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Palliative Care: symptom management and end-of-life care

INTEGRATED MANAGEMENT OF ADOLESCENT AND ADULT ILLNESS

INTERIM GUIDELINES FOR FIRST-LEVEL FACILITY HEALTH WORKERS

June 2004

World Health Organization

TREAT 3 million by 5 2005

Palliative care includes symptom management during both acute and chronic illness and end-of-life (terminal) care.

This module provides guidelines to prepare health workers to provide palliative care treatment and advice in clinic and to back up community caregivers and family members who need to provide home-based palliative care.

For each symptom, the **guidelines for the health worker include both a summary of non-pharmaceutical recommendations for home care and the clinical management and medications** which the health worker might also provide, based on a limited essential drug list on the last page of this module. Alternative or additional drugs can be added during country adaptation.

The home care advice also appears in a Caregiver Booklet which is illustrated. Health workers should use it to prepare families and community-caregivers to care for patients at home. This needs to be locally adapted.

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INTERIM GUIDELINES FOR FIRST-LEVEL FACILITY HEALTH WORKERS IN LOW-RESOURCE SETTINGS

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This is one of 4 IMAI modules relevant for HIV care:

These modules include:

1. **Acute Care** (including opportunistic infections, when to suspect and test for HIV, prevention).
2. **Chronic HIV Care** with ARV Therapy.
3. **General Principles of Good Chronic Care**.
4. **Palliative Care:** Symptom Management and End-of-Life Care.

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How to Use the IMAI Palliative Care Module

The IMAI ***Palliative Care*** module cross-references guidelines in the IMAI ***Acute Care*** and the ***HIV Care*** modules.

For acute problems, first use the ***Acute Care*** module.

If emergency signs are present, use the ***Quick Check*** and ***Emergency Treatment*** module.

When providing care, both specific treatment for the illness and treatment to relieve symptoms are needed. **Often you will use this module as part of a treatment plan for a specific condition; the indications for antimicrobials and other specific treatments are in the *Acute Care* module.** If new signs and symptoms, use the *Acute Care* module or other guidelines to assess, classify the illness, and provide specific treatment. You need to decide whether home care advice is sufficient or if it is necessary to also prescribe medication.

The response to pain and other symptoms is included in this module.

Nurses or other first level facility health workers will usually need to consult with medical doctors, medical officer or specialist palliative care nurses for:

- morphine prescription
- decision that the patient is terminal
- use of steroids in end-of-life care

Patients on treatment for tuberculosis should continue treatment to prevent spread to others and for their own well-being—use the Tuberculosis guidelines. Caregivers may also be TB treatment supporters for Directly Observed Treatment.

Sputums should be sent from any patient with a new, productive cough more than 2 weeks.

instructions

Assess the Patient, Give Specific Treatment and Manage Symptoms

When providing care, both specific treatment for the illness and treatment for symptoms are needed. For all palliative care, consult with the patient, explain the options, and involve the patient in choice of management where possible. Use the General Principles of Good Chronic Care.

This Palliative Care module and the Caregiver Booklet address this

Assess patient:	**Give specific treatment based on classifications:** (use IMAI *Acute Care* module to assess, classify, identify specific treatments, treat and advise/counsel) for emergency signs	**Manage symptoms:** home care and clinical/medication management
1. Quick check		
Includes airway and breathing, circulation, chest pain, severe abdominal pain, neck pain or severe headache, fever from life-threatening cause.	• If emergency signs, give emergency treatments • Acute pain management	Acute pain
2. Check in all patients:		
Cough or difficult breathing	• Pneumonia (antibiotics) • Severe pneumonia or other severe disease (antibiotics plus referral) • Suspect TB—send sputums • Possible chronic lung disease • Cough or cold/bronchitis • Wheezing (bronchodilators)	• Bothersome cough **P31-33** • Excessive sputum • Dyspnoea
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▶ Teach the patient and family how to give good palliative care at home according to the symptoms

- Give home care interventions which will relieve the patient's symptoms, using the Caregiver Booklet.
- Give pain medications (P13-15) and other medications.
- Use other methods for pain control (P16).
- Give information and teach skills.
- Use the Caregiver Booklet to educate the patient, family and community caregivers.

  The content of columns entitled Home Care on pages P20 to P32 is from the Caregiver Booklet. This booklet also has illustrations.

❖ **Record medications with instructions**

- Use a separate sheet of paper with the name of each medication, what it is for, and the dose.

❖ **Leave the patient as much in charge of his or her own care as possible**

- Support the patient to give as much self-care as possible.
- Discuss with the patient who should provide hands-on care.

Examples of non-medical treatment for pain, in addition to analgesics and special pain medications (adapt locally):

- Support and counselling.
  - Psychological, spiritual and emotional support and counselling should accompany pain medications. Pain can be harder to bear when there is guilt, fear of dying, loneliness, anxiety, depression.
- Answering questions and explaining what is happening is important to relieve fear and anxiety.
- Deep breathing and relaxation techniques unless the patient is psychotic or severely depressed.
- Distraction, music, imagining a calm scene.

instructions

How to Use the Caregiver Booklet: the 5A's

ASSESS

- Assess patient's status, and identify relevant treatment, advice and counselling.
- Assess patient and caregiver knowledge, concerns and skills related to his/her condition and treatment.

ADVISE

- Use the Booklet as a communication aid. You are teaching the patient, family member or community caregiver—use it as an aid to this. Do not just give the Booklet to the family or ask them to read it while you watch.
- Only explain the management of a few symptoms or a few skills at a time. Choose those that are most important for the care of the patient now.
- Explain prevention to all.
- Demonstrate skills such as the correct method for range of motion or how to draw up the exact dose of a liquid medicine such as morphine into the syringe.
- Ask if they have questions or will have problems giving the care at home. Ask them to demonstrate the skill or ask a good checking question.

AGREE

- After giving information and teaching skills, make sure that they know what to do and that they want to do it. Empower them to stay in charge.
- Support patient self-management and family care.

ASSIST

- Make sure they have the supplies required for care.
- Encourage them to refer back to the booklet. If they are not literate, they can ask someone to read it to them.

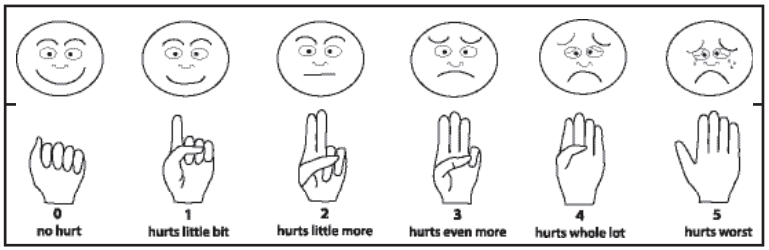
ARRANGE

- Ask them to return, or to ask an experienced caregiver in the community, if they have questions or are confused or concerned about how to give the care.
- Make sure they know when and who to call for help. Let them know how you can provide backup to their home care.

Management of Pain

▶ Assess the patient for pain (in all patients)

- **Determine the cause of the pain by history and examination (for new pain and any change in pain).**
  - Where is the pain? What makes it better/worse? Describe it. What type of pain is it? What are you taking now for the pain?
  - Use the *Acute Care* guidelines to determine if there is an infection or other problem with specific treatment. Prompt diagnosis and treatment of infection is important for pain control.
- **Determine the type of pain—is it common pain (such as bone or mouth pain) or special pains (such as shooting nerve pain, zoster, colic or muscle spasms)?**



- **Is there a psychological or spiritual component?**
- **Grade the pain with the FACES (especially in children) or with your hand (with 0 being no pain, 1 finger very mild pain and 5 fingers the worst possible pain). Record your findings.**

▶ Treat pain, according to whether it is a common or a special pain problem or both:

- With analgesics, according to the analgesic ladder (P12-13).
- With medications to control special pain problems, as appropriate (P15). Explain reason for treatment and side effects; always take into account patient preference.
- With non-medical treatments (P16).

Reassess need for pain medication and other interventions frequently. Repeat grading of the pain. Investigate any new problems with the *Acute Care* guidelines.

Treat Chronic Pain

❖ **By mouth**

- If possible, give by mouth (rectal is an alternative—avoid intramuscular).

