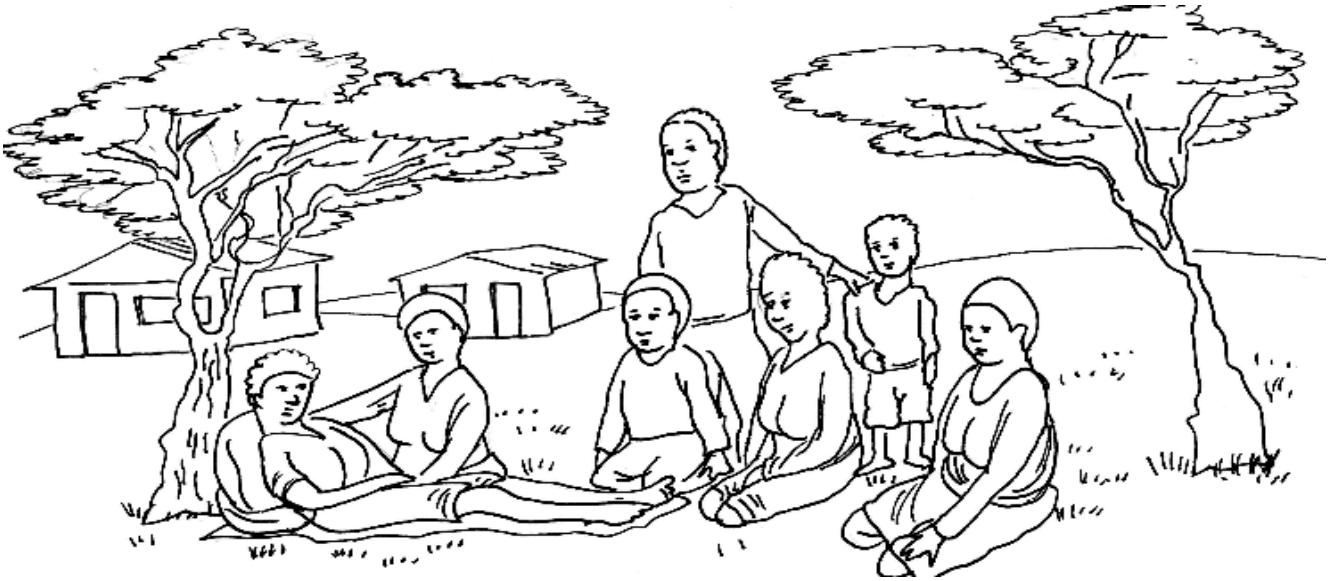
DYING AT HOME

Summary Pages For Carers

Authors
Gerard Manion, OAM
Dr. Helen-Anne Manion, OAM, MBBS, D.Pall.Med. (UWCM). F.A.Ch. P. M.
Kathleen Dansie, Diploma of Teaching, Teacher Librarian

Illustrations
Anthony Manion

WHAT DOES THE DYING PERSON NEED?

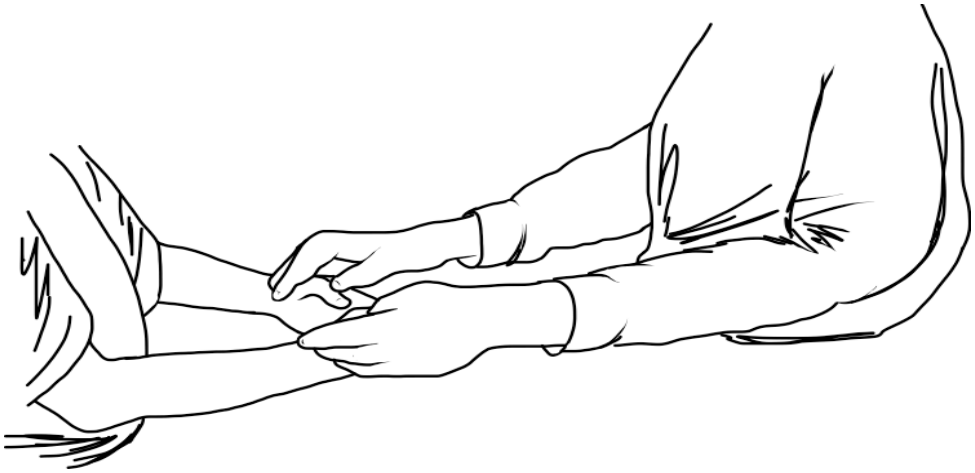


1. **Let them know they will always have someone with them.**

2. **Make them feel safe and comfortable.**

3. **RELAX with the dying person and do not hurry them.**

4. **Listen to and talk with the dying person. Listening and talking brings people together and makes them feel needed, liked and important.**

