

Understanding dying



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

Understanding the changes that happen in the last days of life can help you feel more prepared for what to expect.

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. They can be supported to eat and drink for as long as they are able; their healthcare team can advise you on this. However, as they near death, their appetite often diminishes, 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 may cause discomfort and distress.

Instead, it is often 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

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- Offer drinks through a straw
- 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, you can wet their lips with water
- Good mouth care is important and can help the person feel more comfortable. Their healthcare team can advise you on how to help

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:

- Spend time with them
- Stroke their arm, hold their hand or gently brush their hair
- Speak to them, even if they do not respond, so they can hear the familiar sound of your voice
- Consider any important beliefs, religious or spiritual needs that the person has which might bring them comfort

- 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:

- If appropriate, changing the person’s position or adjusting their pillows may help with rattling breathing; their healthcare team can advise you on this
- 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)

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- 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 are not 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. This is normal, but you may wish to cover their hands and feet with blankets to keep them warm.

People with lighter skin may look slightly blue as they approach



death, particularly on their hands, fingernails, feet, toes and toenails, as the body becomes less able to circulate blood. It can be harder to see any blue colouring on darker skin, but you may be able to see it on the person's lips, nose, cheeks, ears, tongue or inside their mouth.

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
- sedative 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.

Decisions around death

Many people have strong preferences about what they would like to happen around their death. If possible, you can help them make an advance care plan, with the support of family members and health professionals, before they reach the end stages of life. This sets out their wishes for their future care and treatment, including their wishes around the end of life.

It is also important for the person to make a lasting power of attorney (LPA)– this allows them to nominate one or more people to make decisions on their behalf (including decisions about their health and welfare) if they become unable to do so themselves. It is legally binding. An LPA can only be made while someone has mental capacity, which people with dementia often lose towards the end of life, so the person should be encouraged to make an LPA as soon as possible after their diagnosis.

Some people make an advance decision to refuse treatment (ADRT). This is also legally binding and sets out any medical treatments that they do not want to receive, including life-sustaining treatments like CPR and ventilation. As with LPA, if the person with dementia wishes to make an ADRT, they should do this as early as possible while they have capacity to do so.

If the person has an advance care plan, lasting power of attorney or ADRT, it is important to make their health and care staff aware of these. Any decisions about their care must be made in their best interests and involve their family and other people close to them, as well as their health professionals.

Please see Sources of support on p13-14 for more information on



advance care planning, lasting power of attorney, ADRT and mental capacity and decision-making.

Dying at home

Many people express a preference for dying at home. Health and care professionals will support this, if possible. Their GP can arrange for community nurses to provide nursing care at home. They may also be able to refer the person to a palliative/end of life care team which can provide practical and emotional support for the person with dementia and their family carers.

Social services may be able to provide equipment and services to help the person remain at home. You will need to request a free needs assessment – please see Sources of support on p15.

Dying in a care home

If the person with dementia lives in a care home and is nearing the end of life, you can speak to their carers about how their needs can be met. They will have experience in supporting people and their families at this stage. You can also discuss practical matters such as

whether you would prefer the person to remain in their care home to die (if possible), rather than being moved to hospital, which may cause distress.

If the person with dementia lives in a care home and is approaching death, they may still be supported by professionals such as their GP, community/district nurses or a hospital palliative care team. Please speak to their GP for advice.

Dying in hospital

In some circumstances, it may be in the person's best interests to be in hospital at the end of life, even if this is not what they would have chosen – for example if they have intense medical needs that can only be managed in hospital. 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:

- What are the arrangements for staying with the person outside visiting hours?
- Can they be moved to a private room in the final stages?
- Can you be given meals and drinks?
- Can any children in the family visit, if they wish to?
- Could you be provided with a permit to exempt you from parking fees while you visit?

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.

Hospice care

Some people are referred to a hospice at the end of life. These units are smaller and quieter than a hospital with a home-from-home

environment, and are run by a team of doctors, nurses, social workers, counsellors and trained volunteers. Hospice services are free.

Some people who are nearing death are admitted to a hospice, especially if their medical and care needs are intense or complex. This enables them to receive round-the-clock care and support that may not be possible at home. Being admitted to a hospice may also be beneficial if the person does not want other family members – particularly children and young people – to associate their home with their death.

