A GUIDE FOR PATIENTS, FAMILY MEMBERS AND COMMUNITY CAREGIVERS

CAREGIVER BOOKLET



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HOW TO USE THE BOOKLET

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

This booklet explains how to:

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

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

The first section of the booklet covers ways to prevent problems from occuring and should be followed in all patients. The second section explains how to treat specific symptoms that may occur.

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



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

PREVENTING PROBLEMS IN ALL PATIENTS

KEEPING CLEAN

- Mouth and teeth cleaning should be done after meals. The caregiver can assist if necessary.
- Use a toothbrush or stick to gently scrub teeth, tongue and gums to remove food.



A tooth cleaning stick and tooth brush

- Bathe daily with soap and water.
- Ensure privacy during bathing.



Bed bathe the sick person if he or she is unable to bathe alone

- The sick person can wash his or her own private parts while able. When this is not possible, the sick person should choose the caregiver who assists.
- Wash the sick person's clothes and beddings frequently.
- Dry the skin gently with a soft towel after bath.

- Oil the skin with cream, body oil, lanolin or vegetable oil.
- Use plastic sheets under the bed sheets to keep the bed dry in case of loss of control of urine or faeces.
- Massage the back, hips, elbows, and ankles with Vaseline.
- If there is leakage of urine or stool, protect skin with Vaseline applied around private parts and rectal area.
- Support the sick person over the container when passing urine or stool, so as to avoid soiling the bed or injury to the sick person.
- Spread beddings out regularly in the sunshine.
- Finger nails and hair should be kept short, as long nails can hold germs and damage the skin.



Caregiver cutting the nails of a patient

PREVENTING BEDSORES IN BEDRIDDEN PATIENTS

Remember that prevention is always better than cure, therefore:

- If possible, help the bedridden patient sit up in a chair from time to time.
- Lift the sick person to change position in bed –do not drag as it breaks the skin.
- Encourage the sick person to move his or her body in bed whenever possible.
- Change the sick person's position on the bed often—if possible, every one or two hours, using pillows or cushions to hold the position.
- Keep beddings clean and dry.
- Look for damaged skin (change of colour) on the back, shoulders and hips everyday.
- Put extra soft material, such as a soft cotton towel under the sick person.

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

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

PREVENTING PAIN IN MUSCLES AND JOINTS

Due to long periods of inactivity and lack of exercise, the sick person may suffer stiff joints and muscle fatigue.

- Encourage the sick person to get out of bed if possible.
- Encourage the sick person to move in bed.
- Regularly massage the sick person with Vaseline or oil.
- Encourage exercise at least twice daily and help with movement of ankles, knees, hips, wrists, elbows, shoulders and neck (both sides).
- Hold the limb above and below the joint while moving it.
 Support as much of its weight 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 above but with firm steady pressure.
- Exercise the wrists: Bend wrists gently and slowly without causing pain. If you want to stretch, apply pressure bit by bit.

Repeat the exercise several times.

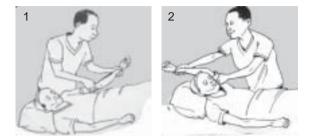




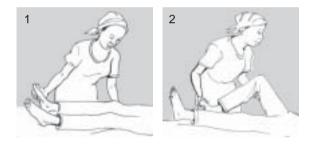
• Exercise the elbows: Gently lift the forearm up and down. Repeat the exercise several times.







• Exercise the shoulders: Gently lift the arm up and bring the hand above and behind the head. Move the arm side to side. Repeat the execise several times.



• Exercise the knees: Gently bring the knee up and to the side. Repeat the execise several times.

In all cases, let the sick person do as much as he/she can do. Help when the sick person can't perform the exercise on his/her own.

PREVENTING DIFFICULTY IN PASSING STOOL (CONSTIPATION)

Prevent constipation:

- · Offer drinks often.
- Encourage fruits, vegetables or porridge.
- Encourage exercise if possible.

PREVENTING MALARIA



- Sleep under an insecticide treated mosquito net (for example K-O net, Smartnet).
- Close windows early in the evening.

