



# Recognising distress and bodily changes in the last hours or days of life

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Information and support  
for relatives and carers

**The dying process is different for every person. It is difficult to be certain that the person you care about is in the last days of life or predict when they are going to die; you may find it difficult to cope with this uncertainty.**

There are bodily changes which come and go over a period of days that indicate a person is likely to be close to death. Some of these changes may be **distressing**. This information will help you to recognise them and to reassure you that they are **normal**.

The nurses and the doctors on the Inpatient unit are available for advice and reassurance so please do not hesitate to ask them questions or seek their opinion or support.



### **Eating and drinking**

At this stage as the body no longer needs food as fuel to keep it going, your relative may lose their desire to eat and drink as they weaken. It can be difficult to accept when your relative stops eating and drinking even though we know that this may be a sign that they are dying.

Their mouth may look dry; this does not mean they are dehydrated. Whilst awake offer sips through a straw or from a spoon; if coughing occurs stop offering fluids, moisten their mouth when they can no longer swallow.

The nurses will use mouthcare products to perform mouthcare and moisten their mouth; you can assist with this if you feel able.

### **Bladder and bowel control**

As muscles relax in these areas they do not work normally. People have fewer bowel movements as they eat less; their urine may become darker and passing urine may be less frequent. This can be distressing for you to see as you worry that they may be embarrassed. Incontinence pads or pants may be used to protect their skin and bed.

### **Breathing**

In the last days of life breathing often changes; it may become shallow and you might notice long pauses between breaths. If your relative is anxious their breathing rate may increase slightly. Sit with them to help reduce their anxiety. A small fan or opening a window might help. They will not need extra oxygen.

Sometimes their breathing may become noisy, like a gurgling or rattling sound. This is because fluid builds up in their air passages as they lay flat and they are unable to cough it up. They may benefit from changing their position onto their side, slightly upright, or from medications to help dry secretions although this does not always help. This may be upsetting for you to hear but it is not distressing to the dying person.

In the last moments of life breathing may become slow and shallow before it stops altogether.

## Restlessness and agitation

This can be caused by many things and can be managed in some simple ways. You might notice this more in the last few days of life; your relative may become confused and may not recognise you; they may hallucinate and see or hear people that are not there.

Quiet reassurance and comfort may help to calm them; remind them you are there and keep noise to a minimum. You may want to read to them or play their favourite music.

Although it may be distressing if they do not recognise you they do not care any less about you; they are unable to know what is real or not, especially if they are sleepy.

Physical problems can cause agitation like constipation or being unable to pass urine. There may be other causes for their agitation and medication may help to settle them.

## Skin changes

Their hands, feet and skin can feel cold or moist and may become blue, mottled or an uneven colour due to reduced circulation. Their hands or other parts of their body may become a little swollen. Swelling is not usually uncomfortable or painful.

Putting extra covers or blankets over them might help to keep them comfortable. It may be comforting to put socks on their feet or gently massage their hands whilst you are holding them.

## Sleep

Your relative will spend more time asleep and be less interested in things around them. They may not respond when you try to wake them but this does not mean that they cannot hear you. You may want to keep chatting with them and hold their hand, so they know you are there. Some people become unresponsive before they die; this varies from short hours to several days.

## Carer support

Being a carer can be physically and emotionally exhausting, at times you will wonder how you are going to cope; this is natural. You will have good and bad days but this does not mean you are not doing a brilliant job.

Do not be afraid to ask for help and support when you need it. It is important to look after yourself and take time out if you need to.

It can be distressing if changes occur at night. If this occurs we will have asked you whether you would want to be contacted.

When your loved one has died, the nurses will wash and dress your relative. You can assist with this if this is your wish. Doctors will complete the death certificate on the following day, in which case we may be allowed to issue the certificate, or we may need to speak with the Coroner, who will arrange for the certificate to be released. These conversations with the coroner can only happen on a Monday to Friday between 9-4.30pm. In some instances this may lead to a slight delay in the certificate being issued.

## Medications

Medications that are not helping will have been stopped. If your relative is awake enough, they may still be able to have some liquid medications.

The 'Just in case' medications to control symptoms such as pain, sickness and agitation will always be prescribed and can be given by nurses when needed. If symptoms persist your relative will be reviewed by the medical and nursing staff and they will discuss if a syringe driver is needed to give continuous medications to help with pain, sickness and agitation and to ensure that we keep your relative comfortable. These are frequently used at the end of life to relieve symptoms especially if people are struggling to take medications orally.



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