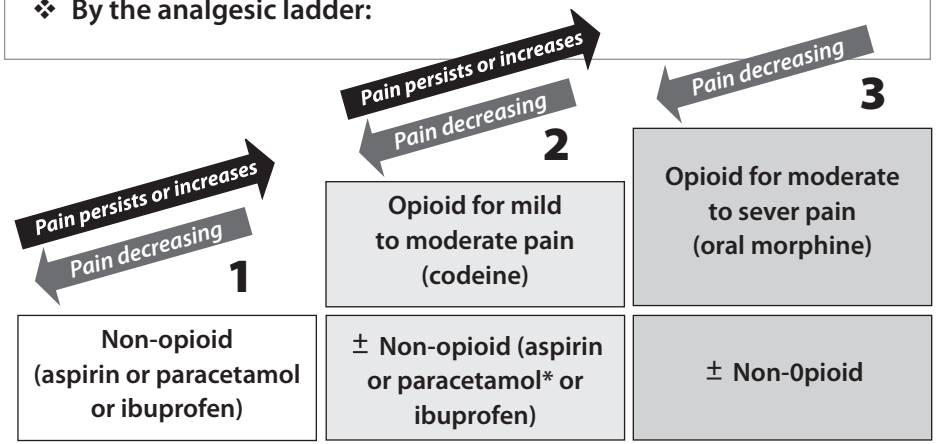
❖ **By the clock**

- Give pain killers at fixed time intervals (by clock or radio or sun).
- Start with small dose, then titrate dose against patient's pain, until the patient is comfortable.
- Next dose should happen **before** effect of previous dose wears off.
- For breakthrough pain, give an extra "rescue" dose (same dosing of the 4-hourly dose) in addition to the regular schedule.

❖ **By the individual**

- Link first and last dose with waking and sleeping times.
- Write out drug regimen in full or present in a drawing.
- Teach its use (P17).
- Check to be sure patient **and** family or assistant at home understand it.
- Ensure that pain does not return and patient is as alert as possible.

❖ **By the analgesic ladder:**



Other therapies helpful for pain can be combined with these drugs. See page P9. Also give medications to control special pain problems—see next page.

▶ Use of opioids and non-opioid analgesics

❖ **Give only one drug from the opioid and non-opioid group at a time:***

**Exception: If no codeine, aspirin every 4 hours can be combined with paracetamol every 4 hours—overlap so one is given every 2 hours.*

	Analgesics	Starting dose in adults	Range	Side effects/ cautions
STEP 1	**Non-opioid**			
	paracetamol (also lowers fever).	500 mg 2 tablets every 4 to 6 hours (skip dose at night or give another analgesic to keep total to 8 tablets).	Only 1 tablet may be required in elderly or very ill or when combined with opioid. Mild pain might be controlled with every 6 hour dosing.	Do not exceed eight 500 mg tablets in 24 hours (more can cause serious liver toxicity).
	aspirin (acetylsalicylic acid) (also anti-inflammatory and lowers fever).	600 mg (2 tablets of 300 mg) every 4 hours.		Avoid use if gastric problems. Stop if epigastric pain, indigestion, black stools petechiae or bleeding. Do not give to children under 12 years. Avoid if presence of any bleeding.
	ibuprofen (also anti-inflammatory, lowers fever, for bone pain).	400 mg every 6 hours.		Max. 8 tablets per day.
STEP 2	**Opioid for mild to moderate pain** (give in addition to aspirin or paracetamol)			
	codeine (if not available, consider alternating aspirin and paracetamol*).	30 mg every 4 hours.	30-60 mg every 4 to 8 hrs. Maximum daily dose for pain 180-240 mg due to constipation—switch to morphine.	Give laxative to avoid constipation unless diarrhoea. **Cost**
STEP 3	**Opioid for moderate to severe pain**			
	oral morphine 5 mg/5 ml or 50 mg/5 ml. Drop into mouth. Can also be given rectally (by syringe).	2.5-5 mg every 4 hours (dose can be increased by 1.5 or doubled after 24 hours if pain persists).	According to need of patient and breathing. **There is NO ceiling dose.**	Give laxative to avoid constipation unless diarrhoea.

See next page

▶ Respond to side effects of morphine or other opioids

If patient has a side effect:	Then manage as follows:
• **Constipation.**	• Increase fluids and bulk. • Give stool softener (docusate) at time of prescribing plus stimulant (senna). • **Prevent by prophylaxis** (unless diarrhoea).
• **Nausea and/or vomiting.**	Give an antiemetic (metoclopromide, haloperidol or chlorpromazine). Usually resolves in several days. May need round-the-clock dosing.
• **Respiratory depression (rare when oral morphine is increased step by step for pain).**	If severe, consider withholding next opioid dose, then halve dose.
• **Confusion or drowsiness (if due to opioid).** • **Decreased alertness.** • **Trouble with decisions.**	Usually occurs at start of treatment or dose is increased. Usually resolves within few days. Can occur at end of life with renal failure. Halve dose or increase time between doses. Or provide time with less analgesia when patient wants to be more fully alert to make decisions.
• **Twitching (myoclonus—if severe or bothers patient during waking hours).**	If on high dose, consider reducing dose or changing opioids (consult or refer). Re-assess the pain and its treatment.
• **Somnolence (excessively sleepy).**	Extended sleep can be from exhaustion due to pain. If persists more than 2 days after starting, reduce the dose by half.
• **Itching.**	May occur with normal dose. If present for more than a few days and hard to tolerate, give chlorpheniramine.
• **Urinary retention.**	Pass urinary catheter if trained—in and out since it usually does not recur.

Reduce morphine when cause of pain is controlled (common in HIV/AIDS complications):

- If used only for a short time: stop or rapidly reduce.
- If used for weeks—reduce gradually to avoid withdrawal symptoms.

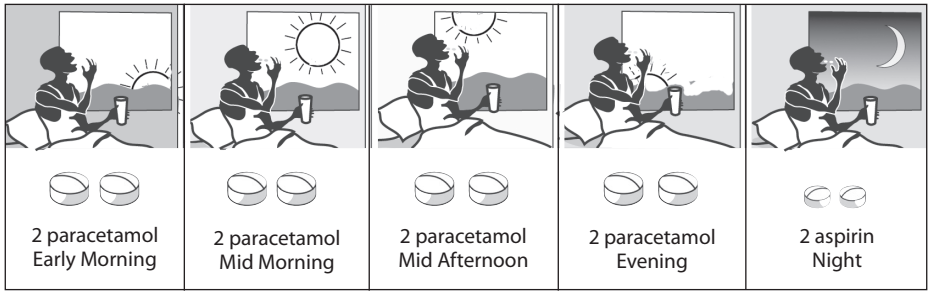
▶ Give medications to control special pain problems

There are nerve injury pains and pains from special conditions which can be relieved by specific medication. **Provide specific treatment in combination with drugs from analgesic ladder.** Also see ***Acute Care*** and ***Chronic HIV Care*** modules and analgesia.

Special pain problem	Medication—adolescent/adult (see P42 for children)
For burning pains; abnormal sensation pains; severe, shooting pains with relatively little pain in between; pins and needles.	Low dose **amitriptyline** (25 mg at night or 12.5 mg twice daily; some start 12.5 mg daily)—wait 2 weeks for response, then increase gradually to 50 mg at night or 25 mg twice daily.
For muscle spasms in end-of-life care or paralyzed patient.	**diazepam** 5 mg orally or rectally 2 to 3 times per day.
• **Herpes zoster (or the shooting pain following it).** • **Refer patients with ophthalmic zoster.**	• Low dose **amitriptyline.** • Early eruption: aciclovir if available; apply gentian violet if ruptured vesicles. • Other locally available remedies:_____ _____ (such as fresh liquid from frangipani tree. (Do not get in the eyes. Apply every 8 hours, if intact vesicles or after healing.) • Late zoster pain: _____ (insert locally available remedies such as capsicum cream).
Gastrointestinal pain from colic only after exclusion of intestinal obstruction (vomiting, no stool and gas passing, visible bowel movements).	**codeine** 30 mg every 4 hours or **hyoscine** (Buscopan®) 10 mg three times daily (can increase up to 40 mg three times daily).
Bone pain or renal colic or dysmenorrhoea.	**ibuprofen** (or other NSAID).
If pain from: • **Swelling around tumour.** • **Severe esophageal ulceration and cannot swallow.** • **Nerve or spinal cord compression.** • **Persistent severe headache (likely from increased intracranial pressure).**	When giving end-of-life care and referral not desired, see P42 for careful steroids use under clinical supervision.

