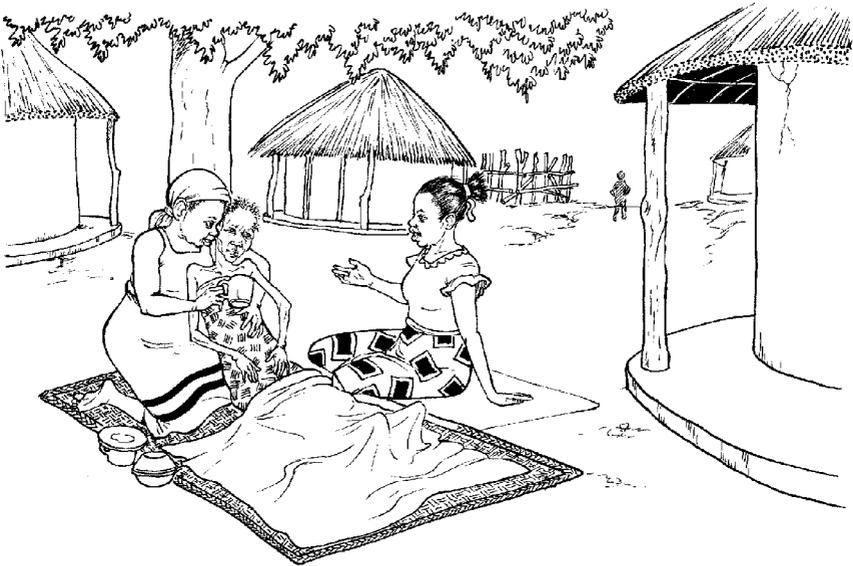


PALLIATIVE CARE

A Field Guide for Community Home-Based Care Volunteers



The field guide was inspired by the patients, families and dedicated care providers of the dioceses of the Catholic Church in Malawi.

Anna Anderson

This field guide was written for community home-based care volunteers who have been trained in palliative care. It may be:

- distributed as a handout during palliative care training
- used as a reference guide to assist the care provider in preventing and solving problems
- used by volunteers and other care providers to teach basic skills to patients and their guardians.

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A Message to Palliative Home-Based Care Volunteers

We hope you will find this booklet a useful guide and reminder of good practice as you provide care, support and counselling to your patients and their families.

You are the eyes, the ears, the hands and the heart of the palliative care team. This field guide is dedicated to you.

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Fig 1. 'I think we should visit Mrs Chilenje. She seems to be alone and in pain. The children look hungry and are not at school. Perhaps we can help.'



Fig 2. Holistic care for the body, mind and spirit.

1. What is Palliative Care?

Palliative care is a special kind of care for people with incurable illnesses. The care is provided in patients' homes, in clinics and in hospitals by families, volunteers, nurses, medical assistants, clinical officers, doctors, pastoral care providers and other health care personnel.

Palliative care:

- helps people with incurable illness, and their families, live more comfortable, active and hopeful lives
- is holistic care: physical, psychological, social and spiritual
- works to prevent and treat pain and distressing symptoms
- involves the community in care-giving and support
- provides care and support during the dying process
- supports the patient and family in their grief.

Remember: Holistic care is important. It means care for the needs of 'whole' person: physical, psychological, social and spiritual.

2. The Tasks of the Palliative Home-Based Care Volunteer

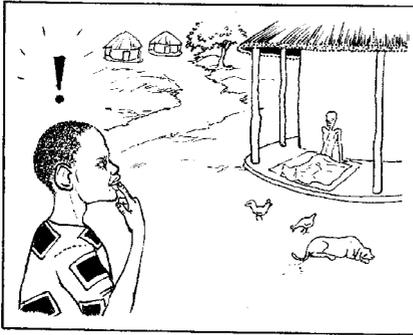
You, the Palliative Home-Based Care Volunteer, are a trusted 'bridge' between the patient, family, community and the palliative care team.

Your tasks are to:

1. Identify patients who need palliative care.
2. Assess the needs of the patient and family.
3. Refer problems to the nurse, the health care facility, pastoral care, social/community services or other care providers as required.
4. Help manage care holistically.
5. Support the patient and family by providing counselling, friendship and listening.
6. Teach patients and families how to provide the best possible care.
7. Help the patient and family prepare for grief and loss.
8. Always work closely with the community.

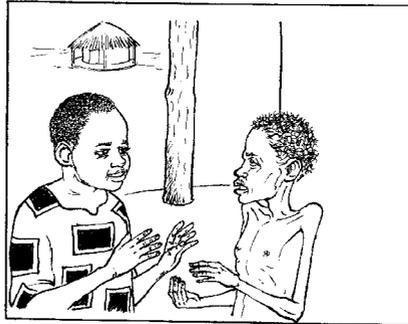
Note to the Volunteer:

In this guide you will find suggestions on what you should report to the nurse or other team members. You must, of course, use the reporting system required in your work setting.



1. Identify the patient.

2. Assess needs and identify problems.



3. Refer the patient and guardian to the nurse or health care facility.

4. Help manage care and provide support.

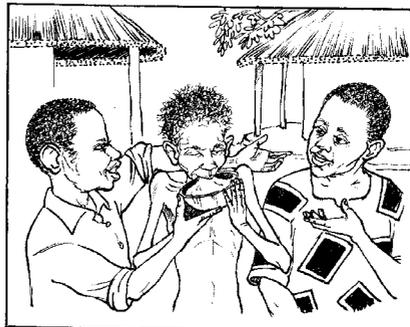


Fig 3. The tasks of the Palliative Home-Based Care Volunteer.

3. Communicating with Patients and Families

Poor communication leads to misunderstanding, loss of trust and loss of hope. It is important to find the best way to communicate with patients and families, so that you will be able to understand and help them.

Some guidelines for communicating:

- Listen, speak and act with respect, warmth and empathy.
- Show that you wish to understand and help.
- Always be honest and trustworthy.
- Find out how the person is feeling. Is he or she worried, in pain, or hungry?
- Reach behind the words for the real message – what is the person *really* trying to say?
- Notice body language and facial expression.
- Make sure you have understood correctly. Ask questions to clarify.
- Support with hope, always focus on what *can* be done.
- Do no harm. Do not make the person feel guilty, ashamed or worried.
- Give the person time to make decisions, to think and to feel.
- Help the person find and use his/her strengths.
- Encourage the person to make his/her own decisions.
- Encourage communication between the patient and the family.



Fig 4. If you try to put yourself in the other person's shoes and see with his eyes, think with his mind and feel with his heart, then you can begin to understand and help.

4. Assessing Patient and Family Needs Holistically

Once you have identified a palliative care patient, you should assess the needs of the patient and family and identify problems. You should update this initial assessment every time you visit.

Ask questions, listen and observe carefully.

Examples of Questions to Ask When Assessing Needs and Problems

1. *Physical needs*

- How are you feeling?
- Do you feel pain? Where?
- Do you have any distressing symptoms, such as weakness, sleeplessness, diarrhoea, fever, nausea or vomiting?
- Are you taking any medications or other remedies? Are they helping you?

2. *Psychological needs*

- What are your worries or concerns?
- Do you sometimes feel confused? Depressed?
- Who can you talk to when you have problems?

3. *Social needs*

- Is someone helping you? Who? How?
- What relationships are important to you?
- Do you feel lonely?
- How is the family managing?
- Are you worried about the family – your children, your wife, your husband?



Fig 5. Psychological needs: 'Oh, how will I manage now without him?'

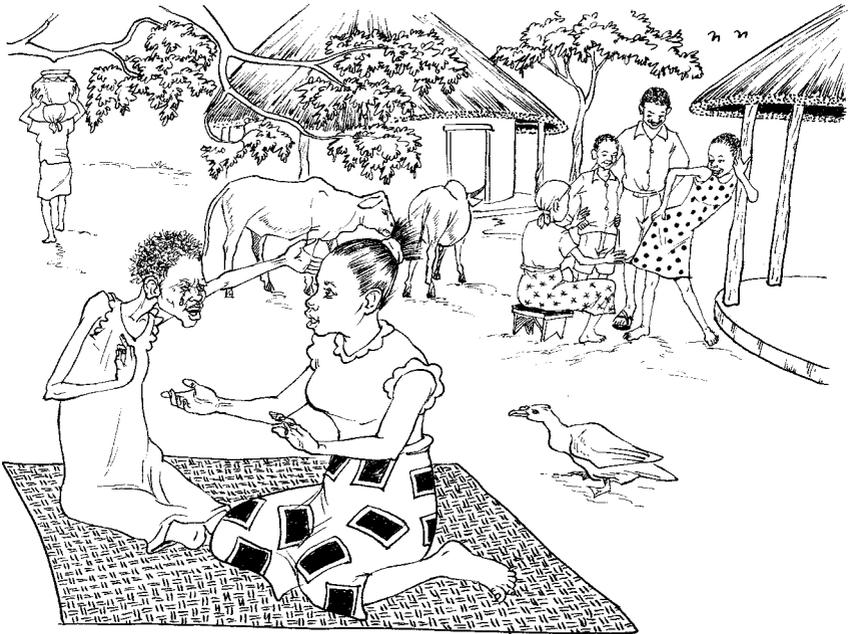


Fig 6. Social needs: 'Look at them. Nobody cares that I am sick and alone!'

4. Financial needs

- Who is providing your food and other things that you need?
- Who is paying school fees for the children?
- Can you pay for transport to the clinic?