ADVICE FOR PEOPLE WITH HIV/ AIDS

Transmission in the home

HIV/AIDS is transmitted through close contact:

- unprotected sexual intercourse with an infected person
- from an infected mother to her child during pregnancy, delivery and breastfeeding
- direct contact with the blood or body fluids of an infected person.



How HIVspreads

Sexual transmission

- 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 agree. Remember to always use condoms even if both partners are HIV positive.



Always use condoms

- Discuss sex and condoms openly with your partner.
- Neither partner should be forced to do something he/she does not want to do.

From the mother to her child

- If you or your partner is HIV positive, your unborn baby may get infected.
- Discuss the decision to have children or not with your partner.



- If it is difficult to talk to your partner alone, consider seeking help from a counsellor.
- If you decide not to have a baby: ask a trained health worker about family planning.
- If you decide to have a baby or are pregnant already: There are drugs to take that can reduce the risk of passing HIV to your baby. Discuss this with a trained health worker.
- You need to take these drugs before delivery. During pregnancy, keep using condoms every time you have sex to protect against passing on HIV.
- An HIV-infected mother can transmit the virus to her baby through breast feeding. Discuss infant feeding options with a trained health worker.

Blood and body fluid contact.

 Do not share anything sharp that can pierce the skin and come in contact with blood such as a toothbrush, razor or needle.



Be careful of sharp objects

- Clean up spills of blood and other body fluids, always wearing gloves or plastic bags (kaveeras) to protect hands.
- Avoid direct contact with open wounds of the sick person. If contact occurs, wash immediately with soap and water.
- Keep wounds of patients AND caregivers covered with plastic, such as kaveera or gloves.
- Keep patient's laundry separate from other laundry if blood, stool or other body fluids on it. Continue to wash, hold an unstained corner, rinse off the blood, diarrhoea or other body fluids with water, then wash in soapy water.
- Wash your hands with soap and water after contact with body fluids or laundry.
- Dispose of things used for cleaning, like cotton wool or toilet paper, in a bin with a lid. Later, burn or bury this rubbish or dispose of it in a pit latrine.



Clean spills



Cover wounds



Separate stained laundry

Wash your hands

Wear gloves, or two kaveeras (polythene bags) when handling body fluids or dressing wounds

HOW TO PREVENT OTHER INFECTIONS

- Use safe drinking water—drink boiled water or tea when possible. Store water in container which prevents contamination (use spigot, do not dip hand or used cup into the water).
- Eat well-cooked food.
- Wash fruits and vegetables very well.
- Avoid people who have cold, flu, herpes zoster, or chicken pox.
- Practice good hand washing after using toilets, before preparing food, after sneezing or coughing, after touching genitals, after touching garbage or working in the fields.
- If possible, apply a local antiseptic to wounds after washing.

MANAGING SYMPTOMS

FEEDING AND MANAGING WEIGHT LOSS

- Encourage the sick person to eat, but do not use force as the sick person may not be able to accept the food and may vomit.
- Offer frequent, smaller meals of foods the sick person likes.



Commonly available foods

 Let the sick person choose the foods he or she wants to eat from what is available.



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.

Never Give Up

WHEN THE SICK PERSON VOMITS OR FEELS LIKE VOMITING (NAUSEA)

If the sick persons feels like vomiting:

- Seek locally available foods that the patient likes (tastes may change with illness) and that cause less nausea.
- Offer frequent small foods such as roasted potatoes, cassava or gonja.



Give the sick person something small to eat

- Offer the drinks the sick person likes, such as water, juice or tea. Take drinks slowly and more frequently.
- There are some effective and safe local remedies like licking ash from wood.
- If possible, avoid strong odours and cooking close to the patient.



Seek help from a trained health worker for vomiting lasting more than one day, dry tongue, passing little urine or abdominal pain.

