



DementiaUK
Helping families face dementia

Understanding dying



Dementia is a progressive, life-limiting condition, which means that everyone with a dementia diagnosis will die with or of it. Some people will die of dementia itself, while others have co-existing health conditions – such as cancer or heart failure – that lead to death.

Characteristics of dying

Everyone will experience dying in their own individual way. However, there are certain characteristics and changes that typically occur as someone nears the end of life. They may be difficult to witness, but they are natural parts of dying and do not necessarily mean the person is in distress.

These characteristics fall into four main categories:

- reduced need for food and drink
- withdrawing from the world
- changes in breathing
- becoming increasingly sleepy/unresponsive

Reduced need for food and drink

Towards the end of life, people no longer have the same need for food and drink as they did before.

If a person with dementia is in hospital or a care home, staff will support them to eat and drink for as long as they are able. However, as they near death, their appetite is often reduced and they may stop eating and drinking completely.

Reasons why this happens include:

- the body's metabolism slowing down and becoming less able to digest food or absorb nutrients
- illness or infection affecting the person's appetite
- inability to recognise hunger and thirst
- the person being very fatigued, so eating and drinking become tiring
- difficulty swallowing

It can be very upsetting when someone stops eating or drinking, but interventions like a fluid drip or a feeding tube tend not to make a significant difference to how long the person lives and often cause discomfort and distress. Instead, it is better to focus on keeping the person comfortable rather than on what they are eating or drinking.

These tips may help:

- Offer just a few small spoonfuls of food or fluids at a time
- Give foods that have an appealing taste and texture – focus on the person’s enjoyment rather than on good nutrition
- If the person has difficulty swallowing, offer soft foods that do not require much chewing and are easy to swallow
- Never force the person to eat or drink as this may cause distress and put them at risk of choking
- If the person’s mouth looks dry, try offering ice chips or using an artificial saliva spray, wet their lips with a damp sponge, or apply lip balm

Withdrawing from the world

Withdrawing from the world is a natural and gradual process towards the end of life.

The person may show less interest in what is going on around them and interact with people less – or not at all. They may be uncommunicative and unresponsive, but they may still find your presence reassuring.



Here are some things you could try:

- Simply spend time with them
- Stroke their arm, hold their hand or gently brush their hair
- Speak to them, even if they don’t respond, so they can hear the familiar sound of your voice
- Use favourite scents, such as wearing perfume or aftershave that reminds them of you, or giving them a gentle hand massage with a hand cream that they used to use
- Play music that they previously enjoyed listening to

Changes in breathing

As a person approaches death, their breathing may slow down.

There may be periods of shallow breathing followed by periods of deep, rapid breathing, sometimes with a pause between the two.

Towards the end of life – often within the final hours – people may develop a noisy rattle to their breathing, sometimes known as a ‘death rattle’. This is due to a build-up of mucus in the chest, which the person cannot cough up.

When the person is very close to death, their breathing pattern may change again, becoming irregular with long pauses between breaths. Also, the abdomen may rise and fall instead of the chest.

Changes in breathing can be upsetting to hear and see but are not thought to cause the person pain or distress. Often, they will be unconscious by this stage, or unaware of their breathing patterns.

The following tips may help:

- Changing the person’s position may help with rattling breathing, if appropriate – if the person is in hospital or a care home, their care or nursing staff can assist
- Medication that breaks up mucus

could be used in some cases – this could be administered via injection or a syringe driver (a small needle inserted under the skin that gives a measured, continual dose of medication and avoids the need for repeated injections)

- Just sitting quietly and holding the person’s hand can bring comfort, even if you are not actively doing anything

Becoming sleepy

A person who is close to death will become increasingly sleepy and difficult to rouse. When they are awake, they often seem drowsy.

Many people will slip into unconsciousness and die peacefully and quietly in their sleep.

Other changes that may occur

Agitation and restlessness

Occasionally, people become agitated as death approaches. For example, they might shout, lash out or try to get out of bed. This may be out of character and upsetting to see.