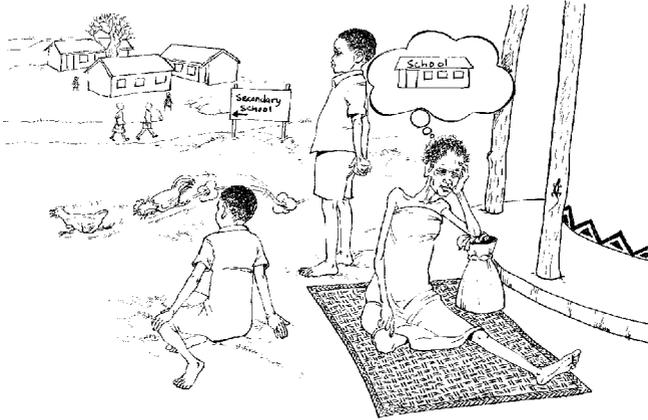


Fig 7. Financial needs: 'I cannot work any more. I cannot even send my children to school.'

5. Spiritual and religious needs

- What gives you hope when you have troubles?
- Are you frightened of anything?
- What kind of support would help console you?
- Do you have support from your church/mosque?
- Do you want to talk to a pastoral care provider?



Fig 8. Spiritual and religious needs: 'I cannot go to church and they don't visit me!'

6. Cultural needs

- Can you explain what is making you ill?
- What do you think can help you to get better?

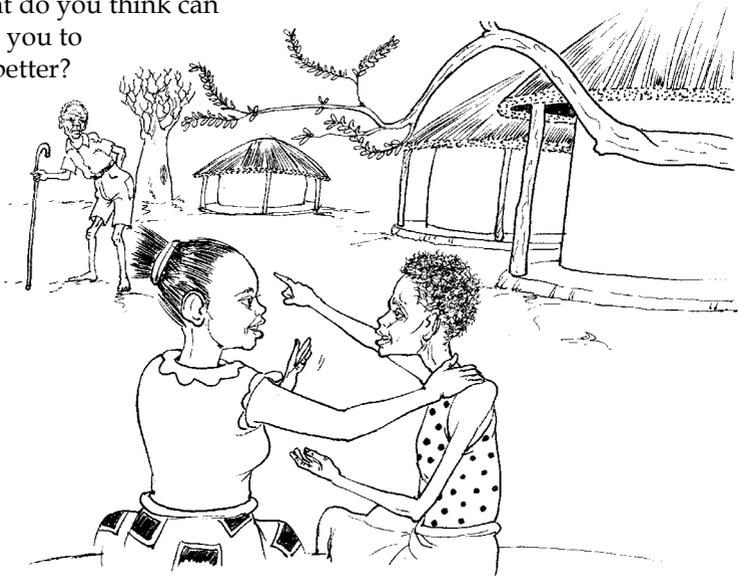


Fig 9. Cultural needs: 'You think that old man has bewitched you?'

7. The special needs of children

- Are you worried about the children?
- Are they being looked after?
- What do you think they need?
- Do the children understand what is happening?
- Who can they talk to?
- Are they going to school?



Fig 10. 'The children seem so sad and I am too sick to take care of them.'

How You Can Help

- Help the patient and family identify and describe their problems.
- Help them begin to work out their problems.
- Provide counselling, education and emotional support.
- Respect the abilities and choices of the patient.
- Encourage community and pastoral support.



Fig 11. 'I don't feel so alone or worried any more.'

REPORT to the nurse or health care facility when you have identified the patient's and family's needs and problems. You may also need to refer them to pastoral care providers, social services, transport services, orphan care, other community services or to village authorities for assistance.

5. Preventing Problems with Good Physical Care

It is much better to prevent problems before they start, if you possibly can. When a problem does occur, however, treat it quickly to prevent unnecessary pain and suffering. This chapter provides some useful suggestions for preventative care.

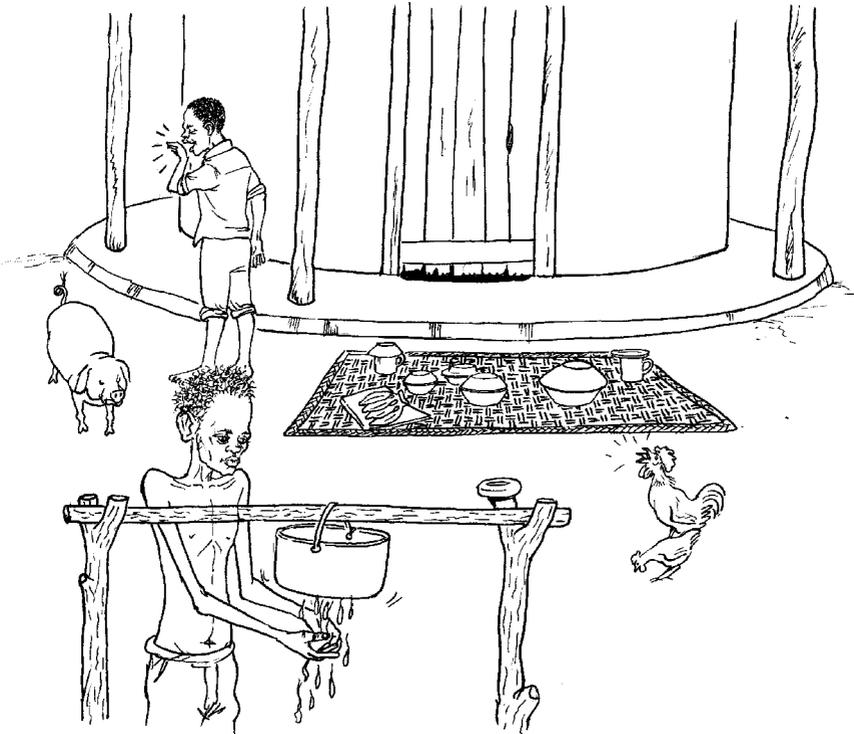


Fig 12. Good hygiene helps prevent and fight infection.

General Rules to Prevent Problems

- Practice cleanliness and good hygiene at all times.
- Wash hands before and after giving care, after going to the toilet and before handling food.
- Use gloves or plastic bags to protect your hands from body waste, body fluids or open sores.
- Avoid contact with open wounds. Keep them clean and covered with a clean bandage.
- Do not share razors, toothbrushes or tooth cleaning sticks.
- Keep laundry that is soiled with body fluids separate from other articles.
- When coughing or sneezing, cover your mouth with the back of your left hand or the inside of your elbow, facing away from people (and encourage others to do the same).
- Take special care to avoid infection when you are near people with TB, colds, other respiratory infections, shingles or chicken pox.
- Wash food well and store it away from insects and rodents.
- Use drinking water from a safe source or boil water for several minutes and allow it to cool before using. Store in a clean, covered container. Each person should use his or her own cup if possible.
- If a procedure (such as dressing a wound) is painful, try giving pain medication 30 minutes beforehand.
- Always observe for signs of abuse or neglect (for example abandonment, malnutrition, injury, isolation, etc.).
- Always ensure that drugs are taken as ordered (including ARVs).

REPORT *problems with hygiene, neglect, infection, abuse, drug compliance, etc. that you are unable to deal with on your own.*

Mouth Care

Having a clean mouth helps prevent infection, sores, bad odour and loss of dignity.

- Gently clean teeth, gums and tongue with a soft toothbrush or a stick after meals to remove food and debris (but use a soft cloth if there are sores or inflammation). Rinse with clean water.
- Use salty water, toothpaste or whatever the patient normally uses, as long as it is gentle.
- If the patient is not eating or drinking, rinse the mouth often with salty water then with clean water.
- Encourage fluids, but not sweet drinks.
- Check the mouth for sores, redness, white plaques or other problems.
- Put Vaseline on the lips sparingly.



Fig 13. Regular mouth care prevents infection and pain.

REPORT signs of infection such as pain, white plaques, bad smell, inflammation or other damage.

Bathing

Regular bathing helps prevent infection and bad odour, and gives comfort and dignity.

- Collect the things you need such as a bowl, water, soap, lotion, oil or Vaseline, a towel or cloth for drying and clean clothes.
- Provide warmth, privacy and dignity by covering the patient with a cloth or towel.
- Close windows and doors to prevent chill.
- Wash the face first.
- Bathe daily with warm water and soap. **Do not** scrub fragile skin, use harsh products or leave soap on the skin. Rinse well and gently pat dry.
- Encourage the patient to bathe independently as much as possible, including washing his or her private parts. Otherwise ask the patient to choose who will help with these personal tasks.
- Apply skin lotion or oil to the skin in a thin layer (too much can promote infection or irritation).
- Gently massage the back and bony areas with lotion (do not massage broken skin).
- Trim nails and hair as needed.
- Check the skin for problems.
- Help the patient put on clean and comfortable clothes.



Fig 14. Regular bathing prevents infection and gives comfort.

REPORT problems such as pain, increased weakness, wounds or signs of infection (pain, fever, wounds with pus, swelling, a bad smell, etc.).

Managing Incontinence

A patient who is incontinent of urine or stool needs special care to ensure dignity and comfort, and to prevent infection and painful sores.

- Always respect the patient's dignity and privacy.
- Clean promptly when there is soiling – with soap and water.
- Wear gloves or plastic bags to protect your hands.
- Protect skin around rectal or private parts with Vaseline (this prevents the skin from drying out).
- Protect the mat or mattress with plastic, but put a cloth over this (*do not* place plastic against the skin).
- When the patient asks to go to the toilet, help immediately to avoid accidents.
- Help the patient to the toilet if he/she is able to walk.
- If the patient cannot walk, provide a container to pass urine or stool (make sure it is not chipped or damaged).
- Support the patient on the container as needed.
- Dispose of the contents into the pit latrine or toilet and clean the pot with Jik or soap and water.
- Keep bedding clean, and place in the sunshine frequently (this helps prevent parasites and infestation).
- Give emotional support and show understanding.
- Use, as needed, available deodorizing methods such as fresh air, charcoal or vinegar in a dish.



