



# Understanding dying



**DementiaUK**  
Helping families face dementia

## Understanding the changes that happen when someone is reaching the last days of their life

Dying is an individual and unique experience: everyone will experience it in their way and have their own needs. However, when someone is approaching the end of their life, there are common characteristics and changes that help us to know when a person is dying.

If your relative is coming to the end of their life in a hospital or within a care home, you might want to consider any questions you have for the clinical or care staff looking after them. If your relative is at home, then you could speak with their GP or a district nurse.

The characteristics and changes that often take place when a person approaches the end of their life fall into four main categories:

- Reduced need for food and drink
- Withdrawing from the world
- Changes in breathing
- Becoming increasingly sleepy/unresponsive

In this leaflet, we will look at how these four changes may appear, and suggest some ways to help the person be comfortable.

### Reduced need for food and drink

Someone in hospital or a care home will be supported to eat and drink for as long as they are able; however, when someone starts to die, their body no longer has the same need for food and drink as before. The body's metabolism slows down and becomes less able to digest the food, or absorb the goodness from it. It can be hard to accept these changes when you know a person is dying.

People stop drinking, and although their mouth may look dry, it's not a sign that they need to drink.

#### Ways to help:

Mouth care will give the person comfort if their mouth is dry. You might try:

- Wetting their lips with a damp sponge
- Applying lip balm
- Offering small sips of fluid, if appropriate

## Withdrawing from the world

For many people, the process of ‘withdrawal from the world’ is a gradual one and this natural process can appear to be accompanied by feelings of calmness and tranquillity. People may spend more and more time asleep, and when they are awake they often seem drowsy. They may show less interest in what is going

on around them. This does not mean they care about you any less.

### Ways to help:

There are some things you can do to bring the person comfort:

- Simply spend time with them
- Touch their arm or hold their hand
- Speak to them, even if they don’t respond, so they can hear the tone and sound of your voice



## Changes in breathing

People who have experienced breathlessness can be frightened by the sensation. They might therefore be worried about the changes in their friend or relative's breathing, believing – mistakenly – that they are fighting for breath. In fact, breathing can slow down and become shallower as the body becomes less active.

Just sitting quietly and holding someone's hand can make a real difference. Just 'being' with people is really important. Don't worry if you are not actively doing anything as your presence alone will bring comfort.

Sometimes, towards the end of life, people can develop an irregular breathing pattern or a noisy rattle to the breathing. This noise is due to a build up of mucus in the chest, which the person is no longer able to cough up.

Noisy breathing can be upsetting to hear, but it is not thought to distress the person. When the person is close to death the breathing pattern may change again, and there could be long pauses between breaths. Also the

abdomen may rise and fall instead of the chest.

### Ways to help:

- Changing the person's position may help with rattling breathing, if appropriate
- Medication which breaks up the mucus could be appropriate; this can be administered by an injection or via a syringe driver, by a nurse (please see below for more information on syringe drivers)

## Becoming sleepy, and other changes that may occur

A person close to death will become increasingly sleepy. Most people will slip into unconsciousness and die peacefully and quietly in their sleep.

Occasionally some people may become more agitated as death approaches. If this is the case, healthcare professionals will talk to you and, having ensured pain and other symptoms are controlled with appropriate medication, will administer some sedation. This may be given at first by an injection and at regular intervals if required,

depending upon how the person responds to it.

The person's skin can become pale and moist and slightly cool prior to death. You may also see changes in the colour of people's hands, finger nails, feet, toes and toe nails, as the body becomes less able to circulate blood.

## Syringe drivers

When people need to have injections frequently a syringe driver may be set up. This is a small needle inserted under the skin which gives a measured, continual dose of medication. It reduces discomfort from injections. This will be managed by the nurses looking after the person.

## Medication

You may hear some medication being referred to as 'anticipatory medications' by care staff and other health professionals. These are medications prescribed in anticipation of someone dying and are used to ensure comfort at the end of life. These consist of pain relief, something for anxiety, something to help with any nausea or sickness, and to ease the noisy

breathing sometimes heard due to excess moisture.

## Practical issues

If you are told your relative or friend is dying and may be approaching their death, it can be helpful to anticipate some of the questions you might like to ask those supporting you.

If your relative or friend is in hospital, you should be given information about visiting, car parking and how to obtain drinks and meals. Some hospital car parks operate a pay and display system, so if you are spending a lot of time visiting the ward the staff can assist you in getting a dispensation ticket. If your relative or friend is in a care home, speak to the staff and discuss what will be helpful for you and the person who is dying.



## Support for you

When someone you are close to dies, it is very likely to be difficult. You may need support and time to work through what has happened. Some people might find it difficult to explain that they have been bereaved, or may not know how to get help. Speak to your GP to find out what local support services there might be in your area, or please call the **Admiral Nurse Dementia Helpline on 0800 888 6678**. You may also find our leaflet on bereavement helpful.

If you have any questions or concerns, please call our Admiral Nurse Dementia Helpline on **0800 888 6678** or email **helpline@dementiauk.org**

## Sources of support

Dementia UK bereavement leaflet

[www.dementiauk.org/grief-bereavement-and-loss-in-dementia](http://www.dementiauk.org/grief-bereavement-and-loss-in-dementia)

Cruse Bereavement Care (CRUSE)

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

Health Education England (HEE)

[www.hee.nhs.uk](http://www.hee.nhs.uk)

The National Council for Palliative Care (NCPC)

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

Dying Matters

[www.dyingmatters.org](http://www.dyingmatters.org)

The information in this booklet is written and reviewed by dementia specialist Admiral Nurses.

We are always looking to improve our resources, to provide the most relevant support for families living with dementia. If you have feedback about any of our leaflets, please email

[feedback@dementiauk.org](mailto:feedback@dementiauk.org)

We receive no government funding and rely on voluntary donations, including gifts in Wills.

For more information on how to support Dementia UK, please visit [www.dementiauk.org/donate](http://www.dementiauk.org/donate) or call **0300 365 5500**.

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If you're caring for someone with dementia or if you have any other concerns or questions, call or email our Admiral Nurses for specialist support and advice.



Call **0800 888 6678** or email [helpline@dementiauk.org](mailto:helpline@dementiauk.org)

Open Monday – Friday, 9am – 9pm  
Saturday and Sunday, 9am – 5pm

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