▶ Teach patient and family how to give pain medications—this applies to all pain medications

- Explain frequency and importance of giving regularly—do not wait for the pain to return. The next dose should be given before the previous dose wears off—usually ever 4 hours.
- The aim of pain treatment is that the pain will not come back and the patient is as alert as possible.
- Write out instructions clearly:



▶ Advise family on additional methods for pain control

Combine these with pain medications if patient agrees and it helps (for local adaptation):

❖ **Emotional support.**

❖ **Physical methods:**

- Touch (stroking, massage, rocking, vibration).
- Ice or heat.
- Deep breathing (see instructions).

❖ **Cognitive methods:**

- Distraction such as radio.
- Music.
- Imagine a pleasant scene.

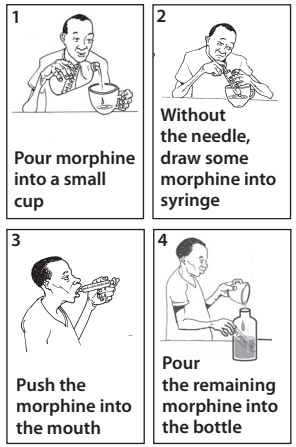
❖ **Prayer (respect patient's practice).**

❖ **Traditional practices which are helpful and not harmful—get to know what can help in the local setting.**

▶ Teach family to give oral morphine

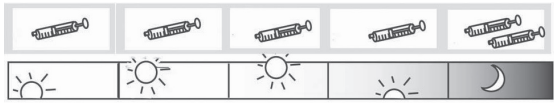
Oral morphine is a strong pain killer. It should be given:

- By the sick person, by the mouth and by the clock (regularly by the sun/moon, or radio, approximately every 4 hours).



❖ **You should advise to:**

- Pour a small amount of the morphine liquid into a cup.
- Draw up your dose into a syringe.
- Then drop liquid from the syringe into mouth.
- Do not use a needle.
- Pour the remaining morphine back into the bottle.
- Take doses regularly, every 4 hours during the day with a double dose at bedtime.



- Give an extra dose if pain comes back before next dose is due.
- Do not stop morphine suddenly.

❖ **Help them manage side effects:**

- **nausea**—this usually goes away after a few days of morphine and does not usually come again.
- **constipation**—see page on constipation (P25).
- **dry mouth**—give sips of water.
- **drowsiness**—this usually goes away after a few days of morphine; if it persists or gets worse, halve the dose and inform the health worker.
- **sweating or muscle jerks**—tell the health worker.

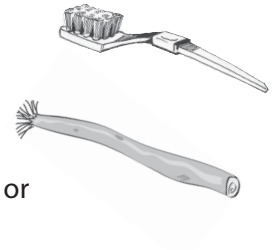
❖ **If the pain is:**

- getting worse, inform the health worker as the dose may be increased.
- getting better, the dose may be reduced by half. Inform the health worker but do not stop the drug suddenly.

NOTES:

Preventive Interventions for All Patients

▶ Preventive oral care for all patients



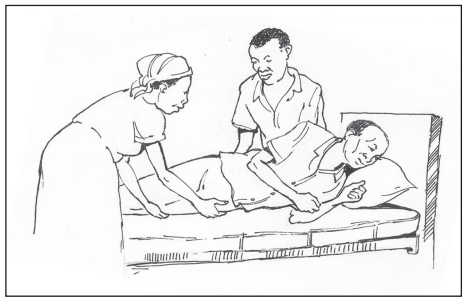
❖ **Instruct all patients in oral care.**

- Use soft toothbrush to gently brush teeth, tongue, palate and gums to remove debris.
- Use diluted sodium bicarbonate (baking soda) or toothpaste.
- Rinse mouth with diluted salt water after eating and at bedtime (usually 3-4 times daily).

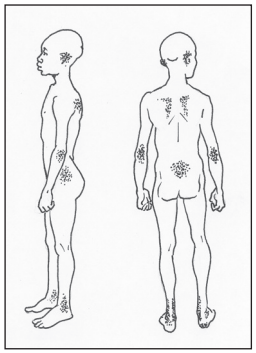
▶ Prevent bedsores in all bedridden patients

❖ **Remember that prevention of bedsores is better than cure, therefore:**

- Help the bedridden patient to sit out in a chair from time to time if possible.
- Lift the sick person up the bed—do not drag as it breaks the skin.
- Encourage the sick person to move his or her body in bed if able.



- Change the sick person's position on the bed often, if possible every one or two hours—use pillows or cushions to keep the position.
- Keep the beddings clean and dry.
- Look for damaged skin (change of colour) on the back, shoulders and hips every day.
- Put extra soft material such as a soft cotton towel under the sick person.



▶ Instructions for bathing

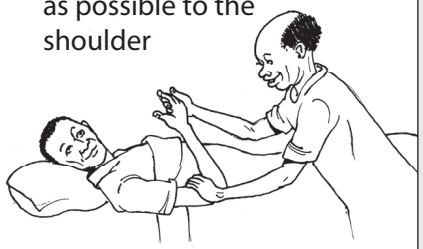
- Provide privacy during bathing.
- Dry the skin after bath gently with a soft towel.
- Oil the skin with cream, body oil, lanolin or vegetable oil.
- Use plastic sheets under the bed sheets to keep the bed dry when one cannot control urine or faeces.
- Massage the back and hips, elbows, ankles with petroleum jelly.
- If there is leakage of urine or stool, protect skin with petroleum jelly applied around private parts, back, hips, ankles and elbows.
- Support the sick person over the container when passing urine or stool, so as to avoid wetting the bed and injury.

▶ To prevent pain, stiffness and contractures in muscles and joints

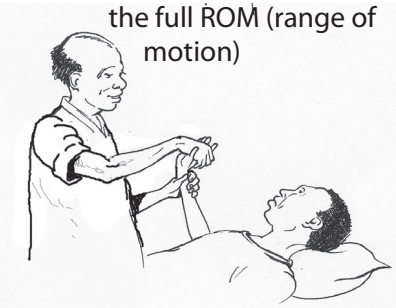
Medication/clinical	Home care
• Check range of motion (ROM)—move limbs gently. • Give diazepam if spasms or very spastic. • Check ROM in the key 7 joints on both sides: **wrist** **knee** **elbow** **ankle** **shoulder** **hip** **neck**	• Encourage mobilization. • If patient is immobile, do simple range of motion exercises: - Exercise limbs and joints at least twice daily—use booklet to show caregiver how to do ROM on each of the key 7 joints (on both sides). - Protect the joint by holding the limb above and below it and support as much as you can. - Bend, straighten, and move joints as far as they normally go; be gentle and move slowly without causing pain. - Stretch joints by holding as before but with firm steady pressure. - Let the patient do it as far as they can and help the rest of the way. - Massage.

Exercises to Help Prevent Pain Stiffness and Contractures

Exercise the elbow by gently bringing the hand as close as possible to the shoulder

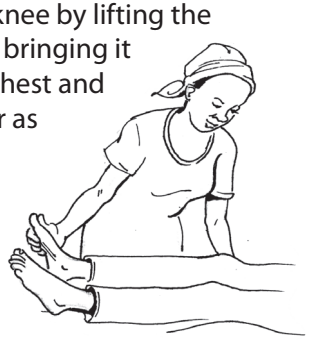


Exercise the wrist doing the full ROM (range of motion)



Exercise the shoulder by lifting the arm up and bringing it behind the head and laterally as far as possible

Exercise the knee by lifting the thigh up and bringing it close to the chest and laterally as far as possible

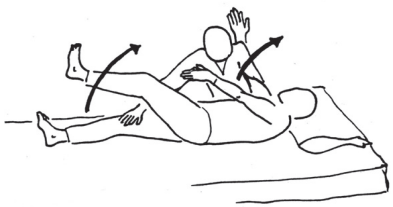


Moving the Bedridden Patient

The following instructions are for a single caregiver. If the patient is unconscious or unable to cooperate, it is better to have two people help with moving.