Fig 15. Help the incontinent patient in a way that protects comfort and dignity.

REPORT pain, diarrhoea, blood in the stool, constipation or signs of urinary infection (smelly, cloudy urine or pain on urination).

Changing Body Position

*Frequent changes in body position are **very important** in preventing **pressure sores**. This is essential for the patient who is unable to move without assistance.*

Pressure sores

Pressure sores usually happen over bony areas when a patient does not change position often enough. They can lead to painful and bad-smelling wounds (see page 44). Preventing them only takes a little time, but treating them is difficult and not always successful.

- Encourage mobile patients to walk or move about from time to time.
- Assist or encourage the bed-bound patient to change position at least every two hours. Even small changes in position can help.
- Protect bony areas such as shoulder blades; elbows; the back of the head and ears; lower back/tailbone; hips; and heels and ankles. Put something soft under these areas such as a folded cloth, small pillow or dried banana leaves under a cloth.
- Keep bedding and clothing clean and free of wrinkles.
- Massage bony areas gently with oil or Vaseline (but **do not** massage damaged skin).
- Use folded cloths or pillows to hold the patient in a comfortable position. The body should be placed in a relaxed position, with bony areas protected from rubbing or pressure.
- Keep skin clean and dry.
- Check skin daily, and observe the patient for signs of pain.
- Encourage good nutrition and intake of fluids.
- Treat any break in the skin immediately.

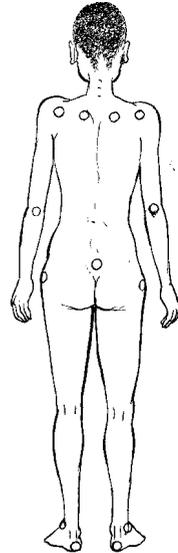


Fig 16. Areas prone to painful pressure sores.

Some tips on moving or turning a bed-bound patient

- If two people are available it makes the job easier if they work together as a team.
- Explain to the patient what you are doing, step by step. Work *with* the patient.

- Keep a clean cloth under the patient at all times. You can use this for lifting, turning and changing position.
- Lift the patient gently with the cloth (*do not drag*) so that fragile skin is not broken.
- Always bend the patient's knees before moving him or her.
- Always place yourself very close to the patient, grasping the cloth close to the patient's body, with one hand at hip level and the other hand at shoulder level.
- If there are two helpers: one person on each side holds the cloth at shoulder and hip level and together they count '1, 2, 3' - moving the patient gently on the count of 3.
- If you are working alone: roll and hold the cloth on both sides of the patient's shoulders, and move the patient a little distance at a time.
- Position the patient comfortably.



Fig 17. Changing body position helps to prevent painful pressure sores.

REPORT pain, sores, changes in ability to move, and any signs of skin damage or infection.

Exercising Muscles and Joints

Exercising muscles and joints helps prevent pain, stiffness and disability.

NOTE: Exercises may not be appropriate in the last days or hours of life.

- Avoid long periods of immobility if possible.
- Encourage or help the patient to do exercises at least once a day.
- Massage the joints – gently – with oil or Vaseline.
- Exercise all joints: wrists, fingers, elbows, shoulders, neck, knees and ankles.
- Bend, straighten, stretch and move joints *gently and slowly* in their natural direction while supporting the limbs. *Do not cause pain.*
- Demonstrate to the patient and guardian how to do the exercises safely.



Fig 18. Exercise gently to prevent pain and stiffness in the joints.

REPORT pain or sudden changes in mobility.

6. Nutrition and Fluids in Palliative Care

Illness affects a person's ability to eat and drink properly. It is very important to ensure that a patient receives enough nutritious foods and fluids.

What You Need to Assess

- Loss of appetite or refusal to eat.
- Physical symptoms that affect nutrition such as nausea, vomiting, taste changes, chewing or swallowing difficulties, diarrhoea, constipation, fatigue, indigestion, pain, infection or side effects of drugs.
- Weight loss, weakness, failure to thrive in children, poor condition of skin or hair, oedema.
- The ability of the patient or guardian to collect and prepare nutritious foods.
- Knowledge about nutrition and hydration.
- Psychosocial or spiritual problems such as neglect, isolation, depression, abandonment, loneliness or hopelessness.

How You Can Help

- Provide nutrition and hydration education and counselling.
- Provide food supplements and other resources as needed.
- Manage symptoms that affect nutrition (such as nausea, pain, infection or diarrhoea – see Chapter 8).
- Suggest nutritious, soft, easy-to-eat foods such as soured milk, thobwa, yogourt, natural fruit juices, likuni pala, porridge of groundnut and maize flours or a 'power drink'.
- Teach water and food safety and hygiene.
- Encourage exercise if appropriate.

Power Drink Recipe (for boosting energy)

1 cup chopped ginger; 2 cups lemon juice; 3 cups peeled, chopped aloe vera; brown sugar to taste; 2 tablespoons honey; 5 litres of water. Boil for two hours. Take 1 tablespoon 3 times daily, if tolerated, to boost energy.



Fig 19. 'I feel so much stronger since I stopped vomiting and started to eat good foods again.'

Nutrition for the Dying Patient

- **Do not** force feed. Only feed a patient who is alert and cooperative.
- Observe carefully for any difficulties with chewing and swallowing.
- Avoid foods that are not tolerated or wanted by the patient.
- Follow the patient's wishes and abilities.
- Position the patient safely and comfortably for eating
- If the patient is refusing food or liquids, keep the mouth moist with frequent mouth care, for example with drops of fluid or a damp cloth – and keep lips moisturized with lotion or Vaseline.
- Provide support, comfort and teaching to the family at this difficult time.

IMPORTANT NOTE:

- Forcing a dying patient to eat or drink can cause choking, suffering and even early death.
- Dehydration and not eating do not cause suffering at the end of life.
- Always give frequent mouth and lip care.

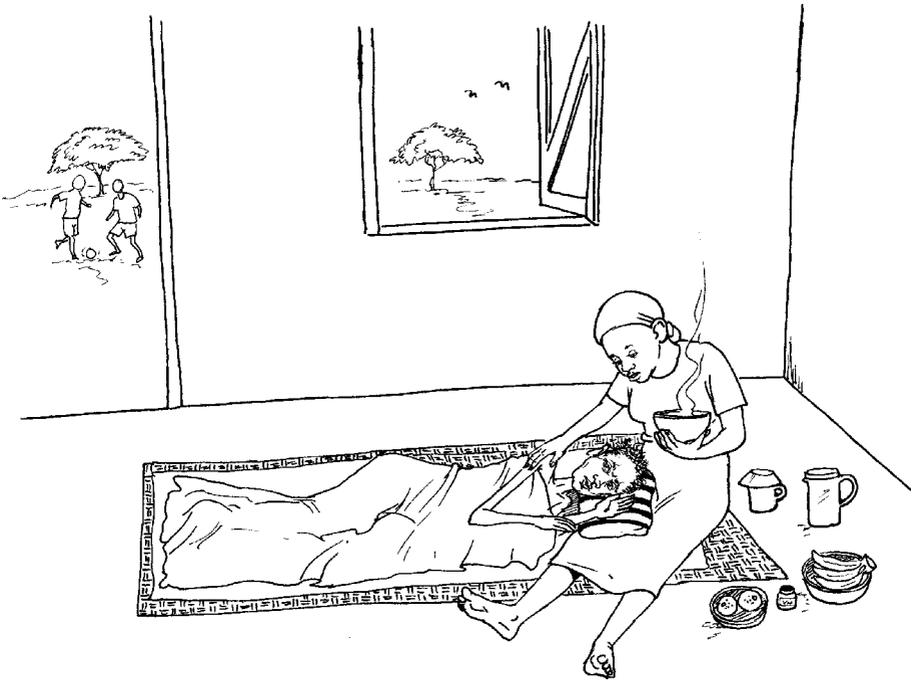


Fig 20. 'I have some warm porridge here if you want to try just a mouthful.'

REPORT if there are sudden changes in nutritional status or food intake, signs of neglect, depression, psychosocial/spiritual problems, food shortages, hunger, lack of funds for food. Also report if the caregiver is unable to provide for basic needs or if there are family problems.

7. Assessing and Caring for the Patient in Pain

Pain can have many causes: diseases such as cancer and HIV/AIDS, drugs and other treatments, pressure sores, infections, damage to body tissues and so on. Pain can be made worse by emotions, loneliness and worries. Every person feels pain differently.

Questions for Assessing Pain

- Do you have pain? How many pains do you have?

Ask the following questions for each pain identified by the patient:

- Where is your pain? Can you show me where your pain is?
- How long have you had your pain? When did it begin?
- How often do you get the pain? Is it constant or does it come and go?
- Does your pain stay in one place or move around?
- How bad is your pain: mild, moderate or severe (*Level 1, 2 or 3*)?
- When is your pain worse: at night? In the morning?
- What does it feel like: stabbing, burning, aching, tingling, numbness, etc? (*This is an important question. The answer may help indicate whether the pain is nerve pain, or 'normal pain'. These two types of pain are treated differently.*)
- Do you have other problems along with your pain? (*For example: constipation, diarrhoea, difficulty breathing*)
- What makes your pain worse? (*For example: activity, fatigue, loneliness, walking, sitting, eating*)
- What makes it better? (*For example: rest, activity, food, company*)
- How does it affect your daily life? (*For example: sleep, appetite, mood, family*)
- What treatments are you taking and how are they helping?
- What do you think is causing your pain?

