first.*)
- Drink lots of fluids, especially if there is fever.
- Move about and turn in bed frequently.
- Sit up when possible.
- Cover the mouth when coughing. Spit into something that can be burned such as a piece of paper, leaf, or a paper box.
- Use any local remedies that are soothing.

Some lung infections that people with AIDS can get, such as pneumonia and tuberculosis (TB), can be treated effectively with modern medicine. TB is contagious to others if it is not treated. Encourage the person to go to a health care facility for any new cough or difficulty breathing, especially if there is chest pain, bloody sputum, or a new fever.

What to Teach the Family

- Elevate head and upper body on pillows or raise the head of the bed on blocks to assist breathing.
- Sit with the person. Difficulty in breathing can be very frightening.

9.10 CONFUSION

What to Teach the Family

- Move loose or dangerous objects out of the way.
- Help the person to stand and walk about.
- Try not to leave the person alone and unattended.
- Keep medicines out of the way if the person is forgetful and might take them incorrectly.

9.11 FEAR, ANXIETY, DEPRESSION

What to Teach the Family

- Listen to the person who is sick.
- Let the person know that their feelings are normal.
- If they need or want professional help, help them to get it if possible.
- Talk to someone; family members may also be depressed and need help.
- Get support from a helping organization in the community. Many health workers and religious and spiritual organizations can counsel people with AIDS and their families.

If people need help and will not accept it, or are so angry that they may hurt themselves or another person, it is a good idea for the family to talk to someone in a helping organization.

What to Teach the Person

- Remember that sometimes the caregivers may also be tired and discouraged. This is

not necessarily directed at the PLWHA personally, but is a result of the situation. They are just tired.

- Despite the pain and discouragement the PLWHA may be suffering, keep in mind that family members are suffering as well. Try to express appreciation for the care that is being given.

9.12 WHEN CAREGIVERS FACE "BURNOUT"

Care for a terminally ill patient is not easy. When the patient is a family member or friend and someone who is loved, the job is particularly painful. And the stigma attached to AIDS makes the job of the caregiver especially trying.

What to Teach the Family

- The burden of caring for an AIDS patient is very real and very big.
- Even the strongest people may reach a point where they feel like running away from the responsibility of caring for someone who is dying.
- There is nothing wrong with those feelings.
- When those feelings begin to come, the caregiver should not be afraid to talk to someone about them, a counselor, priest, imam, friend, or other trusted confidant.
- It might be a good idea to join other families of PLWHAs and form a support group of people who share a similar burden and are willing to do what they can to help each other. If nothing else, they can talk and listen to each other.

On a practical note, caregivers should be encouraged to try to organize the work of caring for the PLWHA so that the burden of work is shared by all family members. Everyone in the family should have a break from work from time to time.

Note: Home care supervisors should remember that the community-based health worker may also face burnout. At the community level health workers may be isolated from supervisors and peers and face a heavy workload. Moreover, it can't be easy to know that day after day so many of your clients are dying, especially when the clients are community members and probably friends. Supervisors should encourage the health

workers to confide in trusted counselors and take breaks from work if possible.

Health workers who have many PLWHAs in their care should also be encouraged to organize peer support groups. Such groups will provide a forum where the health workers can meet, share their problems and solutions, and support each other.

9.13 WHEN THE PERSON IS DYING

Eventually, the person with AIDS is no longer chronically ill. The person is dying. When this change occurs, it is sometimes hard for the person and for the family to accept. A different kind of care is needed now. This care can be provided either in hospital or at home. In both places, the family is very important when a person is dying.

What to Teach the Person and the Family

- Keep the person as comfortable as possible:
 - For pain, provide pain medication at regular times
 - Help the person relax: for example, give back rubs and body massages, serve tea
 - Keep the person clean and dry
- Help the person to be as independent as possible:
 - Accept decisions such as refusing to eat or get up
 - Respect requests such as having or not having certain visitors
- Allow the person to grieve for the losses that are being experienced.
- Let the person talk about how they feel.
- Accept the person's feelings: for example, anger or sorrow.