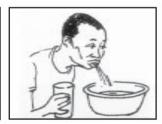
PAINFUL MOUTH ULCERS OR PAIN ON SWALLOWING

If the sick person has mouth ulcers, seek the help of a health care worker. In addition, you can try the following:

- Avoid extremely hot or cold or spicy foods.
- Remove bits of food stuck in the mouth with cotton wool, gauze or soft cloth soaked in salt water.
- Rinse the mouth with dilute salt water (a finger pinch of salt in a glass of water) after eating and at bedtime, or with a half teaspoonful of baking powder (sodium bicarbonate) in a mug of water (500 ml) if there are white patches in the mouth (thrush/candida).
- Use a soft tooth brush or stick to remove debris.
- Where available, mix 2 tablets of aspirin in water and rinse the mouth up to four times a day.







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

- Give soft foods, such as cold milk, porridge, potatoes or honey depending on what the sick person feels is helpful.
- If possible, avoid strong adours and cooking close to the patient.

Never Give Up



Seek help from a trained health worker if no response to home treatment, persistent sores, smelly mouth, white patches or difficulty swallowing.

DRY MOUTH

Give frequent sips of drinks.



- · Moisten mouth regularly with water.
- Let the sick person suck on fruits such as pineapple, orange or passion fruit.



Seek help from a trained health worker if dry mouth persists.

DIFFICULTLY IN PASSING STOOL (CONSTIPATION)

Do exam for rectal impaction (always wear gloves).

Check for rectal impaction

- Encourage movement and exercise if possible.
- Use local herbal treatment: for example, crush some dried paw paw seeds and mix half a teaspoon in water and give to the sick person to drink.

Get some pawpaw seeds



Dry and crush them



Mix in water and give to drink

- Take a tablespoon of vegetable oil before breakfast.
- If stool is hard and will not come out, sit in a basin of water, or gently put Vaseline or soapy water into the rectum. The caregiver can help, always remembering to use gloves.



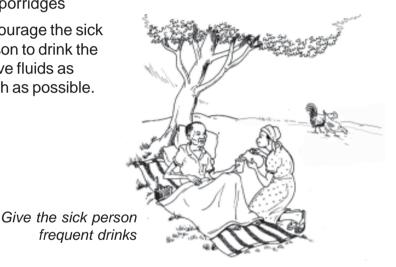
Seek help from a trained health worker for pain or difficulty in passing stool when home remedies do not work.

Never Give Up

DIARRHOEA

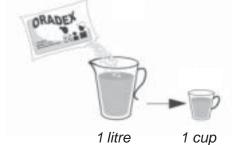
To help someone with this condition do the following:

- Give the sick person frequent drinks in small amounts:
 - water
 - rice soup
 - other soups
 - porridges
- Encourage the sick person to drink the above fluids as much as possible.



Avoid very sweet drinks and alcohol.

· Make oral rehydration solution (ORS) and give as a drink frequently.



• Encourage the sick person to continue eating.

Care for the rectal area:

- After the sick person has passed stool, clean rectal area with toilet paper or soft tissue paper.
- Wash the rectal area when necessary, with soap and water.
- If the sick person feels pain when passing stool, apply Vaseline around the rectal area.



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

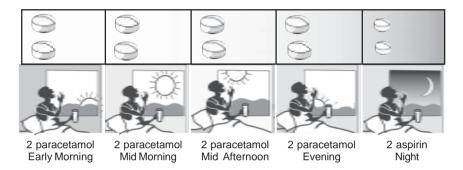
- vomiting with fever
- blood in the stool
- if diarrhoea continues for more than 5 days
- if patient becomes even weaker
- if there is broken skin around the rectal area.

Never Give Up

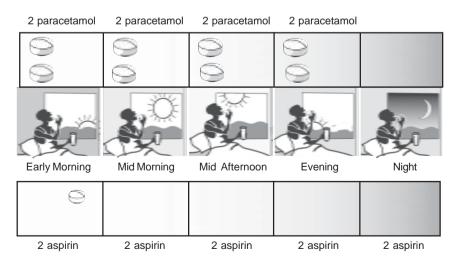
CONTROLLING PAIN OR HEADACHE

Pain is common and can be relieved:

 For mild pain in adults - use paracetamol (Panadol) 2 tablets every 4 hours, and aspirin or ibuprofen at night.



 For pain that re- occurs regularly after regular doses of paracetamol, add aspirin or ibuprofen in between doses of paracetamol and give aspirin or Ibuprofen at night.



Note: All pain killers must be given after meals or a snack.