Important Points to Remember When Assessing Pain

- Remember that a good assessment is the first step in the proper treatment of pain.
- Encourage the patient to talk to you about his/her pain and problems.
- Clarify what the patient tells you. Be sure you understand correctly.
- Remember that most patients have more than one pain.
- Ask simple questions and listen carefully to the patient and to the guardian.
- Observe the patient for signs of pain or anxiety – such as facial expression, restlessness and posture.
- Explain what you plan to do to help.
- Document your assessment, and report pain to the nurse.
- Reassess at every visit.

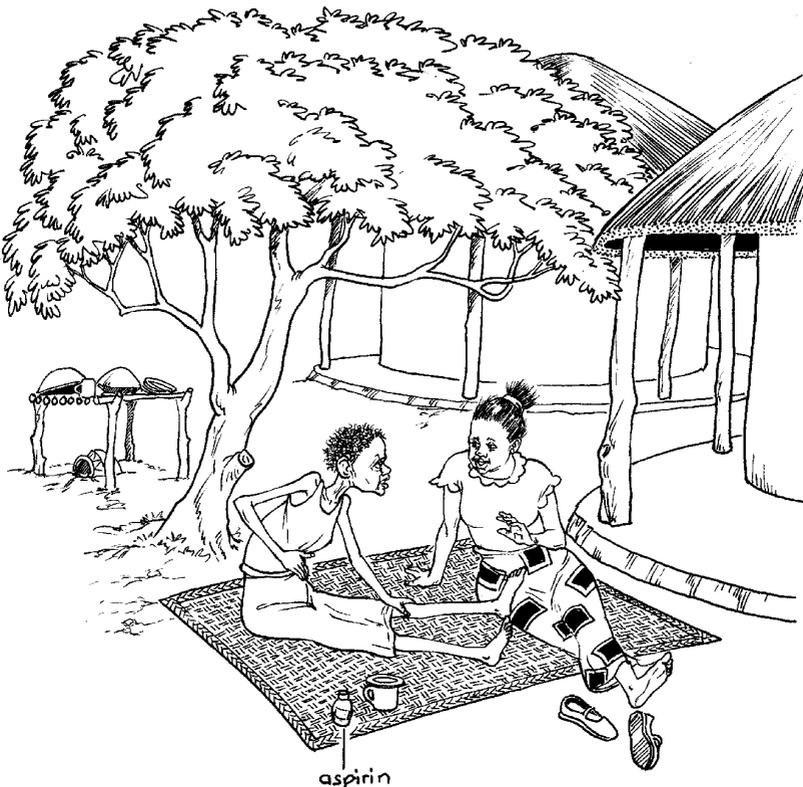


Fig 21. 'Can you show me where your pain is?'

Some Assessment Tools You Might Find Useful

Children may not be able to tell you very much about their pain. If you are assessing a child's pain you may find it helpful to draw faces and ask the child which face shows how he or she feels. Something like this:



Fig 22. Degrees of pain: no pain (0), mild pain (1), moderate pain (2), severe pain (3).

You can also assess pain in the community setting by using stones of different sizes. The child can choose the stone that describes his/her pain the best: the smallest stone for a little pain, the biggest stone for severe (big) pain and so on.



Fig 23. Using stones to define pain.

You can also mark the pains on a body diagram, giving each pain a number to indicate severity (1, 2 or 3). Like this:

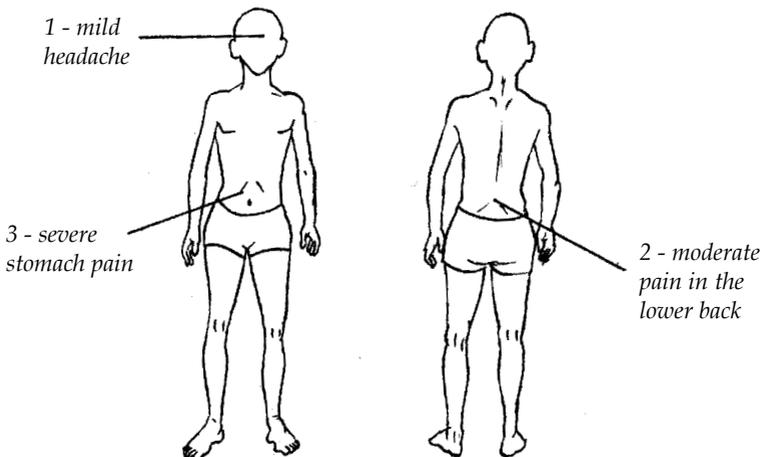


Fig 24. Marking pain on a body diagram.

REPORT your assessment to the nurse.

How Pain is Managed in Palliative Care

Your role in managing pain is very important. As a volunteer, you assess, help, teach, supervise and report. To do this well, you need to understand how pain is managed in palliative care.

Important Information to Keep in Mind:

- Long term (chronic) pain is best treated by taking pain killers *regularly*, usually every 4 to 6 hours. This is to *prevent* unnecessary pain and suffering.
- Drugs must be taken as ordered.
- Different kinds of pain are treated differently.
- Pain needs to be managed holistically.



Treating mild pain

Some drugs for treating mild pain are available in your Home-Based Care Kit, such as **paracetamol** and **aspirin**. **Ibuprofen** may also be ordered by the clinician.

Note of Caution: *Toxic side effects can result from taking too much of one drug.* To avoid this, some patients may alternate drugs. For example, they may take 2 paracetamol every four hours during the day and then 2 ibuprofen or aspirin at bedtime. There are various ways of alternating these drugs so *always check dosages and frequency with the nurse.*

Remember that these drugs should always be taken with food.



Treating moderate pain

Moderate pain is treated with **codeine** or low-dose **morphine**. These are 'DDA' drugs and they must be prescribed by a clinician.



Treating severe pain

The most common drug for treating severe pain is **morphine**.

Treating painful conditions that need other drugs

The clinician may order other drugs for painful conditions such as peripheral neuropathy, infection, inflammation and bone pain.

Some Other Ways to Relieve Pain

Pain can be made worse by lack of sleep, anxiety, loneliness and grief. It can be helped by hope, rest and companionship. There are many holistic ways you can help a person who is in pain:

- Provide comfort and good basic care: bathing, grooming, positioning, cool/ warm compresses, good nutrition, massage and comforting natural remedies.
- Provide helpful distraction: music, games, conversation, reading, etc.
- You might suggest making a memory book or box with photos, stories, pictures or other objects that can then be shared with the children. (A memory box is also a good place to keep important things such as the health book and prescriptions.)
- Provide counselling to help with problems and worries.
- Offer prayer and hope, and ensure that spiritual/ pastoral support is offered.
- Help family and friends learn ways to relieve the patient's pain.



Fig 25. Companionship and distracting activities can help relieve pain.

Morphine

The role of the volunteer when caring for patients taking morphine

- **You are not permitted to administer morphine to patients** but you may supervise to be sure that drugs are being taken correctly.
- Help the patient and guardian find a way to remember to take drugs regularly (by the clock, by the sun, by mealtimes and bedtime, etc).
- Ensure that the patient has good support from the guardian and family.
- Check the amount of liquid or number of tablets left in the bottle at each visit to ensure that the patient is taking the correct dose.
- Check that the bottle is correctly labelled.
- Make sure that the drug is being stored safely *out of the reach of children* and in a cool, dry place.
- Assess pain at each visit.
- Assess whether the patient needs extra doses to control pain.
- Make sure the patient is taking measures to avoid constipation – unless there is diarrhoea.
- Ensure no one else is taking the drugs. They are prescribed for the *patient only*.
- Work closely with the nurse and the palliative care team.

DOCUMENT AND REPORT:

- *confusion or agitation – report immediately*
- *difficulty breathing – report immediately*
- *nausea or vomiting (this usually passes in a few days)*
- *constipation that is not responding to treatment*
- *extreme sleepiness – this usually passes in a couple of days*
- *uncontrolled pain, symptoms or other problems affecting pain*
- *if the patient has needed extra doses of morphine to control pain (the clinician may decide to increase the dose).*

Some Useful Information About Morphine

The two kinds of morphine most commonly available at this time are **liquid oral morphine** and **morphine slow release tablets (MST)**.

1. *Liquid Oral Morphine*

- acts quickly
- is taken every 4 hours
- is prepared by the pharmacist in bottles in two solutions: the weaker solution is green and the stronger solution is pink.

Instructions for the patient and guardian:

1. Take exactly as ordered.
2. Pour a small amount of morphine liquid into a cup.
3. Use a syringe to draw up the correct dose (do **not** use a needle).
4. Put the morphine liquid into the patient's mouth, without touching the mouth or lips.
5. Pour the morphine remaining in the cup back into the bottle. Store out of sunlight and out of reach of children.
6. Rinse the syringe. It can be used again if it has not been in contact with body fluids.
7. Take doses regularly as ordered, with a double dose at bedtime (if ordered).
8. If there is breakthrough pain take an extra dose (if ordered).
9. Prevent constipation by increasing the patient's intake of fluids, fruits, fibres, laxatives or papaya seeds – unless there is diarrhoea (see page 38 on constipation).
10. If the patient is unable to swallow, the liquid can be given rectally or dripped into the cheek.

2. *Morphine Slow Release Tablets (MST)*

- act slowly
- are taken every 12 hours
- work best when the pain is already well controlled and the patient is mobile
- must not be broken. *Slow release tablets are not effective if they are broken.*

Instructions for the patient and guardian:

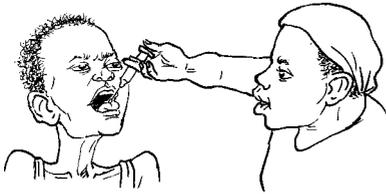
1. Take the tablet(s) as ordered every 12 hours with water, or other liquid, as ordered.
2. Prevent/treat constipation.
3. Give rectally if the patient is unable to swallow.