10. The Final Phase

At some point there is nothing more that can be done for a person with AIDS. You may know this time has come when:

- The body starts to fail—the patient may lose consciousness, stop eating, breathe very slowly or very fast and unevenly, stop passing urine or stool, or lose control of urine and stool.
- Medical treatment is no longer effective or is not available.
- The person says they are ready to die.

10.1 CARE OF PLWHA IN THE TERMINAL STAGE

If the sick person wants to remain at home, you can assist the caregiver to help them to die with dignity:

- By giving comfort
- By having family and friends close by (especially the people they like most)
- By allowing the patient to make decisions
- By helping the patient to prepare for death

It may help to talk about death, especially fears or worries for the family's future:

- It is important for the caregiver not to act as if the patient is dying or act too despairingly.
- The caregiver can assure the patient that they will do what is possible to prevent/relieve pain and discomfort.
- Caregivers can also discuss with the patient about the funeral arrangements if desired.

It is also helpful to

- Keep the place around the patient clean and pleasant to live in.
- Encourage the patient spiritually, e.g., read the spiritual books, pray with and for the patient.

10.2 CARE OF THE BODY OF SOMEONE WHO HAS DIED OF AIDS

It is important to always remember that the AIDS virus can live up to 24 hours in a person's body after death. During that time, take the same precautions with the body as you did when the person was alive.

Objectives

- To prepare the body of someone who has died of AIDS for burial while preventing spread of HIV infection.

Requirements

- Basin
- Soap and water
- Plastic bags/gloves to protect your hands
- Wrapping cloths or clean clothes, according to cultural norms

Steps to Follow

Step 1: Preparing the body

- As soon as the person has died:
 - Provide privacy according to the resources available
 - Limit the number of people treating the body
 - Bring all required materials near the bed
 - Put on plastic bags/gloves; ensure you avoid direct contact with fluids from the body
 - Support the eyelids to close properly
 - Wipe away any materials in the mouth, e.g., saliva
 - Support the closed mouth with a bandage/piece of cloth made like a bandage
 - Pack the nostrils with some cotton swabs/small pieces of cloth
- Clean the body.
- Remove the dirty linen/bedsheets/cloth from the bed.
- Dress the body (as required by the culture).
- Straighten the body, hands, and feet.
- Cover/tie the body in a clean cloth/sheet.
- Keep the body covered ready for burial.

Step 2: Clearing the room and materials used

- Clear away the materials used for caring for the patient.
- Dispose properly of those items that have to be thrown away.
- Rearrange the room to ensure it is orderly.
- Remove plastic bags and wash hands with soap and water.

Step 3: Demonstrating a caring attitude

- Keep talking in a caring manner to the relatives to comfort them.
- Arrange to inform other persons concerned, e.g., the village leadership and health workers.

1. Nursing Care

Nursing care described here includes various aspects of personal hygiene such as bathing and nail care for the patient. It also includes attention to pressure areas, treatment of pressure and other sores, and how to handle body fluids. The chapter presents in detail the objectives of each aspect of nursing care, the materials and resources required, and the steps to follow.

The instructions represent the "ideal" situation. Caregivers should be aware that they can improvise as needed with the resources at hand. The important thing for caregivers to remember is to try to ensure that they do not compromise the health of the person living with HIV/AIDS or their own personal safety.

1.1 BED BATH

Objectives

- To ensure personal cleanliness of the PLWHA.
- To refresh and contribute to the well-being of the PLWHA.

Requirements and Resources for Bed Bath

- Plastic/polythene bags to use as gloves
- Plastic/polythene paper
- Large basin
- Face cloths
- Water (keep a supply of hot water to warm the bath as you proceed)
- Two bath towels/clean cloths
- Soap
- Container for soiled bedding
- Toothbrush, toothsticks, toothpaste (mouth wash if possible)
- Scissors/razor blade
- Comb
- Chair
- Clean linen, pyjamas, as necessary

Steps to Follow

For a person who is conscious and able to move minimally

Step 1: Preparing the resources, patient, and yourself for bed bath

- Gather all the equipment/requirements needed and bring to easy reach for yourself or patient.
- Prepare yourself for bed bath so that you do not interrupt the procedure, e.g., empty your bladder. Explain to other family members that you are starting the procedure. Wash your hands, put on gloves if necessary.
- Prepare the patient by explaining the procedure.
- Explain the role you want the patient to play, e.g., moving in a certain way, etc.
- Close the windows/draw the curtains and close the door to provide privacy.