However, many people who are referred to a hospice will remain at home, with visits from a hospice nurse who will give them the support they need to have a comfortable and dignified death. It may be possible to attend a hospice as a day patient to benefit from a wider range of services than at home. Hospices also provide emotional support for families, including after the person's death.

Please speak to the person's GP if you believe they would benefit from hospice care.

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 services and organisations that may be helpful, including our free Helpline and virtual clinic appointments – please see Sources of support on p13.

Children and young people may need additional support to understand the dying process in an age-appropriate way. It is a good idea to speak to their school/college to inform them of the situation.

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This will enable staff to look out for signs that they need support and put that support in place; and be understanding if they need time off school.

Please see Sources of support on p14-15 for details of organisations that can offer support at this time, including for any children or young people in the family. You can also speak to our specialist dementia nurses for advice.



Sources of support

To speak to a dementia specialist Admiral Nurse on our free Helpline, call **0800 888 6678** (Monday-Friday 9am-9pm, Saturday and Sunday 9am-5pm, every day except 25th December) or email [👉 helpline@dementiauk.org](mailto:helpline@dementiauk.org)

If you prefer, you can book a phone or video call with an Admiral Nurse at a time to suit you: please visit

[👉 dementiauk.org/book](https://dementiauk.org/book)

Dementia UK resources

Advance care planning

[👉 dementiauk.org/advance-care-planning](https://dementiauk.org/advance-care-planning)

Finding help and support at home

[👉 dementiauk.org/finding-help-assistance](https://dementiauk.org/finding-help-assistance)

Frailty and dementia

[👉 dementiauk.org/frailty-and-dementia](https://dementiauk.org/frailty-and-dementia)

Grief, bereavement and loss

[👉 dementiauk.org/bereavement](https://dementiauk.org/bereavement)

Lasting power of attorney

[👉 dementiauk.org/lasting-power-of-attorney](https://dementiauk.org/lasting-power-of-attorney)

Looking after yourself as a carer

[👉 dementiauk.org/looking-after-yourself](https://dementiauk.org/looking-after-yourself)

Mental capacity and decision-making

[👉 dementiauk.org/mental-capacity-and-decision-making](https://dementiauk.org/mental-capacity-and-decision-making)

Recognising the later stages of dementia and moving towards end of life care

➤ dementiauk.org/end-of-life-care

Stages of dementia

➤ dementiauk.org/stages-of-dementia

Supporting children and adolescents when a parent has young onset dementia

➤ dementiauk.org/supporting-children

What to expect from hospice care

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

Other resources

Advance decision to refuse treatment (ADRT)

➤ nhs.uk/conditions/end-of-life-care/planning-ahead/advance-decision-to-refuse-treatment

Child Bereavement Network

➤ childhoodbereavementnetwork.org.uk

Child Bereavement UK

➤ childbereavementuk.org

Cruse Bereavement Support

➤ cruse.org.uk

The Good Grief Trust – bereavement peer support

➤ thegoodgrieftrust.org

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

➤ hospiceuk.org



Marie Curie – care and support through terminal illness

➤ mariecurie.org.uk

The needs assessment

➤ nhs.uk/conditions/social-care-and-support-guide/help-from-social-services-and-charities/getting-a-needs-assessment

NHS: end of life care

➤ nhs.uk/conditions/end-of-life-care

NHS: find palliative care services

➤ nhs.uk/service-search/other-health-services/palliative-care

Winston’s Wish – support for bereaved children

➤ winstonswish.org

**To speak to a dementia specialist Admiral Nurse
about any aspect of dementia:**

Contact our Helpline:
0800 888 6678 or [📧 helpline@dementiauk.org](mailto:helpline@dementiauk.org)

Book a virtual appointment:
[📅 dementiauk.org/book](https://dementiauk.org/book)

**Our charity relies entirely on donations to fund our
life-changing work. If you would like to donate to help us
support more families:**

- Call **0300 365 5500**
- Visit [📧 dementiauk.org/donate](https://dementiauk.org/donate)
- Scan the QR code

Thank you.



DementiaUK
Helping families face dementia



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