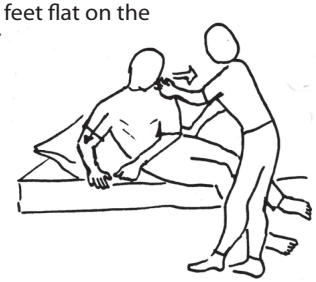
❖ **When transferring from the bed to a chair :**

1. Roll the patient on one side



2. Move the patient to the side of the bed. Ask the patient to bend legs and to prop on the same side elbow

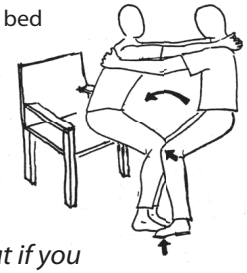
3. Hold your hands on the patient's pelvis, ask to raise him/her buttocks. Sit patient on the edge of the bed with feet flat on the floor



4. Stand in front of the patient and hold both shoulders. Keep patients feet flat on the floor

5. Help patient raise bottom from the bed and rotate him/her towards the chair

6. Transfer from bed to chair. Hold patient by shoulders and knees



Remember that if you lose your balance, it is better to help the patient fall gently rather than hurting yourself.

Manage Key Symptoms

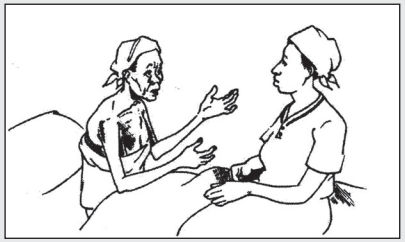
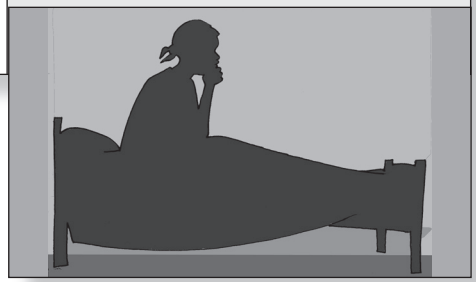
Medication/ clinical	Home care
Treat weight loss	
❖ Treat nausea and vomiting as below. ❖ Treat diarrhoea (see *Acute Care* module). ❖ Treat thrush or mouth ulcers. ❖ Exclude other causes of weight loss as TB. ❖ If end-of-life care, prednisone 5-15 mg daily in the morning can stimulate appetite; stop if no effect after 2 weeks.	❖ Encourage the sick person to eat, but do not use force as the body may not be able to accept it and he or she may vomit. ❖ Offer smaller meals frequently of what the sick person likes. ❖ Let the sick person choose the foods he or she wants to eat from what is available. ❖ Accept that intake will reduce as patient gets sicker and during end-of-life care. *Seek help from trained health worker if you notice rapid weight loss or if the sick person consistently refuses to eat any food or is not able to swallow.*
Control nausea and vomiting	
❖ Give antiemetic: metoclopromide (10 mg every 8 hours). Give only for a day at a time or haloperidol (1-2 mg once daily) or chlorpromazine (25-50mg every 6-12 hours). 	❖ If the sick persons feels like vomiting: • Seek locally available foods which patient likes (tastes may change with illness) and which cause less nausea. • Frequently offer small foods such as roasted potatoes, cassava or _____. • Offer the drinks the sick person likes, such as water, juice or tea; ginger drinks can help. • Take drinks slowly and more frequently. • Avoid cooking close to the sick person. • Use effective and safe local remedies (example: licking ash from wood)_____. *Seek help from trained health worker for vomiting more than one day, or dry tongue, or passing little urine or abdominal pain.*

Medication/clinical	Home care
If painful mouth ulcers or pain on swallowing	
❖ If candida: give fluconazole, nystatin or miconazole gum patch (see *Acute Care* guidelines). ❖ Topical anesthetics can provide some relief. ❖ Pain medication may be required according to analgesic ladder (P11). ❖ For aphthous ulcers: crush one 5 mg prednisone tablet and apply a few grains. ❖ Smelly mouth from oral cancer or other lesions: metronidazole or tetracycline mouthwash (crush 2 tablets in juice and rinse in mouth). ❖ For herpes simplex: 5 ml nystatin solution (500,000 U) + 2 tablets metronidazole + 1 capsule aciclovir (if available)—paint on lesions. ❖ If severe and no response, refer. See P19 for preventive oral care for all patients. 	❖ Remove bits of food stuck in the mouth with cotton wool, gauze or soft cloth soaked in salt water. ❖ Rinse the mouth with diluted salt water (a finger pinch of salt or 1/2 teaspoon sodium bicarbonate in a glass of water) after eating and at bedtime.  ❖ Mix 2 tablets of aspirin in water and rinse the mouth up to 4 times a day. **Diet** ❖ Soft diet to decrease discomfort such as yoghurt or_____, depending on what the sick person feels is helpful. ❖ More textured foods and fluids may be swallowed more easily than fluids. ❖ Avoid extremely hot or cold or spicy foods. *Seek help from health worker for persistent sores, smelly mouth, white patches, or difficult swallowing.*

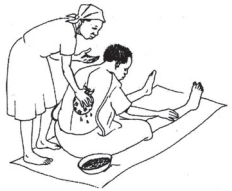
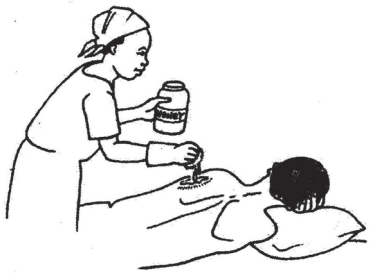
Medication/clinical	Home care
Treat dry mouth	
❖ Review medications—dry mouth can be a side effect (hyoscine, morphine, atropine, amitriptyline, furosemide). ❖ Breathing through mouth can also contribute. ❖ If persistent problem with lack of saliva, play close attention to preventive oral care/mouth hygiene, see P19. ❖ If candida, treat as above.	❖ Frequent sips of drinks. ❖ Moisten his or her mouth regularly with water. ❖ Let the sick person suck on fruits such as pineapple, oranges or passion fruit.  *Seek help from health worker if dry mouth persists.*
Prevent/treat constipation	
Ask patient about normal bowel habits If stool is less frequent or more painful to pass then: ❖ Do rectal exam for impaction. ❖ Give laxative. Options: - bisacodyl 5-15 mg at night, depending on response - senna—start at 2 tablets (7.5 mg) twice daily (up to 2 tablets every 4 hours) ❖ If not available, use: - dried paw paw seeds (5-30 chewed at night) Always give laxative with morphine or codeine.	❖ Offer drinks often. ❖ Encourage any fruits, vegetables, porridge, locally available high-fiber foods_____. ❖ Use local herbal treatment—crush some dried paw paw seeds and mix half a teaspoon full of water and give to the sick person to drink. ❖ Take a tablespoon of vegetable oil before breakfast. ❖ If impacted, gently put petroleum jelly or soapy solution into the rectum. If the patient cannot do it, the caregiver can help—always use hand gloves. *Seek help from a trained worker if pain or no stool is passed in 5 days.*

Medication/clinical	Home care
Incontinence of urine	
❖Boys/men—plastic drink bottle over the penis. Use care to avoid priapism. ❖Girls/women—cotton cloth pads (make from old clothes; wash and dry between use) and plastic pants.	❖Regular changing of cloth pads. ❖Keep patient dry. ❖Protect skin with petroleum jelly.
If vaginal discharge from cervical cancer	
❖If bad smelly discharge, insert metronidazole tablet as pessary or crush tablet and apply powder.	❖Sit in basin of water with pinch of salt. If this is comfortable, do twice daily.
Incontinence of stool	
❖Assess for fecal impaction. ❖If paraplegia, keep patient clean.	❖Use cotton cloth pads and plastic pants. ❖Keep patient clean—change cloth pads as needed.
Rectal tenderness	
❖**If local rectal tenderness**—suggest petroleum jelly or local anesthetic ointment. ❖**If incontinent**—use petroleum jelly to protect perianal skin.	❖**Special care for the rectal area** After the sick person has passed stool. • clean with toilet/soft tissue paper • wash the rectal area when necessary with soap and water • apply petroleum jelly around the rectal area ❖**Sit in basin of water with pinch of salt.** If this is comfortable do twice daily.