1. *'I think you need something stronger for your severe pain.'*



2. *'Take this every four hours for your pain with a double dose at bedtime.'*



3. *'This should help you feel better, I will make you some porridge now.'*



4. *'My pain is so much better I can even take Faith for a walk and visit my friends.'*

Fig 26. Managing pain.

8. Managing Distressing Symptoms

Patients often have many distressing symptoms. You need to ask simple and direct questions about each symptom. Listen and observe carefully. A few of the most common symptoms are described here, with suggestions for helping.

You may use the blank pages at the end of this guide to make your own notes on other symptoms that are not included here.

Important Points for Managing Symptoms

- Ask questions about each distressing symptom (just as you do for pain):
 - How bad is it?
 - When does it happen? How often?
 - What makes it worse? What makes it better?
 - What does it feel like?
 - How does it affect your activities, sleep, appetite, etc?
- Report signs of neglect, abuse, abandonment or depression to the nurse and/or health team.
- Give emotional support to the patient and family.
- Check that patients are taking drugs as prescribed by the clinician.
- Wash hands, maintain cleanliness and good hygiene.

Diarrhoea

This very common symptom of HIV/AIDS can lead to life-threatening dehydration.

Some suggestions for care (see also Managing Incontinence on page 20):

- Encourage liquids such as water, soups, thin porridge, rice water, weak tea, thobwa or ORS (oral rehydration solution).

- Encourage the patient to continue eating and drinking but to avoid sweet drinks and alcohol.
- Limit raw vegetables and fruits.
- Ensure clean drinking water and good hygiene when preparing and storing food.
- Encourage more frequent breast feeding of infants with diarrhoea. They should have extra fluids and food.
- Protect the rectal area by keeping it clean and applying Vaseline after each stool.
- Try a tea made from guava leaves (see recipe on page 60).
- Remind the patient to wash hands after visiting the toilet or cleaning up.
- Soak and wash soiled clothing and cloths using Jik if available, or boil them and hang in the sunshine.

Signs of dehydration

- Passing small amounts of dark urine.
- Dry mouth and tongue.
- Extreme thirst.
- The skin of the abdomen fails to return to normal rapidly when it is pinched.



Fig 27. 'You must eat and drink lots to get strong.'

REPORT if diarrhoea lasts more than a few days, the patient is dehydrated, diarrhoea is bloody, the patient becomes sicker or weaker, or if there is vomiting or fever.

Nausea and/or Vomiting

Uncontrolled vomiting can result in dehydration and malnutrition.

Some suggestions for care:

- Give foods that the patient feels able to eat (not greasy or fried).
- Offer frequent small servings of comforting foods like nsima, porridge, potatoes, cassava or banana.
- Offer a spoonful or two of lemon juice with tea or porridge.
- Offer frequent small sips of fluids like sodas, tea, water or juice.
- Avoid cooking smells and sights that make the patient feel worse.
- Ensure that there is plenty of fresh air.
- Treat dehydration with ORS (see recipe on page 60).
- Refresh the mouth by rinsing, cleaning teeth, sucking on pineapple, lemon, passion fruit or orange.



Fig 28. 'Take some of this medicine and then try a little of your favourite porridge and some tea.'

REPORT if there is dehydration, severe vomiting lasting more than one day, fever, pain, dark or black vomitus, or inability to eat or drink for more than a day.

Constipation

Sometimes passing stool can be painful or very difficult. It is often a side effect of weakness, dehydration or drugs such as morphine. It is best prevented.

Some suggestions for care:

- Increase the patient's intake of liquids, fruits and vegetables.
- Encourage activity if possible.
- Try giving the patient a tablespoon of margarine or vegetable oil before breakfast.
- Insert a lump of Vaseline into the patient's rectum and have he or she hold it in for as long as possible (up to 20 minutes) to soften the stool.
- Encourage the patient to take laxatives as instructed by the nurse or doctor (such as Bisacodyl, usually starting with 2 tablets, then up to 5 at night).
- Encourage the patient to chew 5 to 10 papaya seeds. You can also dry, crush and mix them with a spoonful of water.

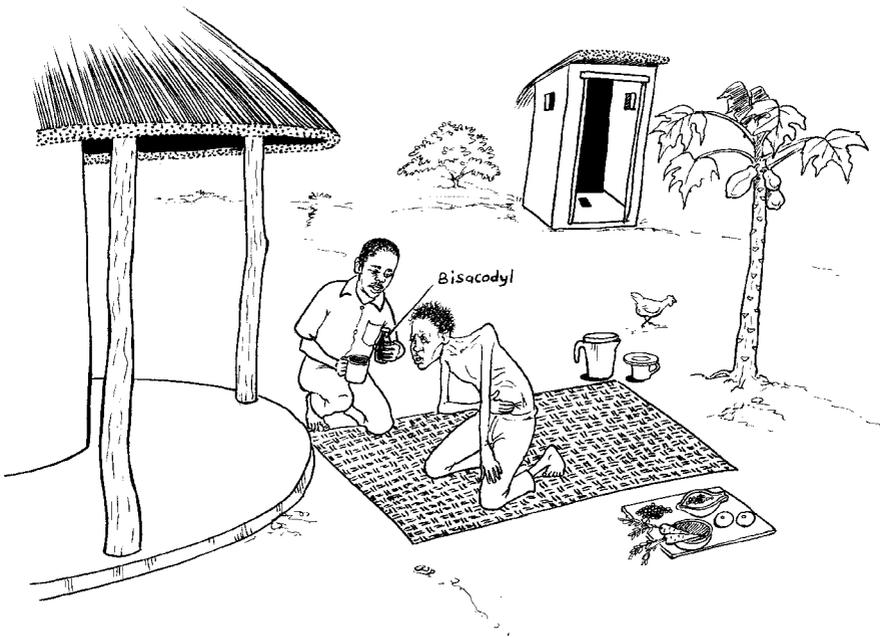


Fig 29. 'You must drink lots, and eat fruits and vegetables. These pills will help as well.'

REPORT if there is pain, fever, nausea/vomiting, or if home remedies do not give relief.

Fever

Fever is a sign of infection. The patient may feel cold and shivery, or be hot and/or sweating, with the forehead hot to the touch. It is extremely important to reduce high fevers. The very ill and the elderly may have infections without a high fever.

Some suggestions for care:

- Bathe the patient with warm or slightly cool water (not hot) to reduce high fever.
- Cover lightly. Avoid heavy covers and clothing.
- Provide fresh air and shade.
- Give paracetamol 3 times daily with food.
- Encourage plenty of fluids.
- Give drugs to treat infection as instructed by the doctor or nurse.

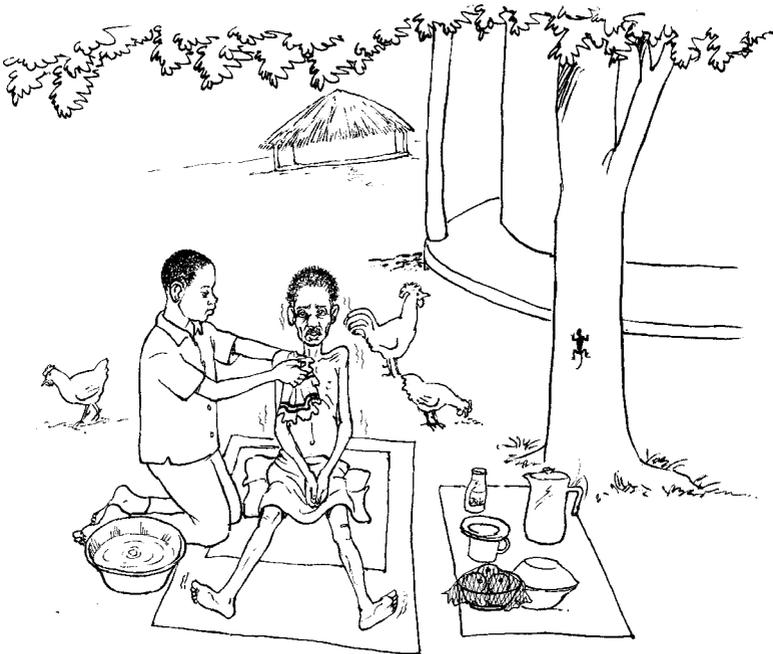


Fig 30. 'This cool water will make you feel much better.'

REPORT urgently if the patient loses consciousness. Also report signs such as coughing, difficulty breathing, stiff neck, pain, severe diarrhoea, fits, confusion or vomiting.

Swelling (Oedema)

Swelling can happen anywhere on the body. It can be related to malnutrition, Kaposi's Sarcoma, other cancers, heart problems and other conditions.

Some suggestions for care:

- Keep the patient's feet raised on pillows or piles of folded cloth if legs are swollen.
- Ensure the patient is wearing loose clothing.
- Treat shortness of breath (see page 42).
- Encourage rest and gentle activity.
- Massage swollen areas gently.



Fig 31. It is important to rest and to elevate swollen limbs.

REPORT if the cause of swelling is not known, or if it causes distress or difficulty breathing.

Loss of Appetite and Weight Loss

This can be very upsetting for families, who may try to force the patient to eat. It can lead to family conflict and even neglect of the patient's needs.