- In addition to giving medicine, talking to sick people and playing soft music can help them relax.
- Avoid things that make pain worse; for example, if a dressing is stuck to a wound, soak it in clean water before removing.
- Move the sick person with care.



Seek help from a trained health worker for more severe pain. Pain control is possible.

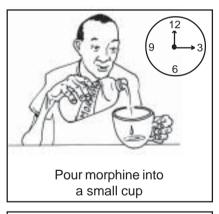
Never Give Up

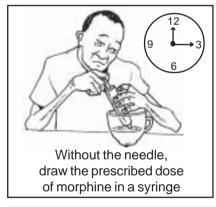
ORAL MORPHINE

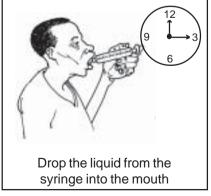
Oral morphine is a strong pain killer. If you have been prescribed oral morphine, follow these directions. Oral morphine should be taken:

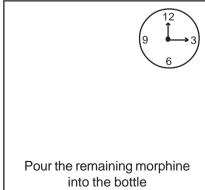
- by the sick person
- by mouth
- by the clock (regularly by the sun/ moon, or radio, approximately every 4 hours).

The dose should be as prescribed.

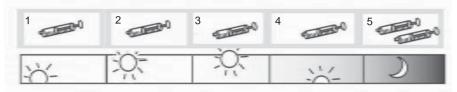








 Take doses regularly, every 4 hours during the day with a double dose at bedtime.



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

Side effects that may occur and simple solutions:

- Nausea: It usually goes after a few days of starting oral morphine and does not usually come again.
- Constipation: it always occurs. Always give preventive local remedies such as dried paw paw seeds or a laxative such as senna at night (see above).

Never give a laxative if the patient has diarrhoea. Morphine will help reduce diarrhoea.

- Dry mouth may occur: give sips of water (see above).
- Drowsiness: may occur in the first few days after starting oral morphine, but do not stop the morphine as the drowsiness usually goes away. If drowsiness lasts more than a few days, halve the dose.

Inform the health worker if:



- The pain is getting worse or you gave an extra dose.
- Drowsiness comes back or you had to reduce the dose.

ITCHY SKIN

Itchy skin is very common. It can be due to infections or the body's reaction to morphine.

You can help the sick person get some relief by trying any of the following:

- Cool the skin or fan it.
- Avoid heat and hot water on the skin.
- Avoid scratching, which causes more itching and sometimes infection.

Do not scratch.

- Cut finger nails short and keep them clean to avoid infection.
- Use cool cloths soaked in water.
- Apply aqueous cream, or Vaseline on the itching part of the body after a bath before drying.
- Put one tablespoon of vegetable oil in 5 litres of water when washing the sick person.
- Rub the itchy skin with cucumber or wet tea bags (or tea leaves put in a clean piece of cloth and soaked in hot water).



Tea leaves soaked in hot water are good for itching.



Seek help from a trained health worker if itching continues or for painful blisters or extensive skin infections.

TREATMENT OF BEDSORES

You can do the following to soothe the pain of bedsores and speed up the healing process:

- For small sores, clean gently with salty water and allow to dry.
- For bedsores that are not deep, leave the wound open to the air.
- For pain, give pain killers such as paracetamol or aspirin regularly.
- For deep or large sores, clean gently every day with salt water, fill the bedsore area with pure honey or with ripe paw paw flesh and cover with a clean light dressing to encourage healing.

Applying ripe pawpaw flesh to the bedsore may help

 For bloody or smelling sores put on enough crushed metronidazole (Flagyl) tablets to cover the area.



Treatment with honey



Seek help from a trained health worker for any discoloured skin or bedsores getting worse.

COUGH AND DIFFICULTY BREATHING

For simple cough, local soothing remedies such as honey and lemon can help. Make a lemon juice-lemonade sweetened with honey.

 Use local remedies e.g. steam with menthol or eucalyptus leaves.