Step 2: Bathing the patient

- Strip the bed and cover the patient with a sheet or other suitable cloth. Expose only the areas you want to wash at a time. (If the bedding is soiled follow the steps for handling soiled bedding, Section 2.3)
- Help the patient into a suitable position.
- Protect the bed with a plastic sheet.
- Place a basin of warm water on the stool/table; be sure the patient can reach toilet articles.
- Permit the patient to bathe self as far as condition allows, even leaving the room for a short time if patient is able to manage alone.
- When the patient has finished to the extent possible, return, change the water and complete the bath by:
 - Washing the patient's back
 - Attending to the patient's feet
 - Taking care of pressure areas (see Section 1.6)
 - Cutting finger and toe nails (see Section 1.3)
 - Helping patient into clean clothes and making bed
- Offer a comb or brush, shaving supplies. Help as required.
- Leave patient in comfortable position.

Step 3: Clearing the materials/items used

- Remove all the things you were using to bathe the patient.
- Dry the area where you were working (if necessary).

- Pour away the water used for bathing.
- Wash and hang to dry any pieces of cloth/towel used during the bath.
- Put soap and other items away for the next use.
- Remove plastic bags/gloves, wash and dry your hands.

For a person who is unconscious or too weak to move

Step 1: Preparing the resources, patient, and yourself for bed bath

- Gather all the equipment/requirements needed and bring into easy reach for yourself.
- Prepare yourself for bed bath so that you do not interrupt the procedure, e.g., empty your bladder. Explain to other family members that you are starting the procedure. Wash your hands, put on gloves if necessary.
- Prepare the patient, if conscious, by explaining the procedure.
- Close the windows/draw the curtains and close the door to provide privacy.

Step 2: Bathing the patient

- Strip the bed and cover the patient with a sheet/*lesu*. (If the bedding is soiled follow the steps for handling soiled bedding, Section 2.3)
- Expose only the area you want to wash at a time.
- Put the patient into a suitable position.
- Protect the bed with plastic sheet.
- Place a basin of warm water on the stool/table; be sure you can reach toilet articles.
- Wash the patient with soapy water beginning from the face, chest, abdomen, hands, back, and legs. Dry each part thoroughly.
- Wash the private parts last.
- Treat the pressure areas at the same time as you bathe if possible (Section 1.6).
- Cut finger and toe nails (see Section 1.3).
- Dress patient in clean clothes and make bed.
- Comb or brush hair and trim the beard as required.
- Leave patient in comfortable position.

Step 3: Clearing the materials used for bed bath

- Follow the same steps as in step 3 for a person who is conscious or able to move.

WASH YOUR HANDS!

Caregivers need to get in the habit of washing their hands frequently when they care for AIDS patients. This will help prevent the spread of germs and cross infections, which can be a big problem for people whose immune system is weak.

To wash your hands most effectively, follow the procedure below.

Requirements and Resources

- A basin of water
- Another container of clean water
- Soap
- A small brush to clean fingernails
- Towel or cloth
- Lotion, hand cream, or Vaseline
- Nail clippers/razor blade/scissors

Procedure

- Wet your hands and soap them well.
- Scrub your palms together, then wash the backs of your hands thoroughly.
- Wash each finger and thumb individually.
- Use the brush to scrub your fingernails.
- Rinse your hands well by pouring water over them from the other container.
- Dry hands thoroughly. Apply lotion, cream, or Vaseline to prevent drying and cracking of the skin.
- Keep your nails trimmed short so they will be easier to keep clean.

1.2 MOUTH CARE

Objectives

- To attend to the mouth in order to: promote the flow of saliva, keep teeth clean, and maintain freshness of the mouth.