Medication/clinical	Home care
Manage diarrhoea	
❖ Manage as in *Acute Care* module (check for dehydration, blood in stool, persistent diarrhoea). **To prevent dehydration:** ❖ Drink extra fluids frequently—see plan A for adults (*Acute Care* module). ❖ Use ORS if large volume diarrhoea or persistent diarrhoea. ❖ Advise to continue eating. ❖ Give constipating drug unless blood in stool or fever or child less than 5 or elderly: - oral morphine 2.5–5 mg every 4 hours (if severe). - codeine 10 mg 3 times daily (up to 60 mg every 4 hours) or - loperamide 4 mg once, then 2mg per loose stool to maximum 16 mg/day.	❖ **Increase fluid intake:** - Encourage to drink plenty of fluids to replace lost water. - Give the sick person drinks frequently in small amounts, such as rice soup, porridge, water (with food), other soups, or oral rehydration solution (ORS) but avoid sweet drinks. ❖ **Continue eating.** ❖ **When to return:** *Seek help from health worker if:* • *Vomiting with fever.* • *Blood in the stool.* • *Diarrhoea continues more than 5 days.* • *If patient becomes even weaker.* • *If broken skin around the rectal area.*
Manage persistent diarrhoea	
See *HIV Chronic Care* module for management of persistent diarrhoea. 	❖ For persistent diarrhoea, suggest supportive diet. * • Carrot soup helps to replace vitamins and minerals. Carrot soup contains pectin. It soothes the bowels and stimulates the appetite. • Foods that may help reduce diarrhoea are rice and potatoes. • Eat bananas and tomatoes (for their potassium). • Eat 5-6 small meals rather than 3 large ones. • Add nutmeg to food. • **Avoid:** - coffee, strong tea, and alcohol. - raw foods, cold foods, high-fibre foods, food containing much fat. - test benefit of avoiding milk and cheese (yogurt is better tolerated). ** These recommendations require local adaptation.*

Medication/clinical	Home care
Help with anxiety and agitation	**Help with worries**
❖ See *Acute Care* module if new problem. Consider cognitive impairment. What is the cause? ❖ Make sure patient has good care and psychosocial support. ❖ Listen carefully and provide emotional support. ❖ Although rarely required, low dose diazepam (2.5-5 mg at night or twice daily) can be used if necessary, not for more than 2 weeks. Usually not needed if care is good. ❖ For severe anxiety/agitation/ delirium—give haloperidol (see *Quick Check* module).	❖ Take time to listen to the sick person. ❖ Discuss the problem in confidence. ❖ Providing soft music or massaging may help the sick person to relax. ❖ Pray together if requested. 
If trouble sleeping	
❖ Discuss problem with patient. ❖ Consider: uncontrolled pain, UTI, anxiety, depression, drug withdrawal (alcohol, diazepam, phenobarbitol). ❖ If patient is getting up to urinate at night, give amitriptyline at night (12.5 to 25 mg). ❖ A drink of alcohol can help (more can disturb sleep).	❖ Listen to the sick person's fears that may be keeping them awake; answer their fears. ❖ Reduce noise where possible. ❖ Do not give the sick person strong tea or coffee late in the evening. ❖ Treat pain if present. 

Medication/clinical	Home care
Care for patient with confusion (dementia or delirium)	
❖ See *Acute Care* module if this is a new problem—try to determine cause and whether it can be reversed (Remember that oral morphine can cause confusion in the first 5 days but this usually improves.) ❖ Explain to the family if it is delirium (acute problem) which may improve or dementia (chronic problem) which progressively worsens. ❖ If paranoia or getting up at night purposefully: haloperidol 5-10 mg (2.5 mg in the elderly). 	❖ Patients with confusion will show the following signs: - forgetful - lacks concentration - trouble speaking or thinking - frequently changing mood - non acceptable behavior such as going naked and using bad language **What to do:** ❖ As far as possible, keep in a familiar environment. ❖ Keep things in the same place—easy to reach and see. ❖ Keep familiar time pattern to the day's activities. ❖ Remove dangerous objects. ❖ Speak in simple sentences, one person at a time. ❖ Keep other noises down (such as TV, radio). ❖ Make sure somebody they trust is present to look after the sick person and supervises the medication.
Detect and treat depression	
❖ Consider depression if abnormally sad, insomnia, loss of interest. **Consult *Acute Care* module:** • Assess and classify. • Give amitriptyline if indicated (limit the tablets to one week supply). • Assess and respond to suicide risk.	❖ Provide support. ❖ If at suicide risk, do not leave alone. Also advise caregiver to gradually take more control of medications.

Medication/clinical	Home care
Treat itching	
❖ Assess for bacterial, fungal or viral cause—if present, treat (see *Acute Care* guidelines); consider that this may be medication side effect. ❖ Local steroid creams may be useful if inflammation is present in absence of any infection (bacterial, fungal or viral). ❖ Chlorpheniramine (4 mg x2) or other antihistamine may be useful for severe itching. ❖ Consider treating for scabies if persistent itching in HIV+ patient, even if no typical lesions. ❖ If multiple skin infections, (0.05%) chlorhexidine rinse after bathing. 	**You can help the sick person get some relief by trying any of the following:** ❖ If dry skin, moisturize with aqueous cream or petroleum jelly mixed with water. ❖ Put one table spoon of vegetable oil in 5 litres of water when washing the sick person. ❖ After a bath, apply on body diluted chlorhexidine (0.05%). ❖ Rub the itchy skin with local remedies (examples: effective and safe herbs, cucumber or wet tea bags or tea leaves put in a clean piece of cloth and soaked in hot water). ❖ Use water for bathing that is at a comfortable temperature for the patient.  *Seek help from a trained health worker for painful blisters or extensive skin infection*.
Treat bedsores	
All patients need skin care to avoid pressure problems ❖ Check for signs of infection. Make sure it is not another problem—see skin pages in *Acute Care* module. ❖ For smelly tumours or ulcers, sprinkle crushed metronidazole—enough to cover the area. 	**You can do the following to soothe the pain of bedsores and quicken healing:** ❖ For small sores, clean gently with salty water and allow to dry. ❖ Apply ripe paw paw flesh to bedsores that are not deep and leave the wound open to the air. ❖ If painful, give pain killers such as paracetamol or aspirin regularly. ❖ For deep or large sores, every day clean gently with diluted salt water, fill the bedsore area with pure honey or ripe paw paw flesh and cover with a clean light dressing to encourage healing.  *Seek help from a trained health worker for any discoloured skin or bedsores getting worse.*

NOTES:

Medication/clinical

For cough or difficult breathing

Use Acute Care module first to decide if patient has pneumonia or tuberculosis.

❖ **Treat pneumonia with antibiotics. If severe**, consult or refer (if referral desired). Patients with pneumonia may seem to be close to death, then respond well to antibiotic treatment.

❖ **Send sputums for TB if cough more than 2 weeks.** Treat if positive to prevent TB transmission and for patient's comfort.

❖ **Patients on treatment for tuberculosis should continue treatment.**

❖ **Control bronchospasm:**

- Give bronchodilators by metered-dose inhaler with spacer/mask or, if available, by nebulizer. Continue until patient is not able to use them or has very shallow or laboured breathing.
- Consult to consider giving prednisone 40 mg daily for a week.

❖ **Relieve excessive sputum:**

- If cough with thick sputum, give steam inhalations.
- If more than 30 ml/day, try forced expiratory technique ("huffing") with postural drainage.

❖ **For bothersome dry cough**, give codeine 5-10 mg four times daily or, if no response, oral morphine (2.5-5 mg).

If patient is terminal* and is dying from COPD, lung cancer, HIV/AIDS lung infection or any terminal pulmonary problem (but NOT acute pneumonia that can be treated with antibiotics), **there are additional measures to relieve dyspnoea:**

❖ Give small dose oral morphine—this can reduce dyspnoea in end-of-life care. Monitor closely but do not let fears of respiratory depression prevent trying this drug.