Honey and lemon

In addition to the treatment given by health worker:

- Help the sick person into the position that eases breathing; usually sitting is best.
 - Leaning slightly forward resting arms on a table may help.
 - Use extra pillows or some back support.
 - Open windows to allow in fresh air.
 - If it is hot, you may fan with a newspaper or clean cloth.
 - Give patient water frequently (it loosens sputum).
- Hit the sick person on the back and chest to loosen sputum and make it easier to cough.



Seek help from a trained health worker if the sick person has difficulty breathing, pain in the chest, cough lasting for more than 2 weeks or bloody sputum. The health worker will check for TB or other chest problems. Make sure TB sputum is sent if new cough for >2 weeks.

Safe handling and disposal of sputum

- Handle sputum with care to avoid spreading infection.
- Use a tin with ash or sand in it for the sputum, then cover it.

Use a tin for spitting and cover

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

TREATMENT OF HICCUPS

Hiccups can be distressing; treat the problem by trying the following:

- · Quickly drink cold water.
- · Quickly eat two heaped teaspoons of sugar.
- Rub with a clean cloth inside the top of the mouth feel towards the back, where the top of the mouth becomes soft.
- Breathe into a paper bag, stopping when you feel uncomfortable.
- Hold your breath, stopping when you feel uncomfortable.
- Pull knees to the chest and lean forward (compress the chest).

Never Give Up

HELP WITH WORRIES AND FEARS

- Take time to listen to the sick person.
- Discuss the problem in confidence.



Take time to listen to the sick person

- Providing soft music or massaging may help the sick person to relax.
- Pray together if requested.



Seek help from a trained health worker if the sick person is abnormally sad, cannot sleep, shows loss of interest or threatens to kill themselves.

TROUBLE SLEEPING

- Listen to the sick person's fears, which may be keeping them awake.
- Reduce noise where possible.
- Do not give the sick person strong tea or coffee late in the evening.
- Give treatment for pain if present.
- Give a comforting drink at night.

CARE FOR THE SICK PERSON WITH CONFUSION

Patients with confusion may show the following signs:

- forgetfulness
- lack of concentration
- trouble speaking or thinking
- frequently changing mood
- unacceptable behaviour such as going naked and using bad language

Unacceptable behaviour



Remove dangerous objects

- As far as possible, keep the patient in a familiar environment.
- Keep things in the same place easy to reach and see.
- Keep a 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 a familiar and trusted caregiver is present to look after the sick person.
- Take gradually more control of the medicine.
- Provide comfort for the sick person.

- · Avoid confrontation (arguing).
- Do not say or do things that could upset the patient since he/ she might still be able to understand.
- Use gentle reminders of place and time.



Seek help from a trained health worker if this is a new confusion or the sick person becomes violent, or for any condition not improving and causing distress.

ARV TREATMENT SUPPORT

To be adapted in countries

TB TREATMENT SUPPORT:

- TB is a disease caused by germs. It spreads most easily when it is in a person's lungs (chest).
- Patients with TB may have many different symptoms, the most frequent being coughing for more than 2 to 3 weeks.
- TB spreads to other people when someone with TB coughs or sneezes.
- It is important for a TB patient to take all TB drugs regularly, on schedule for the full duration of the treatment prescribed.
 Otherwise, the disease becomes incurable.

Prevent spread of TB by:

- Making sure patients take all treatment and are cured of TB.
- Making sure patients cover mouth and nose when coughing or sneezing.
- As a caregiver supporting TB treatment you will:
 - Link with health worker responsible for the TB treatment.
 - Provide the support, advice and encouragement that the patient needs in order to complete the treatment.

This involves:

- Watch the patient swallow the right TB drugs each time.
- Mark the TB treatment card each time the patient takes the TB drugs.
- **Encourage** patient to continue TB treatment.

- Make sure there is always a supply of drugs available for the patient.
- Refer the patient to the health facility if there are problems. If possible, take the patient to the health centre. If patient is not able, arrange for the sputum to be taken at the health centre.
- **Make sure** the patient goes to the health facility when a follow-up sputum exam is due.
- The TB drugs may have side effects. Discuss side effects so the patient can tell you if any of these signs appear:
 - If the person has nausea and no desire to eat, reassure and try giving drugs with food or porridge.
 - If orange/red urine appears, reassure the patient that this is a normal effect of the drug. Nothing needs to be done.

nember that you should help avoid the spread of TB to er family and community members.