If the person is agitated and

restless, their healthcare professionals will try to identify causes, such as pain or an infection, and will address these if possible – for example by giving pain relief.

In some cases, the person may be given sedative medication. If they respond well to it, it may be administered at regular intervals.

Hallucinations

People who are nearing the end of life may experience hallucinations. They may see or hear things that aren't there or feel strange sensations, for example feeling like there are bugs on their skin.

As with agitation and restlessness, sedative medication may help to ease hallucinations.

Skin changes

A person's skin may become pale, moist and slightly cool prior to death. Their hands, fingernails, feet, toes and toenails may have a blue tinge as the body becomes less able to circulate blood. This is normal, but you may wish to cover the person's hands and feet with blankets to keep them warm.

Medication at the end of life

When someone is dying, their health professionals may suggest giving them 'anticipatory medications' to keep them comfortable.

Anticipatory medications include:

- pain relief
- anxiety medication
- anti-sickness medication
- medication to ease breathlessness and noisy breathing
- medication to ease agitation, confusion and restlessness

If the person needs medication regularly, it may be given through a syringe driver. This will be managed by the nurses looking after them.

Practical issues

If the person with dementia is coming to the end of their life in a hospital, you might have practical questions for the staff looking after them. For example:

- Can you stay with the person outside visiting hours?

- Can you be given meals and drinks?
- Could you be provided with a permit to exempt you from parking fees while you visit?

If the person is in a care home, you can speak to their carers about how their needs can be met. They will have experience in supporting people with dementia and their families at the end of life. You can also discuss practical matters such as whether you would prefer the person to remain in their care home to die, rather than being moved to hospital, which may cause distress.

If your relative is at home, you could speak to their GP or a district nurse if you have any questions or need advice on how best to support them. They may be able to refer the person to a palliative/end of life care team.

In some cases, where a person is in hospital or a care home but has expressed a wish to die at home, it may be possible for them to be moved home with support from palliative care nurses.

Some people may be referred to a hospice at the end of life. This

doesn't necessarily mean that the person will be moved into the hospice and die there; it is more common for a hospice nurse to visit them at home and give them the support they need to have a comfortable and dignified death.

Support for you

When someone you are close to is dying, it is normal to have a complicated mix of emotions. Many people will turn to family and friends for support, but your GP can advise you about support services in your area, and there are many other organisations that may be helpful. You can also contact our free Dementia Helpline or virtual clinics – please see Sources of support on p7.

Children and young people may need support to understand the dying process in an age-appropriate way. This is especially important if their parent, rather than an older relative, is dying. The charity Child Bereavement UK can help you at this time, and you can also speak to our specialist dementia nurses for advice.

Sources of support

If you would like to speak to a dementia specialist Admiral Nurse about understanding dying or any other aspect of dementia, please call our Helpline on **0800 888 6678** (Monday-Friday 9am-9pm, Saturday and Sunday 9am-5pm, every day except 25th December) or email helpline@dementiauk.org

To book a phone or video call appointment with an Admiral Nurse, please visit dementiauk.org/book-a-clinic-appointment

Dementia UK resources

Finding help and support
dementiauk.org/finding-help-assistance

Recognising the later stages of dementia and moving towards end of life care
dementiauk.org/end-of-life-care

What to expect from hospice care
dementiauk.org/what-to-expect-from-hospice-care

Grief, bereavement and loss
dementiauk.org/bereavement

Other resources

Cruse Bereavement Support
cruse.org.uk

NHS – find palliative care services
nhs.uk/service-search/other-services/Palliative-care/LocationSearch/1822

Marie Curie – care and support through terminal illness
mariecurie.org.uk

Hospice UK – the charity for hospice and end of life care
hospiceuk.org

The Good Grief Trust – bereavement peer support
thegoodgrieftrust.org

Child Bereavement UK
childbereavementuk.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

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For more information on how to support Dementia UK, please visit 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

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Saturday and Sunday, 9am-5pm



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