Some suggestions for care:

- Ask the patient why he or she does not want to eat (Depression? Worries? Nausea? Constipation? Diarrhoea?)
- Offer some of the patient's *favourite* high-calorie foods that are available and easy to chew, swallow and digest (such as nsima, rice, potatoes, bananas, cassava, etc.).
- Offer small, frequent snacks and meals.
- Encourage gentle exercise.
- Do not rush, force-feed or be angry with the patient.
- Give encouragement to the patient and family.

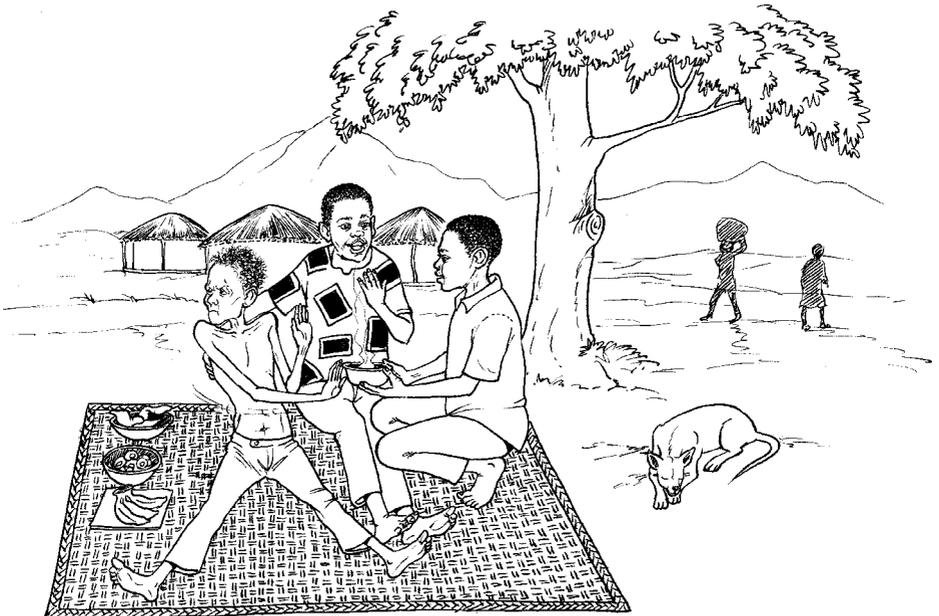


Fig 32. 'Just try a few bites of Irish potato fresh from the market.'

REPORT if the cause is not known or if there is unexpected or rapid weight loss, refusal to eat, inability to swallow, fever, headache, confusion, swelling, muscle spasms or other symptoms.

Shortness of Breath (with or without a Cough)

Shortness of breath is a common and frightening symptom of chest infections, TB, Kaposi's Sarcoma or heart failure. Patients often feel that they are suffocating.

Some suggestions for care:

- Place the patient in the most comfortable position with pillows or other support (usually sitting up and sometimes leaning forward with arms bent to support the body). Pursing the lips may help.
- Refresh the patient with fresh air and/or fanning.
- Give the patient plenty of fluids to loosen secretions.
- Teach coughing and breathing techniques: take a deep breath and then cough.
- Encourage the patient to relax and save energy.
- Offer soothing drinks such as hot drinks, lemon and honey.
- Boil a pan of water to humidify the air.
- Teach hygienic coughing technique: cover mouth with back of the left hand or the inside of the elbow when coughing. Wash hands or arm.
- Teach clean disposal of sputum. Spit into a can of sand. Keep the can covered. Discard in pit latrine. Wash the can with Jik or with soap and boiling water. Wash hands. Or spit into a tissue and discard in a flush toilet. Wash hands.

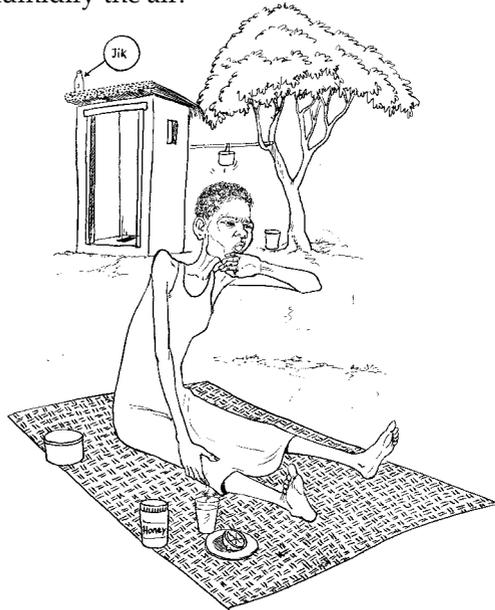


Fig 33. Teach coughing and breathing techniques.

REPORT if there is pain, difficulty breathing, blood in the sputum, a cough lasting more than two weeks, signs of respiratory infection such as fever, green or brown sputum, or if there is chest pain.

Sore Mouth and Swallowing Problems

Sore mouth and swallowing problems can lead to dehydration and malnutrition.

Some suggestions for care:

- Try and identify the cause (infection, sores, inflammation, etc)
- Offer soft foods that are easy to chew and swallow – moisten them with a little liquid to help food go down.
- Offer cool foods – *not* hot.
- Ensure regular mouth care – use a soft cloth if the mouth is sore.
- Rinse mouth with salty water after meals and at bedtime.
- Give small frequent meals, allowing time for the patient to eat slowly.
- If there is pain dissolve 2 aspirin in water and rinse the mouth 3 or 4 times a day with this solution.
- Give frequent, small sips of water or other fluids (not sweet drinks) to keep the mouth moist.
- Suggest sucking on pineapple, orange or other fruit if it is not painful to do so.



Fig 34. 'Maybe these aspirin will help my pain.'

REPORT if problems persist such as difficulty swallowing, pain, sores, white plaques or bad breath.

Wounds and Pressure Sores

The best treatment is always PREVENTION. Pressure sores are difficult to treat and can lead to a painful and even early death (see page 21).

Some suggestions for care:

- Avoid pressure on damaged areas of skin.
- Clean small sores with cooled boiled water in which you have put a pinch of salt. Allow the wound to dry in the air (if it is not deep). You might also try papaya latex water (see recipes on page 61).
- Avoid the use of irritating or strong soaps.
- Clean the skin around wounds and protect with a barrier cream such as Vaseline.
- Ensure painkillers are taken as instructed.
- For bloody wounds or those that have a bad smell, try crushing metronidazole tablets and sprinkle them over the wound before applying a clean dressing.
- To control odour, keep the room airy and put charcoal or vinegar in a pan.
- For deep sores: clean daily with salty water, fill with honey and/or sugar, or apply ripe papaya and cover with a clean dressing. (*Note: do not apply papaya to bleeding wounds or leave on for longer than two hours.*)
- Cover wounds to keep them clean and protect dignity.



Fig 35. 'We are going to clean and cover his wound, and turn him every two hours so it doesn't get worse.'

REPORT if there is pain, bleeding that does not stop, swollen glands, or signs of infection such as bad smell and discoloured skin.

Itching Skin

Itching skin is a common symptom and may be due to disease, drugs, infection, allergy or simply dryness.

Some suggestions for care:

- Cool the patient with fresh air or fanning.
- Try bathing with sodium bicarbonate washes (1tablespoon in small amount of clean, cool water).
- Use cool water, not hot, and apply moist, cool cloths.
- Put a tablespoon of vegetable oil in 5 litres of cool water for bathing.
- Encourage the patient to avoid scratching – keep the skin clean and nails trimmed.
- Apply soothing creams such as Vaseline lightly after bathing.
- Try wrapping tea leaves in a wet cloth and patting gently on itchy areas. Dabbing with slices of cucumber can also soothe itchy skin.
- Apply calamine lotion, menthol cream or cortisone cream if available (do not apply to broken skin).
- Ensure clothing and bedclothes are clean and changed regularly.

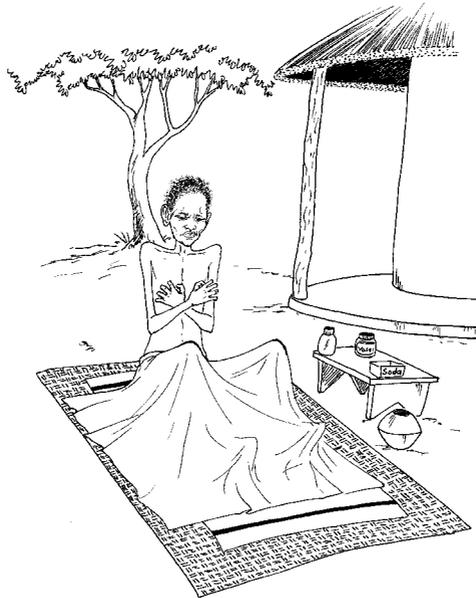


Fig 36. 'Oh, oh, I am itching all over! Where is the Vaseline?'

REPORT if there is unrelieved itching, blisters or signs of infection such as pus, pain, fever, swelling and heat.

Anxiety and/or Difficulty Sleeping

Sleeping problems, anxiety and grief can make pain and all other problems worse.

Some suggestions for care:

- Encourage the patient to talk about fears and concerns. Check for possible causes: physical (pain and symptoms), emotional, spiritual and social.
- If you think the patient is seriously anxious or suicidal, ask direct questions such as: 'Do you feel very sad?' or 'Do you sometimes think about wanting to die?'
- Encourage activities and distractions that the patient enjoys, including visits with friends.
- Give warm, comforting drinks before sleeping.
- Give massage if it helps.
- Provide peace, comfort, quiet and privacy for sleeping if possible.
- Provide a bednet.
- Offer counselling and emotional support.

