



## What to expect as death approaches: Information for families and care-givers

This leaflet explains what you might expect in the last stages of life, and what you can do to support the dying person. It also explains what needs to be done after someone dies. If you have any questions, please ask the doctor or nurse involved in the person's care, as they will be able to advise.

## The last stages of life

It can be helpful to understand the common signs that indicate when someone is nearing the end of life so that you know what you might expect and what you can do to help. However, it is important to remember that not everyone follows a predictable pattern; each person's death is unique. Death can sometimes occur suddenly or unexpectedly, earlier than might have been anticipated. You might observe none, some, or all of these signs in the last days and hours of life. Speak to your doctor or nurse if you have any questions about the likelihood of a sudden event in your situation.

### Withdrawing from the world

As the end of life approaches, the dying person may begin to withdraw from the world around them and lose interest in things that had previously been enjoyable and given them pleasure. There is often a desire to talk less and a tendency to sleep more. Days or hours before death, the dying person responds less to voice and touch and might drift in and out of consciousness. Sometimes, quite unexpectedly, they might suddenly be more alert and talkative, and even look as if they have improved. This may be a 'window of opportunity' to say what you need to say and value this time together.

### What you can do

- Remind them who you are before you speak
- Use gentle touch and provide reassurance

- Allow time for silence. Remember that you are supporting the person to 'let go'
- It can also be reassuring for them to hear your voice. If they are confused, or in a coma, remember that hearing is said to be the last sense to go. Assume that everything you say can be heard and understood, even if they don't respond.

### **Loss of appetite**

As death nears, the dying person will usually lose interest in food and drink because the body no longer needs fuel to keep it going. It can also become more difficult for them to swallow. This is a normal part of dying. It's important not to force food or drink onto someone who no longer wants it as this can cause choking.

### **What you can do**

- Avoid giving food or drink unless requested
- Offer ice chips or sips of fluid to moisten the mouth
- Wet the lips and mouth with a soft tooth brush dipped in water
- Apply lip balm to protect the lips from dryness.

### **Change in bowel and bladder function**

Incontinence, or loss of bowel or bladder control, occurs as the muscles in these areas relax. This is normal and the district nurse can advise you how to manage this.

## **What you can do**

- Keep affected areas clean and dry to promote comfort and avoid pressure sores (also known as bedsores)
- Report constipation and incontinence to the doctor or nurse.

## **Visions and hallucinations**

Visual or auditory hallucinations are often part of the dying experience; the dying person might talk to people or see things that others do not see. It is not unusual for the dying person to see or hear loved ones who have already died. This is quite normal but can be unsettling for loved ones who are unsure how to respond.

## **What you can do**

- Try not to judge or contradict what the person is saying. Often these visions of people who have died are reassuring and comforting to the dying person
- It is important to distinguish between visions of loved ones that are comforting and hallucinations that are alarming or upsetting for the dying person. Tell the doctor or nurse about bad dreams or hallucinations as they might need to make adjustments to the medication.

## **Confusion, restlessness and agitation**

Restlessness and agitation are common but should always be reported to the doctor as there are medications available to

help manage these symptoms. Sometimes restlessness is a result of unresolved issues. People who are dying often want to be assured that things they were once responsible for will be taken care of, that those left behind will be alright, that any wrong-doing has been forgiven, and that their life had meaning and that they will be remembered.

### **What you can do**

- Even if the dying person knows you well, they might not recognise you at this time. Introduce yourself by telling them who you are
- Use a gentle voice and reassuring touch. Gentle massage or music can sometimes be soothing
- Be sensitive to any cues that might indicate there is something the person wants to resolve before they can let go
- Ask the doctor if there are any medications that might help relieve agitation.

### **Changes in breathing**

You might observe a number of different changes in breathing. It can become shallow and quickened, or slow and laboured. There might also be gurgling or rattling sounds as the person breathes. Saliva and mucous, which are usually cleared by swallowing or coughing, collect at the back of the throat; it is air passing through these secretions that causes this sound. It is not painful or distressing for the dying person.

Breathing can also become very irregular. A particular pattern is called Cheyne-Stokes breathing: this is marked by long

periods without a breath, followed by a much deeper breath. This is not uncomfortable or distressing for the dying person, but might be unsettling to observe. It is a sign that death may be near.

### **What you can do**

- Try to remain calm. Your calmness can help reassure the dying person
- Speak gently and lovingly, and use gentle, reassuring touch
- Adjusting the head of the bed (mechanically or with pillows) or turning the person onto their side can sometimes be helpful
- If secretions are pooling in the mouth, turn the head to the side so that gravity can help to drain them
- Inform the doctor or nurse if breathing is especially laboured or you are concerned.

## What needs to be done when someone dies?

When death occurs, you may notice that the person's face suddenly relaxes. They will have stopped breathing. If the eyes are open, you can close them by gently holding the eyelids closed with your fingertips for 30 seconds. If this does not work, the funeral director can help with this. They will also be able to help close the mouth if it is open.

### Who to call

A doctor or appropriate healthcare professional will need to see the body and **verify** the death. Any equipment, such as a syringe driver, should be left in place until it has been properly recorded that death has taken place.

- If the death happened during the night, you do not need to contact the doctor until the following morning unless you want to
- If you want a healthcare professional to attend during the night, you can call Hospital at Home if the person was known to their service. Alternatively, you can call 111 (it is important to say if the death was expected). They might send a doctor, appropriately trained nurse, or a paramedic to verify the death.

### Religious customs or preferences

If there are any religious customs or preferences that need to be observed, please tell any doctor or nurse who is present so that they can respect your wishes and those of the person who has died.

If, for religious or cultural reasons, the burial needs to happen quickly you can get advice from the local Registrar or funeral director.

### **When to contact the funeral director**

*After* the death has been verified, you can contact a **funeral director** to arrange for the body to be removed. There is no rush to do this. The funeral director will often come within an hour of being contacted. If you want a little more time, or need to wait for family or friends to arrive, you can ask the funeral director if they could come a bit later. Funeral directors usually provide a 24-hr service to move the body to a funeral home.

Useful information on choosing a funeral director and planning a funeral can be found from the **Good Funeral Guide**:

[www.goodfuneralguide.co.uk](http://www.goodfuneralguide.co.uk) A list of funeral directors can be found on: [www.uk-funerals.co.uk/funeral-directors.html](http://www.uk-funerals.co.uk/funeral-directors.html)

### **Arranging for equipment to be collected**

Unfortunately, equipment cannot always be collected immediately. Speak to the healthcare professional who arranged its delivery (the occupational therapist or district nurse) so that they can arrange collection. Alternatively, you can call Millbrook yourself on 0333 999 0870.

All unused medicines will need to be returned to a pharmacist for safe disposal.

### **Getting a medical certificate**

After the death has been verified, a doctor will need to **certify** the death. This involves providing you with a **medical**

**certificate of cause of death.** Sometimes a GP will verify and certify the death at the same time, but if a district nurse or an out-of-hours doctor verifies the death, you will need to contact the person's GP to arrange to collect the medical certificate of cause of death.

If the person's regular GP is unavailable, or if the GP has questions about the death, it may need to be reported to the coroner. A death may also be reported to the coroner if someone died from an industrial disease (e.g. caused by asbestos). This might result in an investigation to find out why the death occurred. In these instances, it is the coroner who provides the medical certificate of cause of death.

If you are **planning a cremation**, a second doctor has to complete an additional form before this can take place (this is called a confirmatory medical certificate for cremation). If you tell the GP who provides the medical certificate of cause of death that a cremation is planned, they will arrange for this form to be completed by a doctor from a different GP practice; this doctor might phone to ask you a few questions about the death.

## Registering the death

When you get the medical certificate of cause of death, you will need to arrange an appointment with your local register office. This must be done **within five days** unless the death has been referred to the coroner. If it has, you will need to wait for them to give permission before you can register the death. To book an appointment with the register office you will need to phone **0345 241 2489** (Mon-Fri). This appointment can be

made by a relative, someone present at the death or the person making the funeral arrangements. So that the Registrar can give you the **Death Certificate**, you will need to take with you the **medical certificate of cause of death**.

The Registrar will also explain about the **Tell us Once** service. This helps reduce the number of phone calls you need to make and allows you to inform central and local government departments of the death very quickly; this can be helpful to avoid over-payment of benefits and pensions. If you use this service, you will need to book a longer appointment for registering the death and will need to take with you:

- The person's National Insurance number
- Their passport number (if they had one)
- Their driving licence (if relevant)
- Their vehicle registration number (if relevant)
- Their 'Blue Badge' (if relevant)
- Any concessionary bus-pass
- Details of any benefits they were getting (e.g. State Pension)
- The name and address of their next of kin
- The name and address of any surviving spouse or civil partner
- The name, address and contact details of the person or company dealing with their estate (this is their 'executor' or 'administrator')
- The details of any public sector or armed forces pension schemes they were getting or paying in to.

It is possible to use this Tell us Once service later by phone or on-line; the Registrar will give you the contact details and a unique reference number to enable you to do this.

The Registrar will also provide information about bereavement services.

### **Arranging the funeral**

If there is a pre-paid funeral plan it will usually include details of what the person wanted, as well as which funeral director to use. If they have left instructions for their funeral but there is not enough money available to carry these out, the instructions are not legally binding and you can make changes. You can either make all the arrangements for organising the funeral yourself, ask a funeral director to do this for you, or share the arrangements with them. The funeral itself can be a faith-based ceremony, have no religious element or be something in-between. Advice on arranging a funeral yourself can be obtained from the **Natural Death Centre:**

[www.naturaldeath.org.uk](http://www.naturaldeath.org.uk)

Funerals can be costly. It is important not to sign a contract (or the arrangement form) with the funeral director until you are sure that you want to use their service and you have identified how the funeral will be paid for. Further information on planning a funeral can be found from the **Good Funeral Guide:**

[www.goodfuneralguide.co.uk](http://www.goodfuneralguide.co.uk)

## Further information

- If you have questions or concerns, the district nurse, specialist nurse, or GP, may be able to help
- Further information is available from Dying Matters: [www.dyingmatters.org](http://www.dyingmatters.org)

## Useful phone numbers

It can be helpful to keep these all in one place. Space has been provided here so you can add useful numbers.

District Nurse:

Funeral Director:

Register Office: 0345 241 2489

## Feedback

If you would like to give feedback on this leaflet, we would appreciate hearing from you. You can write to:

Community Team, Sobell House, Churchill Hospital, Old Rd,  
Oxford, OX3 7LE

Or email: [sobell.advice@nhs.net](mailto:sobell.advice@nhs.net)