- **For a patient not on morphine** for pain—give 2.5 mg.
- **For a patient already on morphine**—increase the dose by 25%. If this does not work, increase by another 25%.

❖ If heart failure or excess fluid with pitting edema, give furosemide 40 mg.

❖ Consult to consider giving small doses diazepam.

❖ If excess thin sputum—give hyoscine; it acts as an anticholinergic (10 mg every 8 hours).

**Always consult MD, palliative care trained RN or CO to make a decision of when a patient is terminal.*

Home care

For cough or difficult breathing

For simple cough:

Local soothing remedies such as honey and lemon or steam—plain or with Eucalyptus leaves or Neem tree oil.

❖ If the patient has a new productive cough more than 2 weeks, it may be tuberculosis. Arrange with the health worker to send 3 sputums for examination for TB.

In addition to the treatment given by health worker:

❖ Help the sick person sit in the best position.

❖ Use extra pillows or some back support.

❖ Open windows to allow in fresh air.

❖ Fan with a newspaper or clean cloth.

❖ Give patient water frequently (it loosens sputum).

Educate on most efficient use of remaining lung function:

❖ How to plan activities to accommodate breathlessness.

❖ Avoid crowding, cooking and smoking in the room of the patient.

Safe handling and disposal of sputum:

❖ Handle sputum with care to avoid spreading infection.

❖ Use a tin with ash for spitting, then cover it.

❖ Empty container in a pit latrine and wash with detergent such as JIK or OMO or clean the tin with boiled water.

Use a tin for spitting and cover

Medication/clinical	Home care
Treat fever	
❖ If new fever, consider cause and whether antimalarial and/or antibiotics is necessary (see *Acute Care* module). ❖ Give paracetamol or aspirin every 4 hours (no more than 8 tablets paracetamol in 24 hours). ❖ Make sure patient stays hydrated. 	❖ The sick person will lose a lot of water through sweating; therefore encourage him or her to frequently drink water, diluted tea, fruit juices. ❖ To cool the body temperature, wipe the body with damp cloth or give a bath. ❖ Encourage him or her to wear only light clothes. ❖ Give paracetamol, aspirin or ibuprofen to reduce fever. ❖ Treat the sick person with recommended antimalarial medicine if it is the first time in the last 2 weeks. *Seek help if fever does not improve or comes back after treatment. Also if fever is accompanied by cough, diarrhoea, severe pain, confusion, night sweats, rigors, stiff neck or unconsciousness or fever in pregnancy or after birth.*
Treat hiccups	
❖ First try manoeuvres to control: - If oral thrush, treat (see Acute Care). - If advanced cancer with distended stomach, give simethicone. ❖ If no response or recurrent: - metoclopromide (10 mg tablet, 1-2 tablets three or four times daily). OR - haloperidol (5 mg tablet: 1/4 to 1/2 tablet once to three times daily). ❖ If patient has brain tumor, try anti-epileptic medication.	**Stimulate the throat:** ❖ Quickly eat 2 heaped teaspoons sugar, or ❖ Drink cold water or eat crushed ice, or ❖ Rub with a clean cloth inside the top of the mouth (feel toward the back, where the top of the mouth is soft). **Interrupt the normal breathing:** ❖ Hold breath or breathe into paper bag—stop when you feel uncomfortable. ❖ Pull knees to chest and lean forward (compress the chest).

Special Considerations in Palliative Care

▶ For a patient with HIV/AIDS

❖ **Precautions against infection**

Reassure the caregivers that there is an extremely low risk of getting HIV/AIDS if the following precautions are taken:

Clean spills

- HIV is present in blood and body fluids—wear gloves when contacting these fluids.
- Keep wounds covered (both those of the caregiver and the person with HIV/AIDS).

Cover wounds

- There is no risk from casual household contact (no gloves needed).
  - clean up blood, feces, urine with ordinary household bleach.
  - clean cutlery, linen, bath, etc. with ordinary washing products.
- Keep clothing and sheets stained with blood, diarrhoea or other body fluids separate from other household laundry. Use a piece of plastic or paper, gloves or a big leaf to handle soiled items.

Separate stained laundry

- Don't share toothbrushes, razors, needles or other sharp instruments that pierce the skin.
- Wash your hands with soap and water after changing soiled bed sheets and clothing and after any contact with body fluids.
- Use condoms if sexual activity.
- You can bathe patient without gloves if neither caregiver or patient has wounds.

Wash your hands

❖ **Illness unpredictable**

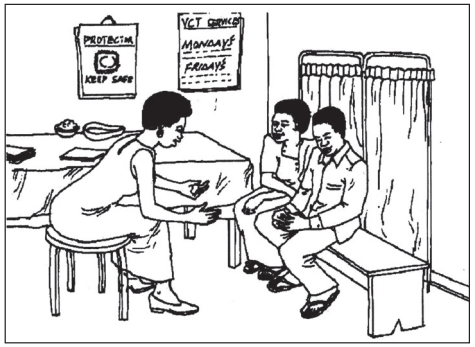
- Course of the illness can change.
- Treatment of infection can often improve the patient's condition.

❖ **Complex family issues**

- Fear in family of also being infected if their own status not known.
- Economic problems common.
- Anger, blame and regret around source of infection in family.
- Role reversals (older parents caring for young adults, young children caring for parents, grandparents caring for orphans).
- Stigma can be a serious problem.
- Shared confidentiality may be needed.

❖ **Use good palliative care as an intervention for prevention of HIV transmission**

- Deliver HIV prevention messages on each visit.
- Encourage disclosure. With good support, patients may be willing to disclose their status. Disclosure and education can help protect family and community.

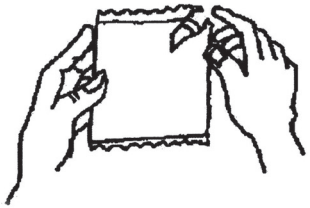


Counselling helps a couple to decide how to protect themselves against HIV infection.

▶ Sexuality in HIV/AIDS patients

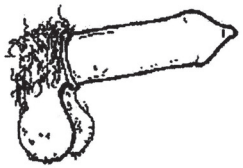
- HIV can be passed on through unprotected sex with an infected person.
- However, even when you are HIV positive, having sex is OK if you and your partner are still interested and capable.
- Always use condoms to reduce the risk of passing on or acquiring HIV, even when your partner is HIV positive.
- Discuss having sex and using condoms with your partner.
- Do not force the other person to do what they do not want to do.

Prevent HIV by Using Condoms



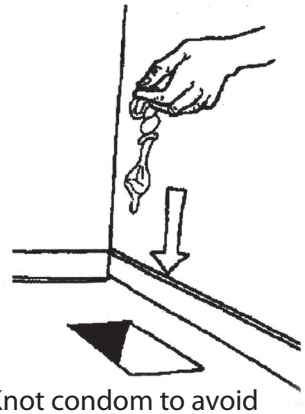
1. Open the untorn condom

2. Squeeze air from the teet of the condom



3. Roll rim of condom on erect penis

4. Hold condom and remove penis from vagina while still erect



5. Knot condom to avoid spilling sperm. Throw used condom in pit latrine or burn them

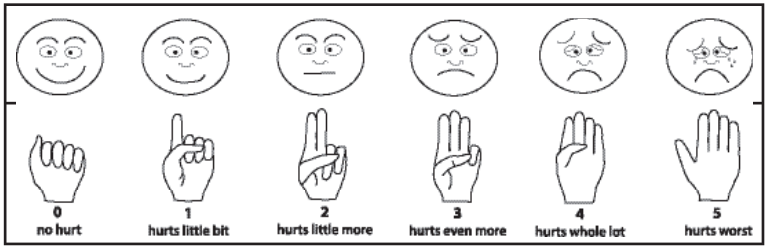
▶ **ARV therapy side effects**—the medication and home care advice in this module are applicable with the following additions:

