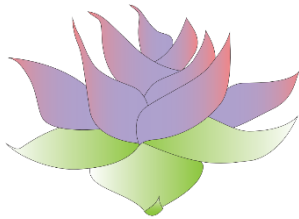


## Patient Information



## Palliative Care

# Information for relatives caring for someone who is dying

### **This information tells you about:**

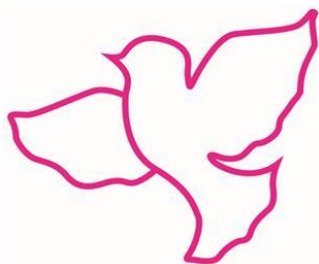
- What happens to a person in the last hours of life
- How the professionals can help
- How relatives and carers can help
- Who to contact if you have any questions or concerns
- Where to obtain more information

If there is anything you are unclear about, please ask your ward nurse or doctor.

If your ward nurses and doctors need further support to care for the dying person or to address your concerns they will contact the Palliative Care Team.



## Patient Information



The DOVE logo is our hospital's symbol for peace and quiet. This also stands for: Dignity Openness Value Everyone.

We are aware that it is noisy in hospital, and noise may cause distress to those in the last hours and days of life. Staff may offer to display the DOVE logo to ensure additional sensitivity, peace and quiet for the dying person and their relatives. If for any reason you would prefer this is not used, please inform your ward nurse who will remove it.

## Caring for someone who is dying

The dying process is unique to each individual, but in most cases when someone is expected to die, there are common changes that help us to know that person is dying.

There are four main changes:

1. Reduced need for food and drink
2. Withdrawing from the world
3. Changes in breathing
4. Changes which occur before a person dies

### 1. Reduced need for food and drink

- When someone starts to die, their body no longer has the same need for food and drink as before.
- The body's processes slow down and the body cannot digest or make use of the food as well as they used to.
- People stop drinking and although their mouth may look dry, gently moistening the mouth will give comfort.

### **2. Withdrawing from the world**

- People who are in the last hours and days of life will often become gradually more withdrawn.
- People spend more time sleeping and when they are awake, they may be drowsier and be less interested in the world around them.

### **3. Changes in breathing**

- As someone approaches the end of their life, their body becomes less active and the demand for oxygen is less.
- When someone is dying, they may spend more time in bed, so their breathing may be less of a problem than if they were up and about more.
- However, breathing problems may be worsened by feelings of anxiety, so having someone near to calm the person can be very helpful.
- Sometimes, in the last hours of life breathing may become noisy. This is due to the build-up of mucus or secretions that the body produces naturally in the back of the throat. When someone is dying, they no longer have the strength to cough or clear their throat and this is what causes the noise.
- Changes in position may be very helpful to alleviate this noise and allow the fluid to clear away better.
- Sometimes a medication is used to try to prevent this noisy breathing from becoming any worse. The noise can be distressing for relatives and carers, but experience shows that this doesn't appear to distress the dying person.

### **4. Changes which occur before a person dies**

- When death is very close (within minutes or hours) the breathing pattern may change. Sometimes there are long pauses between breaths, or the abdominal (tummy) muscles will take over the work, so the abdomen (tummy) appears to rise and fall instead of the chest.
- Some people may become more agitated as death approaches. If this happens, staff will be able to assess the person for any reasons for this, address the cause and provide medication as required to comfort the person and relieve their distress.

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- The person's skin may become pale, moist, and slightly cool before death. Most people do not rouse from sleep but die peacefully, comfortably, and quietly.

## How the professionals caring for the person can help

- When someone is dying, they will be regularly reviewed by the nurses and doctors to ensure that they are comfortable and well cared for.
- Their need for fluids and food will be assessed and this will be explained to you.
- Medication will be reviewed so that the focus of any treatment is for the comfort of the patient. Unnecessary or burdensome medication will be stopped.
- Essential medication will be continued; this may mean that the patient receives this in a different way other than by mouth, for example as an injection under the skin or as a continuous infusion pump called a "syringe driver".
- Medications will be made available "just in case" of pain and other symptoms so that the person will not need to wait should they require these.
- To ensure the person's comfort is prioritised, a plan will be made regarding any monitoring of the person's condition and whether any investigations will be needed.
- It is important that we are looking after the person as a whole and that we care for their psychological, spiritual, and religious needs as far as possible. Similarly, we hope to be able to support close relatives in this way.
- This is likely to be a difficult time for close relatives as they lose someone whom they love and have cared for.
- Nurses, doctors, and other staff are there to provide help and support, so if you have any questions please ask.

## How relatives and carers can help

- The close relatives and carers of someone who is dying will often know that person best and may have thoughts about the best way they can care for and support that person.

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- They may have previously discussed with the person how they would hope to be cared for when they are dying or know best what would be important to that person at this time.
- It may be that the person has considered whether they would like to help someone after they have died by donating their organs or tissue. Tissue can be taken from a wider range of donors than organs can, to benefit other people in the future. Tissue donation gives many people and their families the option of making a difference to others.
- It may be that the person has previously expressed preferences as to where they would like to spend their last days of life. Please let the nurses and doctors know if the person would prefer not to die in hospital.
- Passing on information about the person's preferences to the nurses and doctors will be very helpful.
- If relative and carers are not sure what they can do to help the person, the nurses and doctors can advise on things they may like to do.
- Even if it may seem like the person cannot hear or understand, they may still feel reassured by a familiar voice or the touch of their close relatives or carers.
- If the person is sleepy for much of the time, relatives and carers may choose to spend more time at the person's side when they are most alert, and this may even be in the middle of the night.
- When someone is close to dying, they may become confused, disorientated in time or place and they may not recognise people around them who are well-known to them.
- Although this can be distressing for relatives and friends, it may not be distressing the person who is dying.
- Relatives and friends may help by orientating the person, but there is no need to correct them if they are not distressed by this.

## Useful information

- Please speak to the ward nurses and doctors if you have any questions, concerns, or worries at any time.
- Nurses and doctors can call on the interpreter services to ensure that we can communicate well with people whose first language is not English. Please ask about this service if you feel that it would be helpful.

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- Whatever your outlook on life, there are people who may be able to support your emotional, spiritual, and religious needs. Faith representatives or hospital chaplains are skilled in supporting people and their relatives whatever their beliefs and background. Please ask the nurses and doctors caring for you if you are interested in seeking this support.

If you would like to discuss any issues relating to this information, please contact: -

**Name:**

**Title:**

**Telephone:**

If you would like to talk to someone outside the service, contact the Patient Advice and Liaison Service (PALS) on 0800 028 4203 or email your queries on [feedback@uhcw.nhs.uk](mailto:feedback@uhcw.nhs.uk)

The Trust has access to interpreting and translation services. If you need this information in another language or format, please contact the Palliative Care Team Coordinator on 02476 965498 and we will do our best to meet your needs.

The Trust operates a smoke free policy.

### Document History

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We would like you to tell us what you think about our services. This helps us make further improvements and recognise members of staff who provide a good service.

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