

# What to Expect When Someone Important to you is Dying

answering  
your...



Helen - Nursing



# preparing you for what to expect

*This booklet is designed to help prepare you for what to expect in the very last days and hours of a person's life.*

It may help to answer questions that you may have or you may want to ask at some point. There are likely to be many different professionals involved in the person's care, as well as friends and family. At home, the General Practitioner has overall medical responsibility for this care, alongside the District Nursing team who work closely with Phyllis Tuckwell's Care at Home team. At the Hospice, the team of doctors and nurses, led by a named consultant, is responsible for your relative's care.

## what happens when someone is dying?

This process is unique to each person. It is not always possible to:

- know for sure that a person is in the last days of life;
- predict exactly when a person will die;
- know exactly what changes the person you are caring for will experience when they are dying.

There are certain changes that signify a person is likely to be close to death. It is normal for these signs to come and go over a period of days, and if they do go, this does not usually mean that the person is improving. Some of these changes may be distressing, but the following information may reassure you that many of these changes are not unusual, and suggest how you can help or seek guidance. As a carer, if any of these signs do start to overwhelm or distress you, you may wish to take a break and leave the bedside for a period. It's important to think about your own feelings, as well as those of the person you are caring for.

## Changes in the last days of life

### *why are they not eating and drinking very much?*

The person may no longer wish to eat or drink anything. This is a normal part of the dying process and could be because they find the effort of eating or drinking to be too much, or because they have little or no need or desire for food or drink. Eventually, the person will stop eating and drinking, and will not be able to swallow tablets. Healthcare professionals will discuss alternative ways for medication to be given.

If the person stops drinking, their mouth may look dry, so measures to moisten the mouth, as appropriate, are important. The healthcare team will monitor closely any symptoms which indicate thirst or dehydration and develop a plan with the person, their family members or those closest to the person, should hydration be needed. The addition of hydration must be used carefully as it can add more discomfort as the body begins to 'shut down'.

### **is there anything I can do to help?**

If the person is conscious and they want something to eat or drink, you can offer sips of water, provided they can still swallow safely.

You can give some comfort to a person with a dry mouth by:

- offering a drink through a straw (or from a teaspoon or syringe)
- placing ice chips in the mouth
- applying lip balm.

Your nurse may show you how to use a small soft toothbrush to moisten and freshen the mouth.



## *What if they can no longer take their medications?*

Most medications can be discontinued at the end of life and your doctor or nurse will advise on this. If the person has regular medication e.g. for pain or sickness, this can usually be given by injection and/or using a small pump called a syringe driver, where a small needle is inserted under the skin to ensure these symptoms are managed.

## **is there anything I can do to help?**

You can let the doctor or nurse know if there are any changes so they can check the person and give extra medication to help as needed.

## *I am worried that they are sleepier*

It is normal for a dying person to sleep more and be drowsy even when they are awake. They become less interested in what is going on around them and have less energy to take part. This does not necessarily mean they are no longer hearing what you say to them. They may also drift in and out of consciousness. Some people become completely unconscious for a period of time before they die; this could be for a short time, or for as long as several days.

It is important to know that in these final stages the person may often close their eyes. At some point, they may not open them again. Their eyes can sometimes be half open, although they are not awake.



### **is there anything I can do to help?**

It is important to remember that even when the person is, or appears to be, sleeping or resting, they may still be able to hear you. Do not feel that you need to stop communicating with them. You might want to carry on speaking quietly and calmly to them. You could also try letting them know you are there in other ways, for instance: holding their hand, reading to them or playing their favourite music. As they may still be able to hear you, take the opportunity to say the things that are important to you both. Simply being together can be a great comfort to both of you.

### **why does their skin look different?**

The person's hands, feet, ears and nose may feel cold to the touch (due to reduced circulation). These changes are all normal parts of the dying process. Occasionally, a person's hands or other parts of the body may swell a little, but this is not usually painful or uncomfortable. Their skin may also become mottled and blue, or patchy and uneven in colour.

### **is there anything I can do to help?**

It may be comforting to put loose gloves or socks on the person. You do not need to warm them up – but doing so may be comforting for you. Gentle massage may help – the nurses can show you how to do this. Due to the vulnerability of the person's skin, the person is more likely to develop a pressure ulcer at this time, so regular changing of position is important to help reduce this risk. Your healthcare professional can guide you in what is suitable for the care of your loved one and how you may help with this.

## what about toileting?

The person may lose control of their bladder or bowels. This happens because the muscles in these areas relax and don't work as they did. It may be upsetting to see, and you may worry that the person may feel embarrassed. They may also have fewer bowel movements and their urine may get darker, as they eat and drink less.

### **is there anything I can do to help?**

You can ask a nurse to show you how to:

- keep the person clean and comfortable
- protect the bed.

You can also ask for equipment that may be able to help with this, such as incontinence pads or a catheter (long thin tube that can be put into the bladder to drain urine).

## why are they sometimes restless or agitated?

Restlessness and agitation can be caused by many things. This may happen in the last few days of life, though the person may become more peaceful again before they die. Agitation could be caused by physical problems, like constipation or difficulty passing urine - ask the doctor or nurse caring for the person, if you are concerned.

Sometimes dying people may appear confused and may not recognise familiar faces. If they do not recognise you this may



be distressing, but it is not a sign that they feel differently about you. More likely, it is that they are unable to distinguish clearly between what is real and what is not – especially if they are sleepy and drifting in and out of consciousness, rather like what can happen when we are half-awake or half-asleep. They may hallucinate, and see or hear people or things that are not actually there; for instance, they may see pets or people who have died. Quiet reassurance and the comfort of those who are close to the person may help.

### **is there anything I can do to help?**

Sitting with the person may often help to calm them down.

Keeping things as normal as possible may help comfort the person.

You can also talk to the doctor or nurse, as they can check if there is any treatable reason for this or may be able to offer medication to help relieve this symptom.

You can help by:

- speaking clearly and audibly to the person
  - reminding them who you are (and being prepared to do so repeatedly)
  - keeping their surroundings calm, with minimal noise levels
  - trying not to correct them if they say something wrong, or insist on them getting things accurate, as this may be upsetting for you and for them.
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## will there be any changes to their breathing?

A change in breathing pattern is a normal part of the dying process. The body needs less oxygen, and breathing may become shallower. The person does not usually need extra oxygen at this stage.

If the person is anxious, their breathing rate may increase a little. There may be long pauses between their breaths and sometimes the breathing may also make a noise, commonly known as “death rattle”. This is likely to be because they are not able to re-absorb or swallow the normal fluids in their chest or throat, which can cause a rattling sound. The rattling sound may be upsetting to hear, but it does not seem to cause any distress to the dying person.

In the very last moments of life, the person’s breathing pattern may change. Breaths may become much slower and quieter before they stop altogether.

## is there anything I can do to help?

If the person is anxious, sitting with them so that they know you are there, may help to reduce their anxiety.

Breathlessness can be frightening; a small fan and an open window can help.

If the rattling is very pronounced, it may be helpful to change the person’s position so that they are on their side, if they agree or do not seem too disturbed by being moved. Ask to be shown the best way to move the person.



The doctor or nurse may also suggest medication which may help to reduce the fluids in their chest and throat. This is not always needed, however, and does not always make a difference.

### the person's final moments

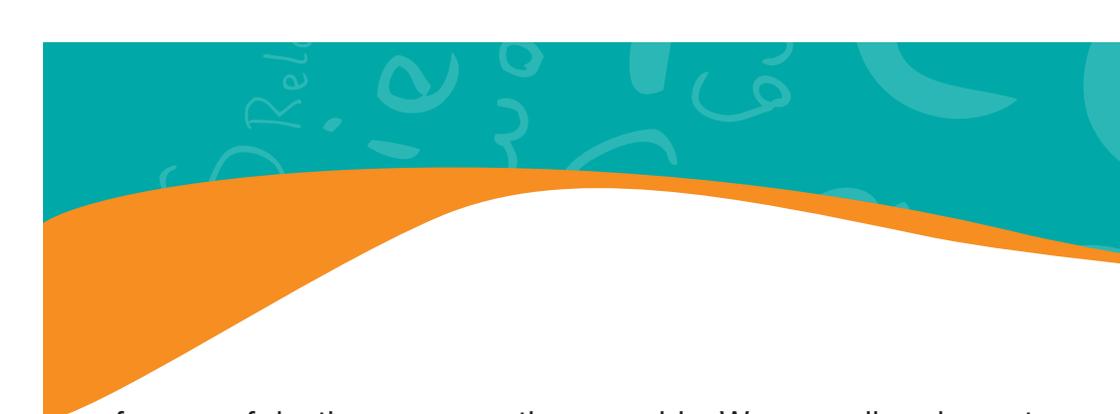
Particularly in the last few minutes, the person's face muscles may relax and they may become very pale. Their jaw may drop and their eyes may become less clear. The person's breathing will eventually stop. Often, the person's body will completely relax. Sometimes it can be difficult to identify the exact moment when the person died. There may be one or two last gasps a minute or so after what seemed like the last breath. However, you should note down the time as close as possible to the moment they died. This is always a distressing moment, even when death has been expected for days. You may suddenly feel overwhelmed with sadness; you may want to be alone, or you may want to ring family and friends. By this time you may be exhausted with the caring and the waiting, and the relief and finality of the moment of death can take you by surprise.

### what happens after the person has died?

If your loved one dies at home, you will need to contact the doctor or district nursing team, so that a professional can come and verify the death. Your chosen Funeral Director can then be contacted. On the following working day, please contact your GP to discuss the best time for picking up the death certificate.

If your loved one dies at the Hospice, a Hospice nurse or doctor will verify the death. Our doctors will write the medical certificate





of cause of death as soon as they are able. We normally ask you to phone after 10am on the next working day, to enquire whether the certificate is ready, and then we shall make an appointment for you to collect it.

Once the person has died, and you have noted the time of death, you may wish to:-

- carry out a particular ritual or ceremony, if there is one that is important to you or the person's culture or beliefs.
- sit and be with the person for as long as feels comfortable for you.

### **what information do I need to give about funeral arrangements?**

***It is helpful to choose a Funeral Director prior to the death.***

***Whether your loved one dies at home or in the Hospice,*** it is helpful to have chosen a Funeral Director prior to the death and to have made an initial contact with them; you will doubtless feel very emotional after your loved one has died, and find it hard to focus on such practicalities.

If your loved one dies at home, and your loved one's death has been verified by a healthcare professional, you are able to contact your chosen Funeral Director so that ongoing care can take place in the Funeral Director's Chapel of Rest.

If your loved one dies at the Hospice, it is important you let us know the details of your chosen Funeral Director as soon as you





can after the death. The staff at the Hospice will make contact with the Funeral Director and ask them to take your loved one into their care.

*It is also important* for the professionals involved in the care to know whether the person who has died will be buried or cremated, as this affects the paperwork that the doctors must provide.

Once your loved one has been transferred to the care of your chosen Funeral Director, they will guide you through the next steps, at a pace that's right for you. All deaths must be registered at the Registration Office within five days, unless they have been referred to the coroner. Please note that you will need to make an appointment.

### *where can I turn for help if I have any concerns or questions?*

This information is a guide, to help you feel more prepared for what to expect. However, if you have any concerns or unanswered questions, please ask a member of staff, who will be able to help you or will direct you to someone who can help.

At home, either contact your doctor, or use the telephone numbers you have been given by the Community Nurses and the Phyllis Tuckwell nursing team.

Contact details for the out of hours medical and nursing services are also useful for you to have.



Phyllis Tuckwell continues to support you as a family after your loved one has died.

We will write to you about nine weeks after the death, to tell you about the services Phyllis Tuckwell provides.

If you wish to access bereavement services before this please make contact with:

**Patient & Family Support team**

01252 729430

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***Large print version  
available on request.***

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