

PATIENT INFORMATION

Coping with Dying

Information for families and carers

This leaflet is to help you know what to expect when someone is thought to be in the last hours or days of their life. Please feel free to ask staff questions or request help at any time. It anticipates some of the questions you may want to ask about what is happening and why and encourages you to ask for further help or information if there is anything at all that is worrying you.

Understanding that a person is dying

As the end of life approaches it can be difficult to estimate how much time is left, but this may now be days or hours.

The dying process is unique to each individual but in most cases, there are common characteristics or changes that help us to know that a person is dying.

These fall into four main categories:

- Reduced need for food and drink
- Withdrawing from the world
- Changes in breathing
- Changes which occur in the last few hours

Often what is important to people at this time is spending time together and letting the person know you are there and care about them. As someone nears the end of their life, they usually spend more time sleeping and will often be drowsy when awake. You should not be discouraged if the person is unable to respond to you, they may still know you are there.

Reduced need for food and drink

Being able to eat and drink is part of our usual day to day life. Lack of interest in food and drink is a normal part of the dying process and a physical sign that the person we care for is not going to recover from their illness. Even if we know someone is near the end of their life and they no longer want to eat and drink, we may find this hard. As someone grows weaker the effort needed to eat and drink may become too much so help may be needed. Food and drink will continue to be offered to someone who is dying until they lose their natural ability to swallow.

Continuing or starting fluids through a drip is not usually helpful in this situation and may add to someone's physical discomfort.

When a person becomes unable to swallow this can be distressing for relatives and friends. Keeping someone's mouth moist and clean is helpful at this time. This can be done by moistening the mouth and applying lip balm. The nursing staff would be happy to show you how to help with this if you wish.

Changes in breathing and other signs

As someone nears the end of their life, their breathing often becomes uneven and may become shallower. Occasionally there may be a noisy rattle with each breath. This is due to a build-up of fluid in the mouth or back of the throat which cannot be coughed up. As people are usually drowsier at this stage, this is often more distressing to friends and relatives than to the person themselves. Medication may be used to dry up these secretions although this is not always successful. Changes in position may also help. The emphasis at this time is on ensuring that someone is not distressed by the changes in their breathing through the use of medication and reassurance.

As someone's condition changes, their skin may feel cold and possibly moist. Sometimes the skin may change colour and become slightly blue or white. This is normal and due to changes in the blood circulation.

Sometimes people may appear restless in the last hours or days of life. This is quite common; reassurance and medication can be used to reduce any distress this may cause.

Medication

Not all medicines are helpful during the last stage of someone's life; the main aim at this time is comfort. The team caring for your friend or relative may therefore suggest changes to their usual medicines.

Spiritual / religious needs

You should be asked if you or your relative or friend have a specific religious, spiritual or cultural belief, as you may wish to obtain comfort and support from a chaplain or the cultural advisor. The staff caring for your relative or friend can also help you to contact your own community chaplain or cultural advisor if you wish.

Please tell those helping to care for your relative or friend if there are any specific personal, faith or cultural traditions that are important to observe before, at the time of or after death. They may be able to help facilitate this and would not wish to cause you any added distress.

The last few hours can be difficult to determine. Sometimes carers can feel frightened or overwhelmed. Some people may wish to sit with their dying relative or friend, but others may feel so overwhelmed that they are not able to be in the room. There is no right or wrong way to behave at this time and different family members may want different things.

Support for you and your family

This is likely to be a difficult and painful time as you lose someone you love or have cared for. We are here to support you during this time. We will help you work through any concerns or worries you may have. If you feel you may be unable to cope, we can supply details of other organisations that may be able to help.

If your relative or friend is in hospital you should be given information about visiting time arrangements, car parking and how to obtain drinks and meals. The hospital car park operates a pay system but, if you are spending a lot of time visiting the ward, staff can assist you in obtaining a dispensation ticket.

Information

The healthcare team will be assessing your relative or friend regularly. We want to make sure you have the information you need about their care and are aware of how to obtain further information if or when you feel you need it. Please discuss with staff members any concerns or questions you have about their care or what may happen before or immediately after your friend or relative dies.

It is natural to forget some of what you are told and the staff will be happy to answer any questions or arrange for a more appropriate member of the team to speak with you.

Further support

Further support and advice is also available from the Specialist Palliative Care team should this be necessary

For further assistance or to receive this information in a different format, please contact the department which created this leaflet.