Signs or symptons	Response:
Nausea	Take with food (except for DDI or IDV). If on zidovudine, reassure that this is common, usually self-limited. Treat symptomatically.
Headache	Give paracetamol. Assess for meningitis (see *Acute Care)*. If on zidovudine or EFV, reassure that this is common and usually self-limited. If persists more than 2 weeks, call for advice or refer.
Diarrhoea	Hydrate. Follow diarrhoea guidelines in *Acute Care* module. Reassure patient that if due to ARV, will improve in a few weeks. Follow up in 2 weeks. If not improved, call for advice or refer.
Fatigue	This commonly lasts 4 to 6 weeks especially when starting ZDV. If severe or longer than this, call for advice or refer.
Anxiety, nightmares, psychosis, depression	This may be due to efavirenz. Give at night; counsel and support (usually lasts < 3 weeks). Call for advice or refer if severe depression or suicidal or psychosis. Initial difficult time can be managed with amitriptyline at bedtime.
Blue /black nails	Reassure. It's common with zidovudine.
Rash	If on nevirapine or abacavir, assess carefully. Is it a dry or wet lesion? Call for advice. If generalized or peeling, stop drugs and refer to hospital.
Fever	Call for advice or refer. (This could be a side effect, an opportunistic or other new infection, or immune reconstitution syndrome.)
Yellow eyes (jaundice) or abdominal or flank pain	Stop drugs. Call for advice or refer. (Abdominal pain may be pancreatitis from DDI or D4T.) If jaundice or liver tenderness, send for ALT test and stop ART (nevirapine is most common cause). Call for advice or refer.
Pallor: anaemia	If possible, measure hemoglobin. Refer if severe pallor or symptoms of anaemia or very low haemoglobin (<8 grams).
Tingling, numb or painful feet/legs	If new or worse on treatment, call for advice or refer. Patient on d4T/3TC/NVP should have the d4T discontinued—substitute ZDV if no anaemia (check haemoglobin).
Cough or difficult breathing	This could be immune reconstitution syndrome. Call for advice. If on abacavir, this could be life-threatening drug reaction. (Stop drug and consult/refer.)
Changes in fat distribution	Discuss carefully with your patient—can he or she accept it?

▶ Management of children

❖ **Special considerations in assessing and controlling pain in children:**

- Children need adults to recognize and respond to their pain. They often do not complain.
  - Brief pain—crying and distressed facial expression.
  - Persistent pain—also look for behavioural signs of pain:
    -- irritability
    -- not wanting to move
    -- lack of interest
    -- decreased ability to concentrate
    -- sleeping problems
    -- changes in how the child moves
    -- restlessness
    -- increased breathing rate or heart rate
- Differentiate pain from anxiety.
- Parents may under- or over-estimate pain in their child.
- The child's judgment of pain control should be valued.
- Older child can grade pain by number of fingers or pointing on a ruler or faces (smiling or frowning):



- Never lie about painful procedures.
- Use cognitive methods to help relieve pain:
  - Age-appropriate active distraction.
  - Older child can concentrate on game, conversation or special story.
  - Music.
- Other non-drug methods:
  - Swaddling, carrying infant, warmth, breastfeeding, feeding.
  - Stroking, rocking, massage.
  - Avoid intramuscular injections in pain control.

- **Special considerations for skin care in children.**
  - ***Skin care.***
    They are prone to rashes, some of which are itchy. Clean and cover moist areas with a dressing, or expose and apply GV solution if there are not too many flies around. Keep finger nails short and clean to help reduce scratched areas from getting infected. Give an antihistamine for sleep at night if sleep is disturbed by scratching. Sometimes an oil-based cream or a short course of a weak steroid cream is helpful.
  - ***Nappy area.***
    Diarrhoea may cause a nappy rash or sores near the anus. Encourage careful washing with soap and clean water, and the application of a protective ointment (eg vaseline). Avoid the constant use of plastic pants over nappies. Change wet pants or nappies often.
- **It is essential for children to be able to play every day.**
  - Drawings, stories, games, favorite toy.
- **Encourage siblings and friends to play with child.**
- **Continue schooling where appropriate.**
- **Active listening and empathy are very important.**
  - Use language appropriate to age.
  - Get down to level of the child.
  - Show you value what they say.
- **Encourage family to be open with the child about what is happening.**
  - Involve child in decisions on care, according to age.
  - Allow children to ask questions about their health.
  - Children often know far more than we think.

Kinds of Home Care That Are Important for Chronically Ill

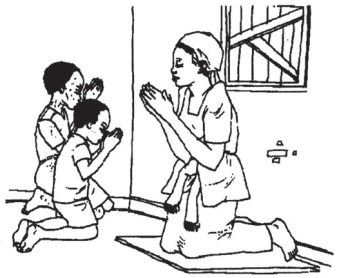
Social Interaction

A sick child always feels loved when left to interact with others.Involve sick children including HIV infected children in all childhood activities.

Playing

Playing brings happiness to children. Sick children need to play too or to watch others playing if they are too weak to join.

Spiritual Care



Praying gives hope to the sick and also the caregivers. When strong, take the sick child to his/her church.

Nutritional Care

Proper feeding improves the health of a sick child. Give frequent small amounts of soft foods to the sick child. Ensure regular meals.

Home Based Nursing

Sick children feel happier when nursed at home. Know when the child is too sick to receive visitors.

Tender Loving Care

Showing love and affection to a sick child promotes fast healing. Touching, hugging, eliminates/reduces stigma but avoid handling potentially infective material with bare hands.

Illustrations courtesy of SCF UK Uganda

Special Considerations in Palliative Care—Children

Pain medications—dosing for children			
AGE or WEIGHT	**paracetamol** Give every 4 to 6 hours **100 mg tablet**	**codeine** Give every 4 hours **30 mg tablet**	**oral morphine** 0.15-0.3 mg/kg **See P5** **5 mg/5 ml**
2 months up to 4 months (4–< 6 kg)	-	1/4	0.5 ml (dose reduced in infants < 6 months)
4 months up to 12 months (6–< 10 kg)	1	1/4	2 ml
12 months up to 2 years (10–< 12 kg)	1 1/2	1/2	3 ml
2 years up to 3 years (12–< 14 kg)	2	1/2	4 ml
3 years up to 5 years (14–19 kg)	2	3/4	5 ml
6 years up to 8 years (19–29 kg)	3	1	6 ml
8 years up to 10 years (29–35 kg)	4	1	8 ml

Other palliative medications—dosing for children			
AGE or WEIGHT	**prednisone** Initial 0.5-1 mg/kg Give twice daily Maintenance 0.1-0.5 mg/kg/day **5 mg tablet**	**amitriptyline** Initial 0.2-0.5 mg/kg Give oncedaily. Increase by 25% every 2-3 days **25 mg tablet**	**metoclopromide** 0.1-0.2 mg/kg1 Give every 2 to 4 hours **10 mg tablet**
2 months up to 4 months(4–< 6 kg)	Initial: 1/2 Maintenance: 1/4		1/10
4 months up to 12 months (6–< 10 kg)	Initial: 1 Maintenance: 1/2		1/5
12 months up to 2 years (10–< 12 kg)	Initial: 1 1/2 Maintenance: 1/2		1/4
2 years up to 3 years (12–< 14 kg)	Initial: 1 1/2 Maintenance: 1	1/4	1/4
3 years up to 5 years (14–19 kg)	Initial: 1 1/2 Maintenance: 1	1/4	1/3
6 years up to 8 years(19–29 kg)	Initial: 3 Maintenance: 1 1/2	1/2	1/3
8 years up to 10 years(29–35 kg)	Initial: 4 Maintenance: 1 1/2	1/2	1/2

▶ Support community caregivers, family, siblings and school friends

❖ **Preparation for home care**

- Prepare using Caregiver Booklet.

❖ **Technical assistance/clinical back-up**

- Visits by health workers and community volunteers are important support.
- Make clear when and how caregivers can access help from the health centre.

❖ **Supplies**

- Regular provision of medications and medical supplies are important.
- Network with organizations that can give support and material assistance.

❖ **Psychosocial support and advice**

- Detect and respond to burn-out.
- Follow guidelines on psychosocial support (see next page, H3 and other guidelines).

❖ **Traditional or complementary medical practitioners**

These can be very helpful if family has used them before. (adapt locally)

❖ **Respite care (day care)**

- Arrange for this if possible near health facility during day or church or other day care.
- Provide relief for the caregivers (substitute other community workers).
- Include in your week a time to discuss patients together.