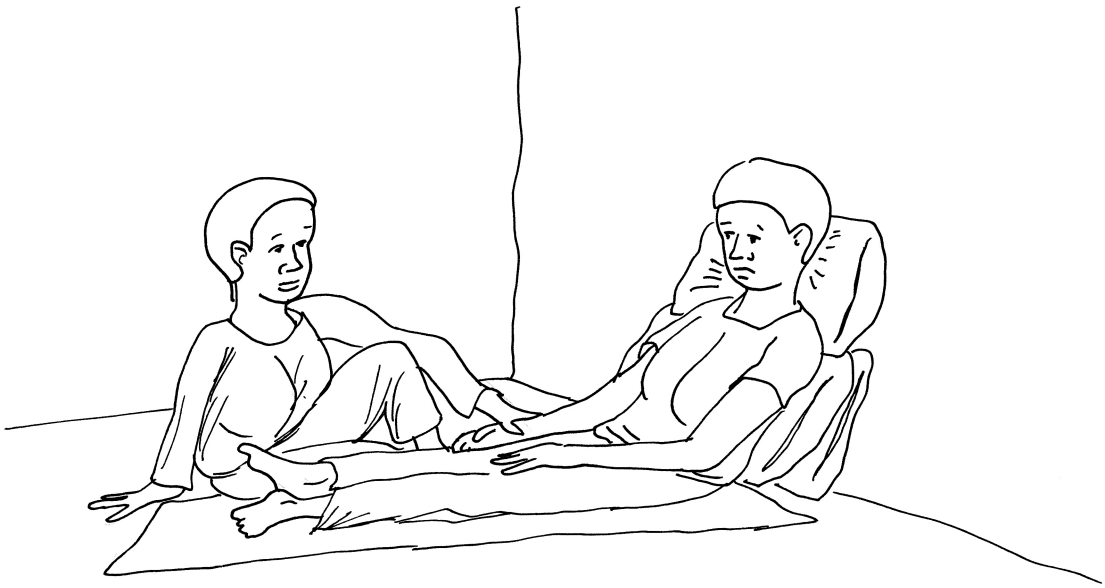


5. **SHARE: feelings, hopes, sadness, fears, worries, even anger.**

6. **TOUCH the dying person and show affection as it is so comforting and tells the sick person you care.**

Hold hands, stroke a forehead, stroke shoulders, gently massage a painful area.

7. **If the dying person does not want to talk then SHARE the SILENCE with them. They will feel loved by the touch of your hand and because you are there**



8. **ENCOURAGE RELAXATION and DEEP BREATHING.**

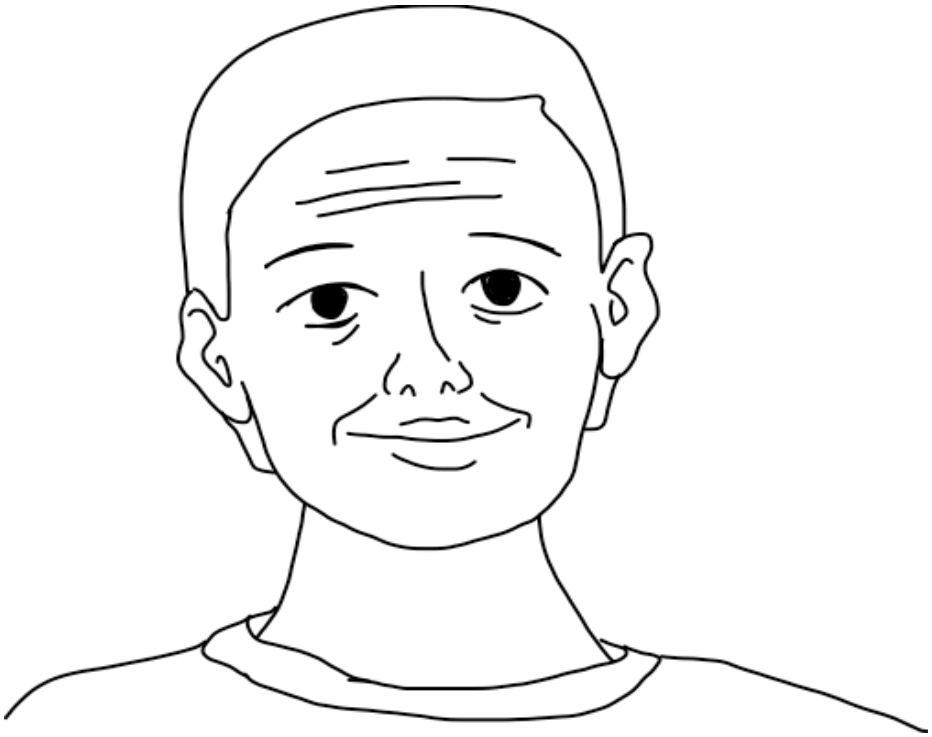
Relaxation and breathing will help the sick person become calm which will help relieve pain.

Use a CALM, GENTLE VOICE.
Say your NAME to a dying loved one to let them know you are near.

9. **ALLOW FORGIVENESS.**

10. **Say loving, healing things the dying person needs to hear and you need to say.**

BE CHEERFUL. Talk about happy memories that the sick person has experienced to MAINTAIN HOPE.



Maintaining hope is a necessary part of living.

11. Tell stories, play music, sing songs to help the dying forget their pain.

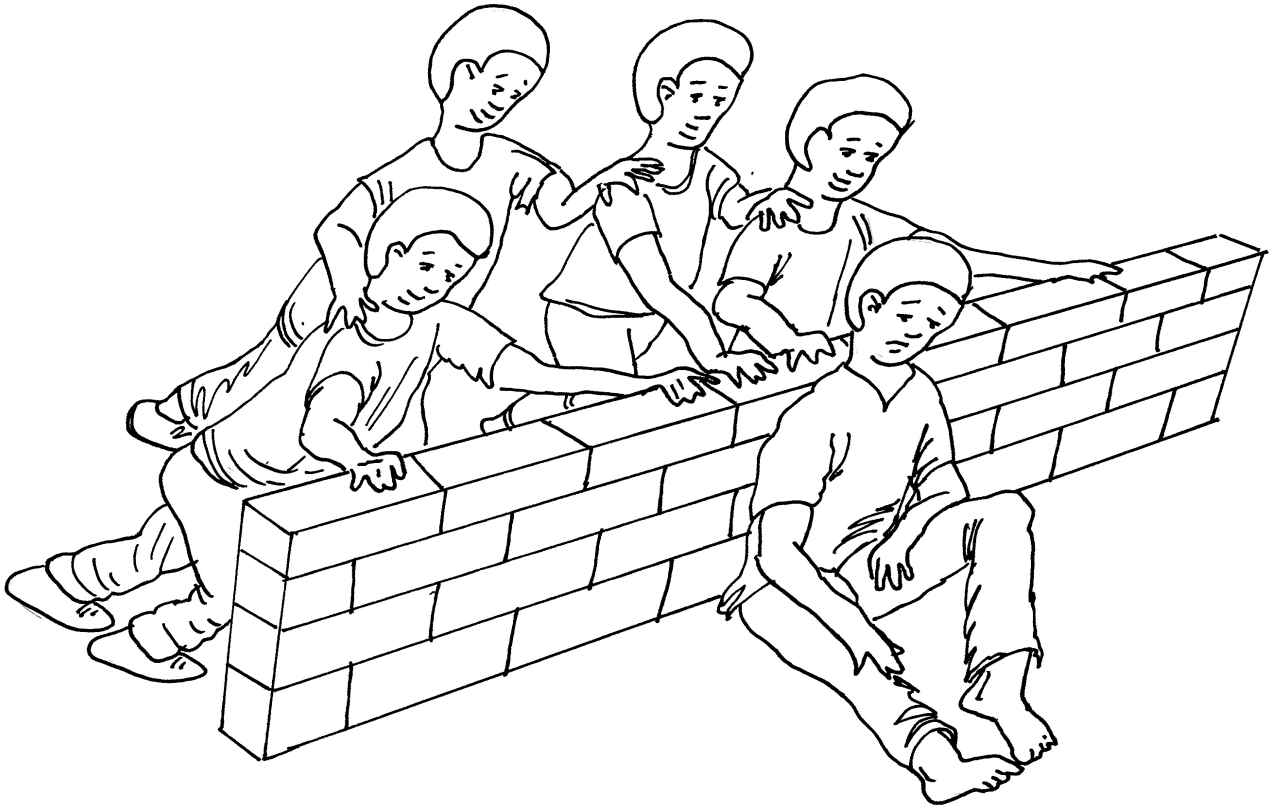
It is good to CRY together, LAUGH together and PRAY together.

12. A dying person has spiritual needs so encourage and talk about them.
OBSERVE CULTURAL and RELIGIOUS RITUALS.

13. Make the dying person feel needed by keeping them in the midst of the family and family activity. Make the dying person a part of the family daily life until the end.

14. BE HONEST AND OPEN.

15. It can be better for the dying person if there are no secrets between them and their Family Caregiver and their family. SECRETS can be like walls that make everyone worry.



16. Talk about dying, if APPROPRIATE, honestly but gently.
Death does not need to be frightening but it is difficult to talk about.

Sharing the fear with your dying loved one can often help relieve worry and bring people close together, then these last weeks and days can become more precious.

17. It is OK to say, "I don't know the answer to that question". You can reply by asking a question such as, "What do you think?", or "What would you like?"

18. Ask questions if there is a Health Worker or Doctor.

19. Talk to family and relatives and involve them in daily life and decisions.

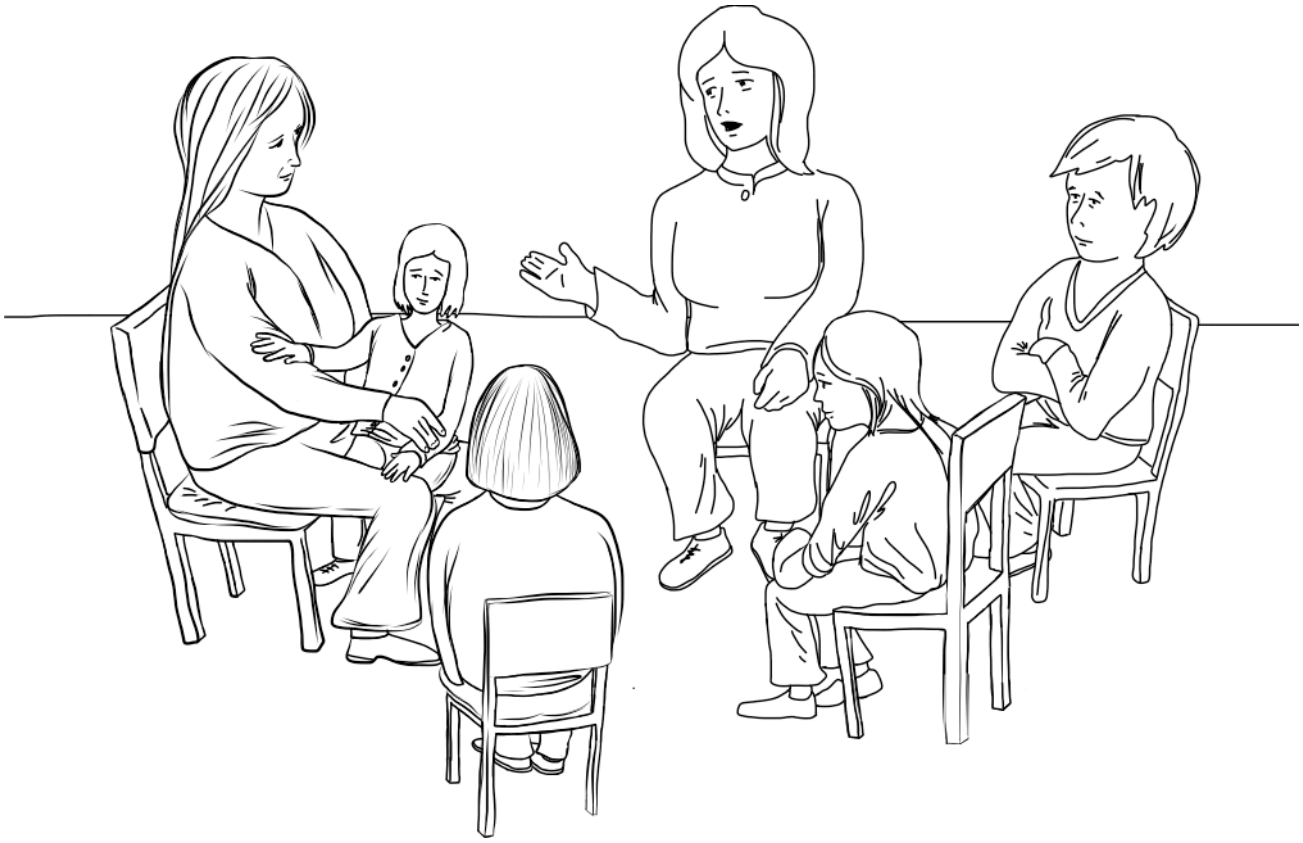
20. Remember that HEARING is our last sense to be lost, so the dying person can hear right to the end even if not responding to talking.

21. Talk about children and those who are surviving.

'THE GATHERING'. SPECIAL HELP THE FAMILY CAREGIVER NEEDS

One essential part of the DYING AT HOME program is called THE GATHERING and is to be used as soon as possible.

The GATHERING is about bringing together family, friends and neighbours in an organised way. It will give you and your family more time and energy to spend with your dying loved one so that you can *live* each day together.



When other people learn you are caring for a dying loved one at home many, especially your friends, will offer to help you and ask, "Can I help you?" That is what a friend is.

YOU CAN NOT CARE FOR A DYING LOVED ONE ALONE.

It is important that your help is from your friends. Who among your friends would be happy to support you in this special work?

Ask that person to sit down with you and together follow the steps that lead to having your Gathering.

A. **Make a list of all those friends and family who you would choose to be with you in this work.**

B. **Make a list of all the ways in which you need help, such as cooking, washing, minding children, sitting with the sick person, chopping wood (see sheet on page 9, *What Help Does the Family Caregiver Need*).**

C. **If you would prefer, ask your good friend to invite those friends on your list to the Gathering to discuss the jobs you need help with.**

The sooner people are invited to help you, the better.

- **When they arrive explain why their help will be so important to you and to your dying loved one and how grateful you are.**

- **Your good friend will read the list of jobs, and call for a person to help with each job. Record on that separate job list page the name of the person for each job, and what days they can help.**

The good friend will watch over these helpers to keep them happily involved as the weeks go by.

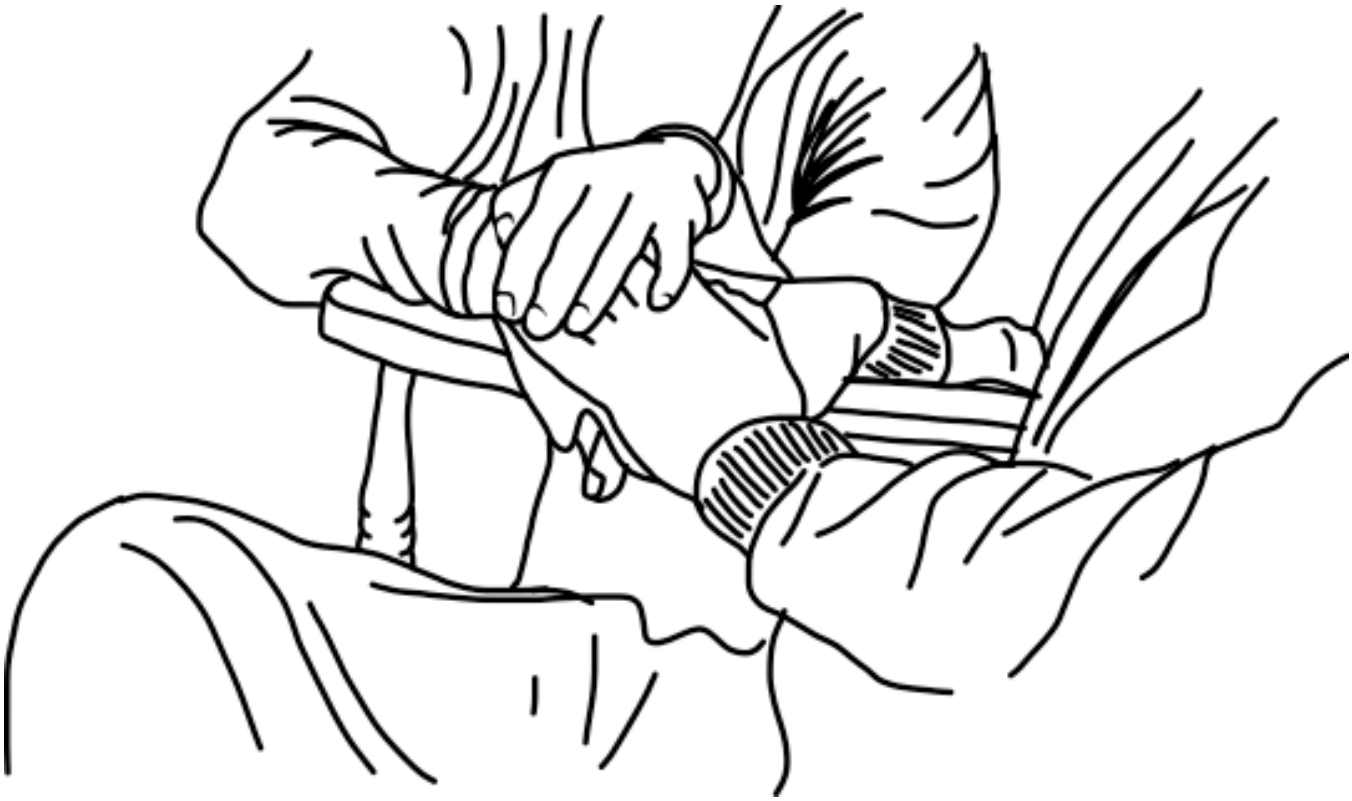
It is of the utmost importance that you, the Family Caregiver, have help and that it is organised.

The dying person will have a sense of relief to see their Family Caregiver and family so supported.

The alternative is stress and exhaustion for the Family Caregiver, and anxiety for the dying loved one.

Everyone involved in this work of love will feel good about being of help and will learn, through the experience, the value of one another.

Most important, they will be there with you after your loved one has passed away as the best support when you are grieving.



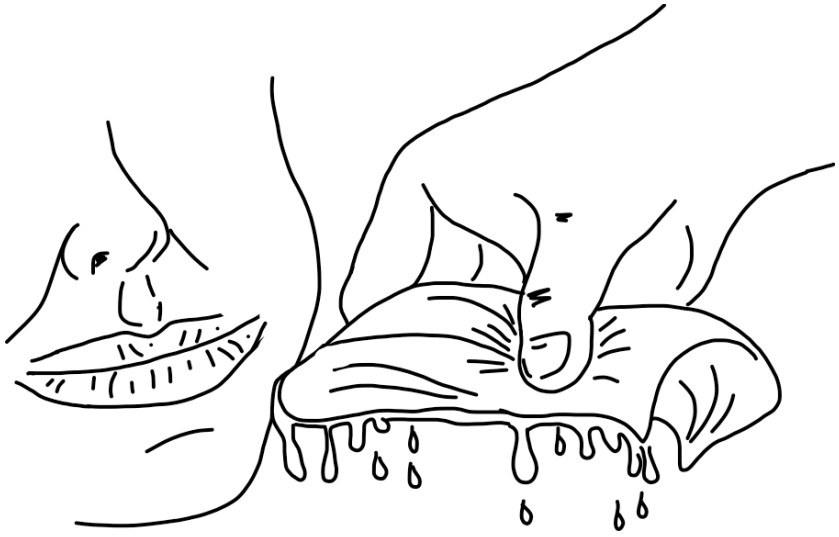
WHAT HELP DOES THE FAMILY CAREGIVER NEED?

JOBS AND NEEDS	WHO CAN HELP	WHEN CAN THEY HELP	HOW CAN THEY HELP
COOKING			
MINDING CHILDREN			
GARDENING			
CHOPPING WOOD			
SITTING WITH SICK PERSON			
CARRYING WATER			
MUSIC & SINGING			

SIGNS THAT DEATH MAY BE NEAR

1. **The dying person gets much weaker, they will die sooner if an infection occurs.**

2. **The dying person loses all interest in food. The body is wearing out. The patient will eventually take no food but may take small sips of water. Encourage that until they cannot swallow anymore. Keep their lips <u>moistened</u> for comfort with water and oil.**



3. **They become very sleepy. They are often in a deep sleep waking occasionally.**

4. **Hands and feet feel colder than the rest of the body as circulation slows down.**

5. **Sometimes very close to death, about a day before, mucus in the chest can cause a rattly sound. It can be quite loud but is not distressing to the patient. It will help if you sit the patient up.**

6. **Ankles may become swollen.**

7. **Fevers can occur or sometimes the opposite, chills.**

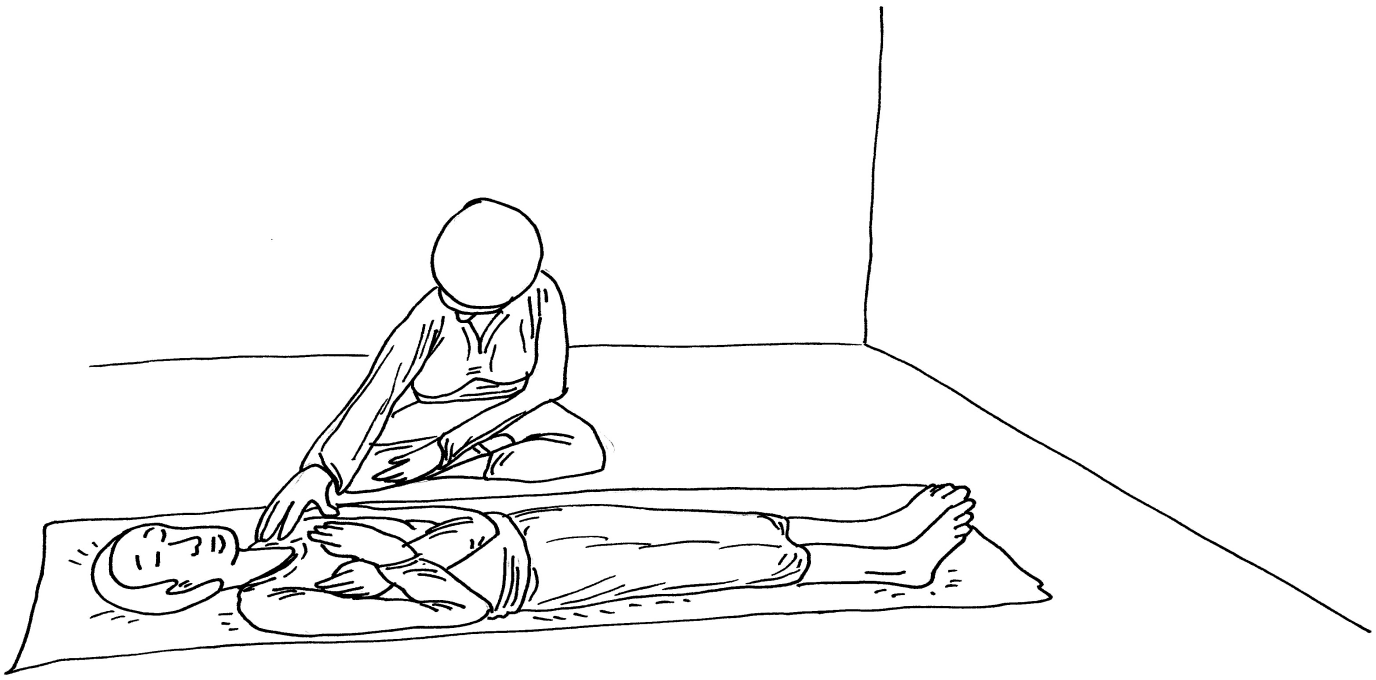
8. **All muscles become very weak even the eyelids may <u>not</u> close when the patient is asleep.**

9. **Sometimes a moaning sound occurs because of these weak muscles.**

10. **Sometimes your loved one will say words you can't understand or be anxious. Just calmly reassure them with your voice and touch, or sing to them.**

11. **Breathing becomes very irregular, sometimes rapid, sometimes very slow.**

12. **As death occurs there are 2 or 3 last breaths then all is still. The face and the body relax and become still.**

By staying close to your loved one you have helped them as far as you can go. It is so very sad to part and your sadness will be there for a very long time. Some people feel sad, others feel relief that suffering has come to an end. Some can feel angry that death has occurred in someone so young. <u>All is natural, normal</u>.

Children are to be encouraged to share in this event as sharing will help their grieving.