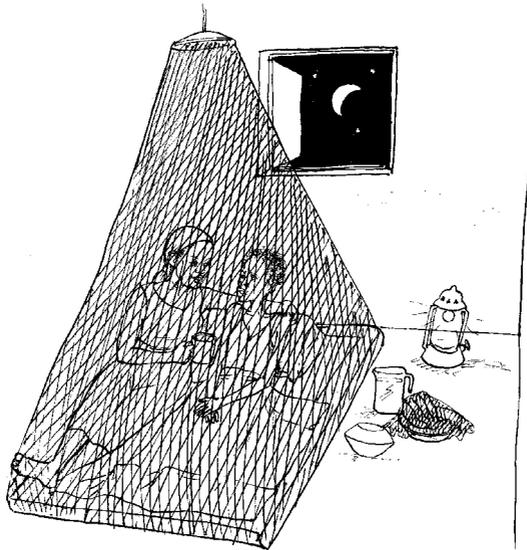


Fig 37. 'This hot drink will help you relax and sleep, do you want anything else?'

REPORT if home remedies do not help or if there is pain/distressing symptoms. Report **urgently** when the patient is very depressed and you think he or she may be thinking of suicide. Involve pastoral care from a trained worker or a priest, pastor or imam if appropriate.

Confusion

This is a common symptom in advanced illness. There may be problems remembering, thinking or talking sensibly. The patient may become fearful, quiet and withdrawn, and/or may even see or hear things that are not there.

Some patients may behave very strangely and swear, shout or go about undressed. Confusion may be worse at night. Some drugs can make this condition worse.

Some suggestions for care:

- Explain to relatives and caregivers that the patient is not crazy or bewitched. Confusion is caused by the illness.
- Speak to the patient calmly, clearly and in a friendly manner.
- Remind the patient where he/she is, what time of day it is, and so on.
- Try to ensure that care is given by people the patient knows and trusts.
- Ensure safety and remove dangerous objects and drugs.
- Keep to the familiar daily routine. Keep everything calm and quiet.
- Have a night light if it is safe to do so.

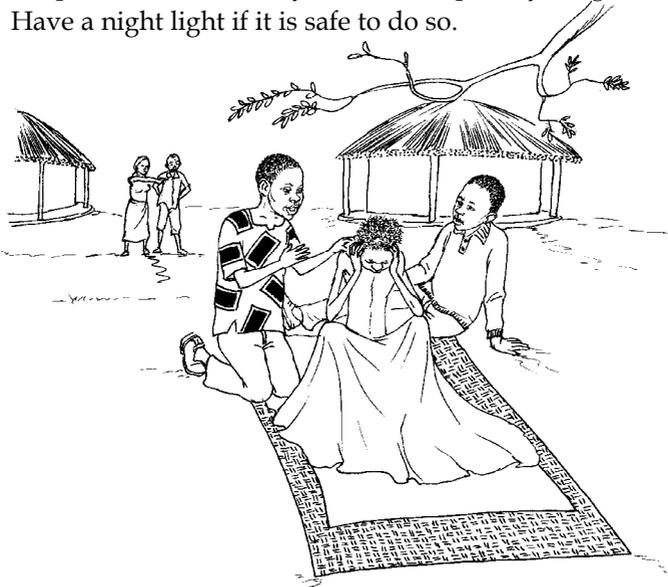


Fig 38. 'No, you are not crazy. You are confused because you are sick.'

REPORT any new confusion or if confusion is causing aggressive or dangerous behaviour, extreme distress of the patient or family, if the family cannot manage, or if the patient is being blamed for his or her confusion.

9. Counselling

The purpose of counselling is to help patients and families express their feelings and worries, identify their needs and their strengths, and manage their problems.

Steps in Counselling

1. Prepare yourself

Know how much time you have and be ready to listen. Have a pen and paper to make notes, if available. Think about what you already know and what more you need to find out about the patient and family situation.

2. Prepare the setting

Make sure the patient is comfortable and that there is privacy, if possible.

3. Begin

Explain how much time you have and why you are here. Explain what you need to know and how you might be able to help.

4. Conduct the session

- Identify and assess the person's needs and wishes holistically. What does he/she want to change?
- Identify the most urgent problems.
- Discuss possible solutions and the how they might work.
- Make a plan of action together.

5. End the session

Sum up. Are there more questions or issues that should be discussed? Praise his/her efforts. Make referrals as needed to pastoral or other services. Plan the next visit.



Fig 39. 'I know you are worried about the children. I came today to meet with you both to talk about how we can get them back to school.'

REPORT and REFER to the appropriate service and/or person when there are serious problems such as pain, abuse, violence, depression, risk of suicide, hunger, neglect, poverty and so on.

Making a Will

Encourage your patients to write a will early in their illness to protect their loved ones. Ask a local extension worker or social worker to help your patient make a will.

The will should be kept in a safe place such as the District Commissioner's office, the office of the pastor or of another trusted individual.

What is a will?

- It is a legal document that states how a person wishes to distribute his or her property after death. It helps protect the survivors, including widows and children, from property grabbing, theft and other kinds of loss of property that can leave them in a state of poverty.
- It may also include other directives in line with the person's wishes concerning burial or care of children, for example.

How to make a legal will

- Anyone over 18 years of age and of sound mind may make a will.
- It may be handwritten or done by a lawyer.
- It requires the signatures of two witnesses (also over 18 years of age).
- It must contain the full name and address of the person writing the will as well as the full names of spouse(s), children and other beneficiaries.
- It must include a description of properties owned by the person making the will and how they are to be distributed in the event of their death.

10. End of Life Care: Helping the Patient and Family

At the end of life a person becomes weaker and may begin to refuse food and/or fluids. This may happen slowly in cancer patients, but it is more unpredictable in patients with HIV/AIDS. At the end of life, patients and families need extra care and support.

Responding to Emotional Needs at the End of Life

The patient's needs

- Listen to the patient's concerns, wishes and feelings. Provide help or counselling as needed.
- Pay attention to the patient's efforts to communicate – his or her words, facial expressions and body language.
- Answer questions honestly. Make sure you understand what the patient is really asking before you answer.
- Help the patient plan for the support of children and family members.
- Arrange for pastoral care if desired. Pray together if asked.
- Respect the patient's wishes and feelings.
- Try to ensure the atmosphere is calm.
- Do not leave the patient alone if this is possible.

The family's needs

- Help family members with their needs and concerns.
- Be calm with the family and help them understand what is happening.
- Tell family members the patient can hear and feel touch even if unable to respond – encourage them to communicate with the patient.
- Show the family how to do mouth care, positioning and so on.
- Encourage family members to allow the patient to die peacefully. They may try and close the patient's eyes and straighten the limbs. Help them understand that this may be causing pain; they can do this later.
- Allow family members to express their grief in their own way as long as it is not upsetting to the patient. Try to ensure the atmosphere is calm for the patient at all times.



Fig 40. Encourage the family to allow the patient to die peacefully.

Management of Symptoms at the End of Life

Pain

- It does not usually become worse but may be harder to assess.
- Look for pain in facial expression, or signals such as clenched hands or a tense body.
- Look for and treat anything causing discomfort, for example the patient's position, incontinence, pressure sores and so on.
- Try to reassure the patient gently if he or she is anxious.
- Remember that moaning may not always be a sign of pain, but may be due to confusion.
- Morphine doses may need to be reduced (but not stopped) as the patient becomes dehydrated. Sometimes it is given rectally or dripped very slowly into the patient's mouth (as ordered by the clinician).

Weakness, fatigue, loss of ability to move and communicate

- The patient will need more help with turning, bathing, mouth care, eye care, pressure area care and small changes in position.
- Explain to the family that the patient may still hear what they are saying even if he or she is unable to respond.

Refusal of food or fluids

- Do not force the patient to take food or fluids, instead increase mouth, eye and skin care.
- Explain that dehydration is not painful.

Noisy and/or irregular breathing

- Reassure the family that this is usually not distressing to the patient.
- Position the patient so that breathing is quieter – lying on his or her side.
- Give mouth care, especially when the mouth is open much of time.
- Clean out excessive saliva gently with a cloth, but do not cause choking.

Confusion and/or restlessness

- This is a common problem.
- Try and find out what is distressing the patient.
- Do not argue with the patient who may see and hear things that are not there; be gentle.
- Help families to be calm and talk quietly to the patient.
- If there are fits, protect the patient. Remove hard objects and place a pillow under the head. (Assure the family that the patient is not generally aware when having fits.)
- Restlessness may be due to overheating. Explain to the family that the patient may have cold hands, arms, feet and legs, but they can have the feeling of being hot. Keep covers loose and provide fresh air.

Bad odour

- Keep the patient, clothing and covers clean, and ensure there is plenty of fresh air.
- Control odours with charcoal or vinegar in a dish. It can also help to crush tablets of metronidazole and sprinkle onto wounds.

Sudden death

- The most frightening cause of sudden death is bleeding, internal or external.
- Be calm and support the family.
- Hold and support the patient, and place in a side-lying position to prevent choking.

At the Time of Death

- Respect the family's feelings and needs.
- Talk to the family gently but honestly to avoid panic.
- The signs of death may be: breathing and pulse stop; eyes are partially open, fixed and glazed; the jaw drops and the mouth is often open; the patient may pass urine or stool; and there is no response to touch or voice.
- Calmly support family members in their grief.
- Respect religious and cultural traditions.
- Handle the body with respect and tenderness.
- Do not judge them in their reactions or forbid them from weeping.
- Offer prayer and pastoral care.
- Offer to assist in caring for the body if the family wishes.
- Pay special attention to the needs of children.
- Offer continuing support to the family.



Fig 41. Religious and cultural traditions can be a source of comfort for the family.