Seek the help of a trained health worker if patient has joint pain or a burning sensation in the feet. If a new skin rash, itching, yellow skin or eyes, repeated vomiting, deafness, dizziness, or eyesight problems occur, STOP treatments immediately and then seek help from a trained health worker or take the patient to the health facility.

BURN-OUT

Burn-out is caregiver exhaustion. It can cause:

• Irritability, poor sleep, fatigue, poor concentration, emotional numbing, lack of joy, alcohol or drug use.

You should:

- Discuss this problem with others caregivers, family members and friends.
- Divide care tasks into manageable parts (small acts of care).
- Find somebody who can regularly replace you for periods of time.
- Do something outside the home, such as joining social gatherings, visiting friends, going for a walk.
- Take care of your own health and take time to rest.

PROVIDING EMOTIONAL SUPPORT NEAR THE END OF LIFE

- Be aware that the sick person may go through a range of reactions from anger and fear to sadness and acceptance.
- Learn to listen, showing that you understand and feel what the sick person is going through.
- Be sensitive—the sick person may be thinking about losing family and friends soon, and may want to talk about this.
- Listen to the concerns of the sick person, counsel and give emotional support when needed.
- Encourage other family and community caregivers to do the same.
- Discuss worrying issues such as custody and support of children, school fees and funeral costs.
- Arrange for spiritual support if asked (respect the will and faith of the person, even when converted).

Pray together if requested

 Do not take the belongings of the sick person for your own benefit.

Seek counseling for the caregivers and loved ones

GRIEVING AFTER THE LOSS OF A LOVED ONE Mourning and grief after the death of a loved one

Mourning is the natural proces of accepting a major loss:

- It may last months or years.
- It may include religious events or just being with friends and family to share feelings about loss.
- It is very important that you express grief. Feeling sadness is a part of continuing to live.

Grief may cause physical symptoms or emotional reactions:

- Stomach pain or upset.
- Loss of appetite.
- Sleep disturbances.
- Tiredness or loss of energy.
- Worsening of other illness.
- Worry or panic.
- Depression or thoughts of suicide.

Living with grief

It is natural to experience grief when a loved one dies and there are many ways to cope with pain. You might want to:

- Seek out caring people: Find relatives and friends who can understand your feelings. Join support groups with others who have had similar losses.
- Express feelings. Tell others how you are feeling.

- Take care of your health. You should try to stay healthy, eat properly and get plenty of rest. Be careful not to develop a dependence on medication or alcohol to deal with grief.
- Accept that life is for the living.
- Hold off on major life changes. Wait to make any major changes, such as moving, remarrying, changing jobs or having another child, until you have time to adjust to your loss.
- Be patient. It can take months or even years to grieve.
- Seek help when necessary. Getting help for grief is a sign of strength, not weakness.

Looking to the Future

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

PREPARING FOR DEATH

Be compassionate, and be willing to talk about the concerns of the patient (see "Providing Emotional Support" above).

Provide physical contact, such as holding hands.

Provide care:

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

If it is a child who is near the end of life:

- Be willing to talk and answer questions.
- Help the child feel loved and not alone.
- Ensure that family members are around to play when the child is able.

TAKING CARE OF CHILDREN WHOSE PARENT IS NEAR THE END OF LIFE

- Children need to talk about the loss of their parents. If you don't talk to them, they may suffer more later.
- Talk in a simple and direct way so that they can understand.



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

- Do not take children away from their dying parent as they need to be close to each other.
- Help children feel that they will still be loved and cared for, even after their parent dies.

WHO Integrated Management of Adolescent/ Adult Illness (IMAI) Project.

Field test version: This is based on the Ugandan adaptation of the IMAI Palliative Care Caregiver Education Booklet. Health workers can learn to use this booklet to educate patients and caregivers in home-based care. It should be used in conjunction with the IMAI Palliative Care module to provide clinical care.

Country adaptation is needed before use. If you wish to adapt and use this booklet please contact WHO Geneva IMAI Project. Email: imaimail@who.int

