

Understanding the changes that may occur during the dying process

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*Information for relatives and
carers*

This leaflet describes some of the physical and psychological changes that happen to people as they start to die. A plan of your relative's* care will be discussed with you. Please ask for further help or information if there is anything at all that is worrying you.

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Each person's experience of the last few days of life will be different and it can be difficult to predict exactly what will happen or how quickly any changes will occur. These changes fall into four main categories:

- Less need for food and drink
- Withdrawing from the world
- Changes in breathing
- Changes which occur shortly before death.

This leaflet has been given to you to help explain about those changes but please ask the nurses or doctors, or if at home your Community Nurse or GP, if you have any further concerns or need more information.

Less need for food and drink

When someone is no longer interested in eating and drinking, it can be very hard to accept, even when you know it is because they are dying. The body's metabolism slows down and is unable to digest food so well or take any goodness from it. The effort of eating and drinking can become simply too exhausting. A small mouthful at a time may be all that can be managed or desired. Help with feeding and drinking at this time might be

**We use 'relative' to mean the person you are caring for.*

appreciated. Eventually, a person may stop drinking altogether. Their mouth may appear dry, so you can moisten it with a damp sponge, a baby toothbrush dipped in water, or a spray may be comforting. A lip salve will also help. If there is little apparent response, this may be due to weakness not lack of appreciation. Simply caring and being together may be of great comfort to both of you.

Medication and treatment

Medication is reviewed when swallowing becomes difficult. Anything that is no longer helpful or cannot be taken in the normal way may be stopped, given by an alternative route, or a new preparation may be prescribed to treat any physical or psychological symptoms such as pain, nausea, breathlessness, anxiety or agitation. Medication may be given by injection or, if needed regularly, by a continuous infusion placed just under the skin via a pump called a syringe driver. At home this is set up by the Community Nursing Team and replenished daily.

If someone is no longer strong enough to talk about symptoms they are experiencing, pain can be shown by becoming restless or grimacing. Anxiety or agitation may also be shown by restlessness but is sometimes associated with confusion, twitching or jerky movements as well. All these symptoms can be helped with medication. If you are worried about any of these, please phone your doctor's surgery or Hospiscare nurse.

Our care is focused upon comfort and dignity. You may wish to talk about measures which can be taken to promote comfort whilst lying in bed (such as positioning and pressure relieving equipment) or the need for regular mouth care. Please ask if you have any concerns.

Withdrawing from the world

For most, the process of ‘withdrawal from the world’ is a gradual one. The person will spend more time asleep and will often be drowsy when awake and show less interest in what is going on around them. This is a natural process and may even be accompanied by feelings of calmness and tranquillity. Eventually, this may lead into a state of unconsciousness which may last for a few minutes, a few hours or a few days. A person may still be aware of your presence and be able to hear what you are saying. Don’t be afraid to talk to them and explain any care given. You may wish to sit quietly and hold hands or recall shared memories and play some background music.

Changes in breathing

Towards the end of life, as the body becomes less active, the demand for oxygen lessens. People who suffer from breathlessness are often worried that they may die fighting for breath, but often it is found that breathing eases as they start to die. Breathing can be easier than it has been for a long time.

However, any breathing difficulties can be made worse by feelings of anxiety or fear. Reassurance, medication or the comforting knowledge that someone is close at hand can make a real difference. A much loved pet may also play a major part in reducing breathlessness caused by anxiety or fear.

Occasionally, in the last hours of life, there can be a noisy rattle to the breathing. This is caused by a build up of mucus in the chest which the person is no longer able to cough up. Medication may be used to reduce it and changes of position can also help. The noisy breathing can be upsetting to hear but it does not appear to distress the dying person.

If you are at home it is important to contact your surgery or out of hours service so that additional medication can be given to relieve symptoms.

Changes which occur shortly before death

The dying process is unique to each person but in most cases there are some common signs which help to indicate that a person is dying. For example, their breathing pattern may change again. There are sometimes long pauses between breaths and/or the abdominal (tummy) muscles will take over the work. The abdomen rises and falls instead of the chest. Breathing can appear laboured but this is more distressing to you than to the person dying. Medication can be given if there are signs of distress but these changes in breathing are an expected part of dying.

Some people can become more restless and agitated as death approaches. If this is the case, medication can be administered in the form of pain relief and/or a sedative to help ease symptoms that are causing distress.

If you are home it is important to contact your surgery or out of hours service so that additional medication can be given to relieve symptoms.

The skin can become pale, moist and slightly cool prior to death. Most people do not rouse from sleep but die peacefully and comfortably. Their breathing will get slower and eventually stop. Sometimes it is difficult to pinpoint the exact moment of death. After a short time, the body may relax completely and look peaceful. Even though the death is expected, it can still be a huge shock when it actually happens.

What happens now?

When someone dies, there is no need to do anything immediately. You may need a few minutes (or longer) to understand what has just happened.

When you are ready, you will need to ring your doctor's surgery (or the out of hours service) to inform them of the death. A doctor or community nurse has to visit to verify that the person has died. A death certificate is unlikely to be issued at this time. The visiting doctor or community nurse will provide you with further information regarding this.

If you wish, you may phone the funeral director while you are waiting for the nurse/doctor to visit (or you can wait until afterwards). The funeral directors will provide further guidance at this difficult time.

You may also wish to ring a relative or a friend who can stay with you and offer their support for a while.

Please feel free to talk to any of the Hospiscare team.

Hospiscare is a charity

We make a difference in Exeter, Mid and East Devon because we are part of our local community, because we are supported as a charity, and because we are professionals in a range of disciplines. We are only able to provide our vital services to families with your support – our dedicated, professional care is free to those who need it, so we need your help to employ specialist nurses, doctors and consultants. If you would like to make a contribution towards the charity, please let us know.

Tell us about your experience of Hospiscare

Hospiscare welcomes feedback, compliments and complaints, and we use them to develop our staff and services.

We know the majority of people have a positive experience, but encourage all your feedback, positive or negative. We investigate complaints thoroughly and treat them as an opportunity to learn and improve our practice.

To tell us about your experience of Hospiscare please contact:

Director of Patient Services

Hospiscare, Searle House, Dryden Road, Exeter EX2 5JJ

Phone: 01392 688000

Should you make a complaint, we will send you a letter or email with details of any investigation with an expected timescale where possible. If you wish to see a copy of Hospiscare's Complaints Policy, please ask. If you are dissatisfied with our response you can contact:

The Parliamentary and Health Service Ombudsman

Millbank Tower, Millbank, London SW1P 4QP

Email: phso.enquiries@ombudsman.org.uk

Customer Helpline Tel: 0345 015 4033

Let us know if you would like the information in this leaflet in a different format; for example in large print or spoken word.

Hospiscare is registered by: Care Quality Commission, 151 Buckingham Palace Road, London SW1W 9SZ www.cqc.org.uk

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Hospiscare

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