▶ Burn-out (in yourself, family or community caregivers)

❖ **Recognize burn-out:**

- Irritability, anger.
- Poor sleep.
- Poor concentration.
- Withdrawal from others—avoidance of patients and problems.
- Fatigue.
- Emotional numbing—lack of pleasure.
- Resorting to alcohol and drugs.
- In survivors of multiple loss—afraid to grieve.

❖ **Prevent and respond:**

- Be confident that you have the skills and resources to care for the patient and family.
- Define for yourself what is meaningful and valued in care giving.
- Discuss problems with someone else.
- Be aware of what causes stress and avoid it.
- Use strategies that focus on problems, rather than emotions.
- Change approach to care giving:
  - Divide tasks into manageable parts (small acts of care).
  - Learn how to adjust the pace of caregiving.
  - Ask others to help.
  - Encourage self-care by the patient.
- Use relaxation techniques such as deep breathing.
- Take care of your life outside of the caregiving (other interests, support, family, friends).
- Develop your own psychosocial support network (such as caregiver support groups).
- Take care of your own health.
- Develop respite care solutions or substitutes; caregivers need a break.
- Take time off on a regular basis.
- Be aware that you can't do everything and need help.
- Include in your week a time to discuss patients together.
- Share problems with your colleagues
- Organize social activities. .

End-of-Life Care

▶ Help provide psychosocial and spiritual support

❖ **Offer patients active listening, counselling and social/emotional support**

❖ **Spiritual support is very important:**
Be prepared to discuss spiritual matters if patient would like to.

- Learn to listen with empathy.
- Understand reactions to the losses in their life (the different stages of grief).
- Be prepared to "absorb" some reactions, for example anger projected onto the health worker.
- Connect with spiritual counsellor or pastoral care according to the patient's religion and wishes.
- Do not impose your own views. If you share religious beliefs, praying together may be appropriate.
- Protect your patient from overenthusiastic evangelists.
- For some patients, it is better to talk about meaning of their life, rather than directly about spirituality or religion.

❖ **Empower the family to provide care:**

- As human beings, we know how to care for each other. Reassure the family caregivers that they already have much of the capacity needed.
- Give information and skills.

When giving end-of-life care and referral is not desired, if:	Medication—in consultation with doctor/ medical officer
❖Swelling around tumour (except Kaposi). ❖Severe esophageal candidiasis with ulceration and cannot swallow (while treating with antifungal, but poor response). ❖Liver pain from stretching of the capsule.	Oral dexamethasone 2 to 6 mg per day (or prednisone 15 to 40 mg). Consult with clinician before giving, if possible. Reduce dose to lower possible; withdraw if no benefit in 3 weeks. This will also improve appetite and make patient feel happier.
❖Nerve/spinal cord compression. ❖Persistent severe headache due to increased intracranial pressure (after diagnosis and treatment of the specific cause such as cryptococcal meningitis).	Oral dexamethasone 16 to 24 mg. Reduce by 2 mg per day until headache or compression symptoms resolved with the minimum dose.

▶ Special advice for end-of-life care

❖ Preparing for death

- Encourage communication within family.
- Discuss worrying issues such as custody of children, family support, future school fees, old quarrels, funeral costs.
- Tell the patient that they are loved and will be remembered.
- Talk about death if the person wishes to (keep in mind cultural taboos if not in a close relationship)*.
- Make sure patient gets help with feelings of guilt or regret.
- Connect with spiritual counselor or pastoral care as patient wishes.

❖ Presence

- Approach, be present with compassion.
- Visit regularly.
- Someone needs to hold hand, listen, converse.
- Move slowly.

❖ Caring

- Comfort.
- Provide physical contact by light touch, holding hand.

❖ Comfort measures near the end of life

- Moisten lips, mouth, eyes.
- Keep the patient clean and dry and prepare for incontinence of bowel and bladder.
- Only give essential medications—pain relief, antidiarrhoeals, treat fever (paracetamol round-the-clock) etc.
- Control symptoms with medical treatment as needed to relieve suffering (including antibiotics and antifungals, especially in HIV/AIDS).
- Eating less is OK.
- Skin care/turning every 2 hours or more frequently.
- Make sure pain is controlled.

▶ Signs of imminent death

- Decreased social interaction—sleeps more, acts confused, coma.
- Decreased food and fluid intake—no hunger or thirst.
- Changes in elimination—reduced urine and bowel movements, incontinence.
- Respiratory changes—irregular breathing, "death rattle".
- Circulatory changes—cold and grayish or purple extremities, decreased heart rate and blood pressure.

▶ Signs of death

- Breathing stops completely.
- Heart beat and pulse stop.
- Totally unresponsive to shaking, shouting.
- Eyes fixed in one direction, eyelids open or closed.
- Changes in skin tone—white to gray.

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▶ Bereavement counselling:

❖ For patient

- Look and respond to grief reaction—denial, disbelief, confusion, shock, sadness, bargaining, yearning, anger, humiliation, despair, guilt, acceptance.
- Keep communication open—if patient does not want to talk, ask, "Would you like to talk now or later?"
- Help the patient accept his/her own death.
- Offer practical support—help patient making a will, help in solving old quarrels, plan for children's custody.
- Ask them how they wish to die: with pastoral care, with family only.
- Make sure that what the patient wants is respected.

❖ For family

- Look for and respond to grief reactions: denial, disbelief, confusion, shock, sadness, bargaining, yearning, anger, humiliation, despair, guilt , acceptance.
- Help the family accept the death of the loved one.
- Share the sorrow—encourage them to talk and share the memories.
- Do not offer false comfort—offer simple expressions and take time to listen.
- Try to see if friend/neighbor can offer practical help—cooking, running errands can help in the midst of grieving.
- Ask if they can afford funeral costs and future school fees, and help finding a solution if possible.
- Encourage patience—it can take a long time to recover from a major loss.
- Say that they will never stop missing the loved ones, but pain will ease and allow them to go on with life.

Essential Drugs for Palliative Care From First-Level Facility*

Drug	Indication
aspirin (acetysalicylic acid)	**Step 1** analgesic ladder: pain Anti-pyretic (reduces fever), anti-inflammatory, painful mouth ulcers or sore throat (gargle)
paracetamol	**Step 1** analgesic ladder: pain Anti-pyretic
ibuprofen	**Step 1** analgesic ladder: pain Anti-pyretic, anti-inflammatory
codeine	**Step 2** analgesic ladder: pain Cough, diarrhoea, colic
oral morphine*	**Step 3** analgesic ladder: pain
hyoscine (Buscopan®)	Colic, bowel obstruction (when surgery not indicated), antiemetic, excessive thin sputum at end of life
chlorpheniramine	Itching, insomnia
amitriptyline	Depression, insomnia, nocturia, post-zoster pain, painful leg neuropathy
haloperidol or chlorpromazine	Severe agitation, antiemetic, hiccups, dementia with paranoia or getting up at night purposely
diazepam	Anxiety, insomnia, muscle spasms, convulsion
metoclopromide	Antiemetic, hiccups
metronidazole	Necrosis with bad smell in mouth, or tumour—crush and apply
chlorhexidine	Skin abscess, itching (in some patients)
bisacodyl	Constipation
senna	Constipation
loperamide	Diarrhoea
prednisone* **dexamethasone*** (0.5 mg tablets)	Anti-inflammatory, bronchospasm with difficult breathing, aphthous ulcers (crush and apply) Terminal care—painful swelling, stimulate appetite, persistent severe headache from raised intra-cranial pressure, cannot swallow from severe esophagitis (also give antifungal), nerve compression
furosemide	Heart failure or excessive fluid
petroleum jelly (Vaseline®)	Barrier to protect skin from persistent diarrhoea, disimpaction of severe constipation, skin moisturizer (when mixed with water)

**In many settings, provisions of drugs marked with an asterisk will require medical doctor or medical officer consultation and prescription.*

Palliative Care also requires the key drugs listed in the *Acute Care* module such as:

- Antimalarials
- Antibiotics
- Antifungal agents (fluconazole, nystatin, miconazole gum patch, Whitfield's ointment)
- Bronchodilators (salbutamol metered-dose inhaler)
- Scabies treatment
- Oral rehydration salts (ORS)
- Ringers lactate

Effective local remedies	Use for:

*Recipe for oral morphine preparation from morphine powder: