

Fact Sheet

The last days of life...

Information for relatives and carers to help understand the changes that occur before death.

Introduction

The coming hours or days are likely to be challenging for you, your family and friends because someone close to you is dying.

Our care and treatment are now aimed at providing comfort for this person and support for those close to them.

We want to be able to respect the person's needs and wishes, and provide the best care we can.

Please help us to do this by telling us **what matters most to the person and to you**.

Also, please feel free to be involved in caring for the person as much as you'd like to be.

If you have questions or concerns at any time, please ask the nurse looking after the person, who will seek further guidance if needed.

Practical things

You are welcome to visit at any time. Please ensure that you respect the privacy and need for rest for all the patients.

There is a balance between a dying person's need for rest and quiet, and the needs of the family and friends to visit and spend valuable time with them.

We understand and respect that each family will need to decide what best works for them and the dying person.

Some family members may need to spend long hours in the hospital.

Please ask the nurses about any of the following that may make your stay easier:

- > Practical arrangements can be made if you would like to **stay overnight**
- > Please use the **bathroom facilities** if the room has its own. Ask for extra towels if needed.
- > One daily **car park exit ticket** is available per family.
- > **Food and drink** are available from the hospital café. Remember to drink, eat and rest.
- > **Pets** may be able to visit in certain circumstances.
- > The doctors are able to supply **carer's leave certificates** if needed.

Information sharing

- > We are here to answer any questions or concerns that you may have.
- > Please inform us who to contact regarding changes in the person's condition or other urgent issues. Having a single contact who is responsible for contacting others in the family helps us to focus on the person's care.
- > Please let us know if visiting needs to be restricted in any way.



- > We will inform the GP and anyone else involved in the person's care of their condition and death.
- > We will ask you whether the person has ever expressed a wish to be an Organ Donor. In this case, eye donation is the only donation possible..
- > We will also ask you whether the person has made arrangements to donate their body to a university.

What often happens in the last days and what you can do

The last few days of life may not be the same for everyone, but there are some common experiences.

The dying process involves the gradual slowing down of the major organs and systems of the body, and most, if not all of the changes listed below, arise because of this.

We are aware of these changes and will be anticipating problems and regularly checking the person for any discomfort.

Please let us know if you think the person is uncomfortable in any way or if you have any questions or concerns.

Treatments and tests.

We are very mindful of not disturbing a restful person unnecessarily.

You will notice that most tests and procedures will stop because they are disturbing and can be uncomfortable. This will usually include blood tests, including blood sugar levels.

Changes in a person's vital signs, like pulse, blood pressure and temperature, are a normal part of the last days of life; we expect these changes and do not need to measure them.

We are committed to keeping the person as comfortable as possible.

Food and Drink

The dying person will be offered food and drink, and supported to take it, if they are awake and want it.

You are welcome to bring in any food or drink that the person requests or prefers. Foods that don't need chewing are best because they take little effort to eat.

A dying person uses little energy and they have very little appetite. This is a natural process and will not be distressing for the dying person, but can be to those observing.

Please understand that the person may not want even their favourite food or drink and that they may change their minds within minutes about what they do want. Trying to convince them to eat or drink when they don't want to is likely to cause distress to the dying person.

Mouth care that moistens the mouth and lips will be helpful, and we appreciate your help with this.

Medication changes.

The doctors will discuss the reasons for medication changes with you.

Any medication that does not help to keep the person comfortable is unhelpful now, and will need to be stopped. This will include some of the long term medications that have been previously prescribed.

Medicines to ensure the person stays comfortable can be given when needed.

A person who is in the last days of life usually becomes very weak, sleepy and then unconscious. This means that giving medications by mouth is often not possible, so they will be given by injection.

These injections are given just under the skin, and a very small plastic tube is inserted so that numerous injections are not required. Sometimes, we attach a pump to the tube because medication is needed continuously. This pump is called a syringe driver or NIKI Pump.

Morphine or similar medicines may be given. These medications are excellent for relieving pain and breathing discomfort, and we give only enough to relieve the person's discomfort. These medicines do not hasten death.

Becoming unconscious is a normal part of the dying process but sometimes, it can seem as though the person has become unconscious because of the medications that have been recently given, and this is usually not the case.

You know the person very well and can best judge whether the person looks comfortable or not. Please let us know what you think and we can adjust medications if required.

Weakness

Increasing weakness is to be expected at the very end of life. A person is likely to not be able to toilet themselves, hold a cup of drink or even sit up in bed. Any physical exertion eventually becomes an enormous effort. This includes speaking and swallowing.

Sleep, alertness and withdrawal from the world.