REPORT the death to the nurse.

REFER to community supports and to pastoral care as desired by the family.

FOLLOW UP to assess the needs of the family.

11. Grief and Bereavement

People need to grieve their losses in order to move forward in their lives. Listen to them, and give them your support and attention. Such support may help prevent long-term social and emotional problems.

Some Common Grief Reactions

Emotional and psychological

Shock; denial; anger; sadness; depression; guilt; confusion; worry; fear; constantly thinking about the dead person; thinking about killing oneself.

Spiritual

Loss of faith; wanting to join the dead person; asking for answers; turning to God; wanting spiritual support.

Social

Avoiding friends and family; secrecy and shame; conflict and blaming someone for the death.

Physical

Loss of appetite; trouble sleeping; pain in the chest; difficulty breathing; diarrhoea; crying; sighing; restlessness; fatigue; drinking alcohol to forget; promiscuous sexual behaviour.

How You Can Help

- Allow the grieving person to express feelings of pain and grief – listen to their feelings, thoughts and memories.
- Be a friend. Be understanding. Be patient.
- Help family and friends understand that people need to grieve, to talk about the dead person and their pain. It is healthy and necessary. It takes time.

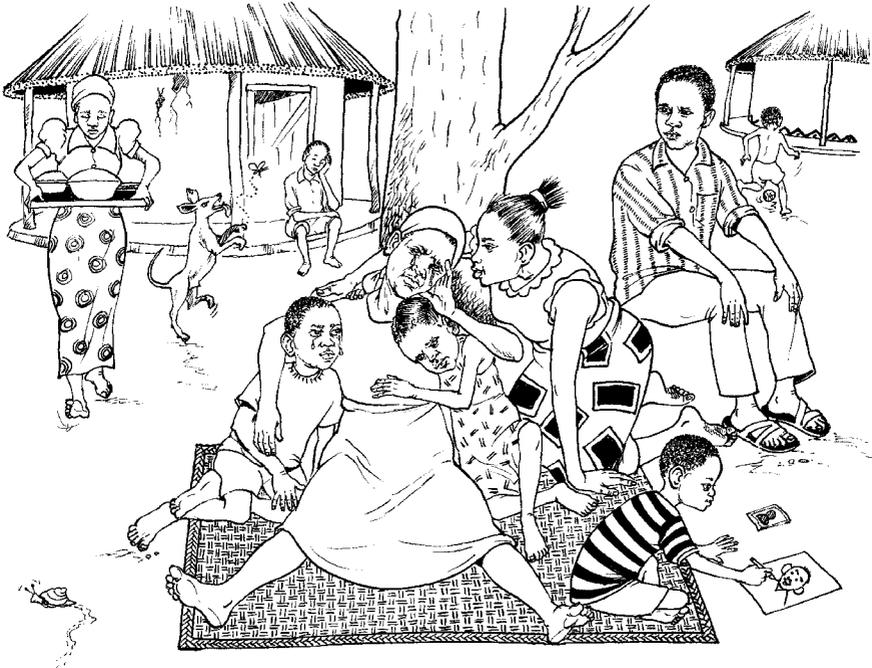


Fig 42. 'Everyone is feeling sad. Little Grant is drawing a picture of his daddy because he misses him!'

- Help the grieving person to make decisions and solve practical problems.
- Do not encourage hasty decisions.
- Encourage the person to eat well and to take care of him or herself.
- Encourage activities that help heal the pain, such as looking at photos, making a memory book, joining a support group if appropriate, drawing pictures, playing games and so on.

REPORT if the person has been grieving for a very long time, is unable to manage daily life, is getting drunk or being destructive or suicidal.

REFER to a pastoral care provider, a priest, a pastor or imam for spiritual support; to community/social resources for financial or other problems; to a child specialist if a child appears to be having a very difficult time coping with grief.

Helping Grieving Children

Children grieve differently from adults. As a result their needs are often neglected. Children may imagine that the dead person has just gone away for a short time. They often think they did something to cause the person to die. They imagine many things and are frightened to speak of them. They may feel abandoned (perhaps because other adults are busy dealing with their own grief) when they need love the most.

Children may show their grief in different ways, such as:

- being disobedient, angry and aggressive
- having bad dreams, fear of being alone
- losing interest in school or friends
- imitating the person who has died
- starting to behave like a much younger child.

You can help children by:

- giving them love and acceptance
- listening to them and being with them
- talking to them honestly
- letting them visit and talk to their parent or relative who is dying
- understanding that crying is necessary and normal
- praying with them, making a scrap book, looking at photos, telling a story, letting them draw pictures
- encouraging family members to support the child and to understand the need to grieve
- asking for help if you do not know how to help the child.

12. Caring for Yourself

You do very difficult work. You do it from the kindness of your heart. You often work without enough resources. You work long hours and travel long distances. You are rewarded by seeing the relief of the pain and suffering of your brothers and sisters in your community. But your patients still die. And many die alone and in pain, even with all your efforts. So you have many losses and may often feel that you can never do enough. Over time, this takes its toll on you. This is called burnout. You need to take care of yourself and of each other. If not, you can become ill, depressed and unable to work.

So Who Takes Care of You?

You need to:

- Recognize the signs of burnout in yourself and in your colleagues: fatigue, loss of interest in your work or even in your family, feelings of helplessness, loss of self-esteem, withdrawal, not sleeping, depression, not caring, crying, giving up, forgetfulness, irritability, bowel upset and many other signs and symptoms.
- Act immediately to correct these problems.
- Give yourself rest, nutritious food and time away from your work.
- Acknowledge that the work is indeed stressful. Share problems and solutions with colleagues. Perhaps form a support group at work.
- Ask for support from your co-workers, family and friends.
- Take time to do things you enjoy.
- Ask for a refresher course or some training.
- Lighten your workload for a while.
- Take time off for yourself.

Remember that without you, there can be no palliative care.

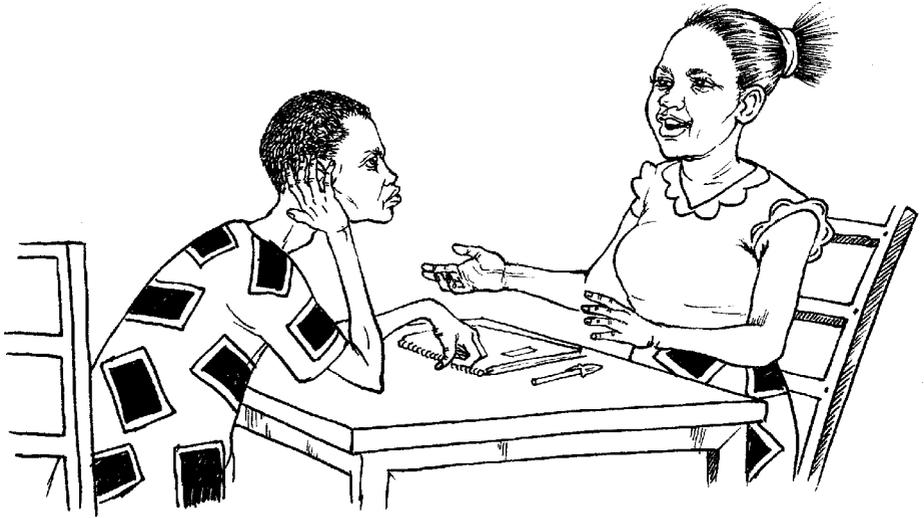


Fig 43. 'You work so hard. You need also to rest, eat well and go and play soccer again with your friends!'

13. Recipes

For Mouthcare

Salty water mouthwash

Salt (1 tablespoon) and clean or boiled water (4 cups).

Mixed salt/soda mouthwash

Salt (1/2 teaspoon), baking soda (1 teaspoon) and clean or boiled water (4 cups).

Sodium bicarbonate mouthwash

Baking soda (1 teaspoon) and clean or boiled water (2 cups).

For Diarrhoea

Guava leaf tea

A fistful of guava leaves and clean or boiled water (1 litre). Boil for 10–20 minutes and strain.

For Constipation

Papaya Seeds

Give the patient 5 to 10 papaya seeds to chew first thing in the morning, or put 1/2 teaspoon of dried, crushed papaya seeds in porridge for children.

For Dehydration

Oral rehydration solution (ORS)

Clean or boiled water (1 litre or 4 cups), salt (1/2 teaspoon) and sugar (2 tablespoons).

Drink several glasses daily: 3 litres for adults, and smaller amounts for children (1/2 litre to 3 litres according to their weight and age).

For Cleaning Wounds

Papaya latex water

Take 5 drops of latex from a washed unripe papaya still on the tree and mix it with 1 litre of cooled, boiled water.

For Treating Wounds and Pressure Sores

Honey and/or sugar

Wash the wound daily with boiled and cooled salty (1 tablespoon/litre) water.

Apply one of the following:

- a) Honey/sugar mixture to cover the wound. Cover with clean dressing and re-treat a few times a day.
- b) A spoon of sugar (brown or white) to cover the wound. Apply as above.

Papaya

Apply a slice of not-too-ripe papaya on the wound and hold it in place. Do not put on bleeding wounds and do not leave it in place for more than 2 hours.

For Itching Skin

Sodium bicarbonate washes

Dissolve 1 teaspoon of sodium bicarbonate (baking soda) in a small amount of water and apply to the skin.

For Boosting Energy

Power drink

1 cup chopped ginger; 2 cups lemon juice; 3 cups peeled, chopped aloe vera; brown sugar to taste; 2 tablespoons honey; 5 litres of water. Boil for two hours. Take 1 tablespoon 3 times daily, if tolerated, to boost energy.

14. Notes