Requirements and Resources for Mouth Care

- 3 small containers (e.g., small cups)
- Toothpaste/salt water/baking soda

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GLOSSARY

Abstinence - Avoiding sexual activity altogether

AIDS - Acquired immune deficiency syndrome, a progressive, usually fatal condition (syndrome) that reduces the body's ability to fight certain infections. Caused by infection with human immunodeficiency virus (HIV).

Analgesics - Medicines for pain

Antacids - Medicines for pain in the lower chest and upper abdomen caused by too much acid in the stomach

Antibiotics - Medicines for treating infections caused by bacteria

Antidiarrheics - Medicines for diarrhea

Antitussives - Medicines for cough

Asymptomatic - Not having any symptoms, even though infected with a disease

Bacteria - Micro-organisms; some are helpful to body functions, but many cause diseases

Concept - An idea

Condom - A rubber sheath worn on an erect penis during sexual intercourse to prevent pregnancy and sexually transmitted diseases

Community-based health worker - A trained person, often a volunteer, who works within a community to teach people about health practices, provides some simple treatments, and refers sick people to clinics/medical centers for other necessary treatment

Contamination - The process of introducing harmful substances, such as germs

Counseling - Communication between two people in which one person has a problem and the other is trying to help solve the problem

Decontamination - The process of removing or destroying harmful substances such as germs

Diagnosis - A doctor's or medical practitioner's conclusion about what a sick person is actually suffering from

Diary - A book in which community-based health workers record their activities in the community

Draw sheet - A bed sheet, usually used with a waterproof pad, that is placed on the bed of an incontinent patient to protect the other bedding

Drug administration - The manner in which medicines are given to the sick

Environmental hygiene - Keeping the surroundings, houses, compound, etc., clean

General hygiene - Keeping the body and surroundings fresh and clean

Home-based care - Services given at home to people who are ill. Services to people with AIDS focus on general hygiene, nutrition, sexual behavior, support, treatment of AIDS-related conditions, and physical therapy

Immune system - The part of the body's structure and function that fights against infections

Infection - Invasion and multiplication in the body of disease-causing germs

Integrated - In this context, combining services to prevent/manage sexually transmitted infections (including HIV) with services for family planning and mother/child health care

Linen - Sheets, blankets, pillowcases, quilts, and other bedding

Massage - Treatment by rubbing/kneading parts of the body to improve circulation, muscle tone

Mode of transmission - The way a disease spreads from one person to another

Module - In this context, a specific part of a training curriculum

Mouthwash - A solution to freshen the mouth

Nutrition - Food, feeding; providing a balanced diet

Operational definition - The meaning of terms according to the way they are used in a particular curriculum, book, etc.

Opportunistic conditions - Infections and diseases that take advantage of HIV-weakened immune system

Oral rehydration salts - Medicines given to people having diarrhea and/or vomiting to replace the lost water and salts

Peer assessment - Evaluation and comments about a colleague's performance or knowledge

Physical therapy - Treatment through physical means such as exercises, massage, etc.

Prescription - A written order by a doctor or health worker indicating the name(s) of medicine(s) a specific sick person should take and how they should be taken

Procedure - The specific way something is done

Quality control of training - Making sure that training is of the required standard

Referral - Sending sick person from the home or community to a health facility (hospital, health center, dispensary) or from the health facility to the community

Sedatives - Medicines given to people having problems with getting to sleep

Self-assessment - Making your own comments about an activity you have performed

Semen - Fluid containing sperms that is produced by men during sexual intercourse

Sexually transmitted infections/diseases - The term given to a group of diseases affecting both men and women and generally transmitted during sexual activity

Signs - What the health worker finds when examining a sick person

Soiled linen - Bedding having sick person's feces, urine, pus, blood, etc.

Spatula - A wooden or metal instrument used for examining the throat

Symptoms - The aches, pains, or other problems a sick person describes to a health worker

Unscreened blood - Blood that has not been tested for HIV

Virus - The smallest disease-causing organism

Vitamins - Substances found in food that are essential for the proper functioning of the body

White blood cells - The part of the blood that guards the body against disease-causing organisms

Zero grazing - Restricting your sexual activity to one sexual partner whose only partner is you



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