A dying person often needs to spend a lot of time asleep with only limited periods of wakefulness. They gradually withdraw from the world, spending less and less time awake. This is normal and expected. The person often seems tranquil and peaceful. Eventually, most dying people are not able to be woken.

A dying person's seeming lack of interest and responsiveness is not a snub to those who care, but rather a sign that the end of life is approaching.

As the person's systems slow down, too much stimulation, such as noise or lights, and even touching, can cause restlessness or agitation. Each person is different and their response to stimulation is best judged by those who know them.

You may still continue speaking to and touching the dying person, even when they are no longer awake. A soft, quiet, natural tone of voice, and gentle touch are less likely to distress the person.

Pain

Dying is not usually a painful experience and we do not expect existing pain to increase.

Morphine or similar medications may be given by injection if pain is a problem or if we are concerned that it may become a problem.

You may hear moaning as a person's breathing changes; this is expected and usually does not indicate pain.

We will regularly assess whether the person has any pain and treat it appropriately. *Your assistance in monitoring whether or not the person has pain and the impact of medications on it is appreciated.*

Incontinence

The urine will become darker and reduce in volume as the person stops drinking. Bowel movements will also decrease. There may be some loss of control of the bladder and/or the bowels, if this happens, incontinence aids such as pads and absorbent sheets will be used for comfort and hygiene.

Breathing

Breathing will change in the last days and hours of life. There are a variety of ways that this may happen; there may be times when breathing is very shallow, it can go from fast to slow, it may be irregular and there may be long gaps between breaths, especially at the very end. These breathing changes do not normally cause discomfort for the person. If discomfort is present Morphine or similar medications can help with this.

It is not uncommon for the breathing to be very noisy, with gurgling, bubbling or a rattling sound heard, especially towards the end. This is due to the loss of the normal swallowing and cough reflexes which causes some saliva and mucous to collect in the back of the throat. The sound can be very distressing to family and friends but is not usually a problem to the dying person due to their decreased conscious state. A change of position usually helps, and if it is causing distress, there are some medications that may help.

If you are worried, call the nurse and discuss your observations and concerns.

Confusion, restlessness and agitation

Confusion is common at the end of life and is not always distressing for the dying person. Restlessness and agitation can occur during the dying process. This is due to circulation changes in the brain.

Things you can do include:

- Speaking in a calm, quiet, natural way
- Gently massage the person's hands or forehead
- Play soft, calming music

Take your cues from the dying person; if what you are doing seems to work, continue with it. If it seems to irritate the person, stop. Please don't be concerned that this is a reflection on you, it is a common occurrence. If the agitation persists, medications can assist with these problems.

Body temperature

The person may feel hot to very cold to touch, and may vary in different parts of the body. It is not unusual for the hands and feet to feel cold, and be blotchy and darker in colour. This is due to changes in circulation and is a normal part of dying.

Spiritual and religious needs

The hospital chaplain will visit you. They will listen to what your needs may be. If you or your loved one want to be visited by any specific religious person we can assist you with this. The Spiritual Care brochure gives you more information.

You may also want to think about funeral planning at this time, please ask staff for assistance.

Caring for yourself

The next few hours or days is likely to be tiring and stressful. You may experience varying levels of grief and distress, upsetting emotions and unresolved feelings. You may wish to talk to someone now, or arrange to talk to someone at a later date. Please feel free to discuss the options with the health team. The chaplain or social worker may be able to offer some immediate assistance or help with arranging assistance at a later date.

Do not hesitate to ask for help.

After the death

Death has occurred when breathing ceases and the heart stops beating. The mouth may fall slightly open and the eyes may be open and be fixed in one spot.

A doctor will visit to confirm that death has occurred. You may want to stay and have some quiet time with the deceased and have other family or supportive friends with you. At some stage the deceased will be moved from the ward to the hospital mortuary until funeral arrangements have been finalised.

The Coroner is not usually involved in an expected death. The doctor will discuss the implications with you if the Coroner is required.

Notifications after death: The government has a website detailing the processes involved after the death of a family member <http://www.humanservices.gov.au/customer/subjects/what-to-do-following-a-death>

Grief and bereavement

It is normal and healthy to grieve and every person grieves in their own way and in their own time. If you feel that support would be helpful, contact your GP or

Grieflink www.grieflink.asn.au

Lifeline Tel 131114 www.lifeline.org.au

Beyond Blue Tel 1300 224 236 www.beyondblue.org.au

For more information

Property Name

Division etc

Address Line 1

Address

Telephone:

www.sahealth.sa.gov.au

Confidentiality (caveat if required)-I#-A#

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