



DementiaUK

Helping families face dementia

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



Dementia is a progressive neurological condition that is life-limiting. This means that everyone with dementia will die with or from it, although many people die as a result of other conditions (such as cancer or heart failure) before they reach its later stages.

Whether a person has dementia alone or other health conditions alongside, it is important that plans are made to ensure they receive good care throughout their life. Towards the end of life, this may include a shift away from treatments that may cause distress or have limited benefit, and more towards a focus on comfort.

The end of life stage can be hard to identify and accept – by the person with dementia, if they are aware of what is happening, and their family members, who often play a vital role in supporting them. However, good end of life care can enhance the person's quality of life and ensure their needs are met.

Amongst professionals, it is usually understood that a person will move towards end of life care when it is thought that they are within the last months or years of life.

However, this can be very individual and is often difficult to predict, so it is better to focus on their needs rather than on how long they may have left to live.

Identifying the later stages of dementia and the end of life

Signs that a person with dementia might be approaching the end of life include:

- significantly reduced appetite: loss of interest in food and drink, or refusing it completely
- becoming increasingly frail
- weight loss
- swallowing difficulties (for example, coughing/throat-clearing during or after eating or drinking; taking a long time to chew food; choking on food; or storing food in their mouth)
- frequent infections
- reduced mobility, perhaps requiring care in a bed or chair
- frequent falls
- reduced communication



- becoming more withdrawn, or agitated and/or restless
- sleeping more, seeming drowsy and less aware
- difficulties controlling their bladder and/or bowel (incontinence)
- needing help with most daily activities

If the person you care for is showing a number of these signs or you have any concerns, make an appointment with their GP – there may be an underlying cause that could be treated or managed better, such as pain or delirium. Please see Sources of support on p14-15 for our leaflets on these.

Decision-making towards the end of life

If the person you care for is entering the later stages of dementia or another condition, it is important to think about how their end of life care should be provided. Making a clear, documented plan will help everyone work together to support the person in the later stages of their life. It can bring a sense of calm and control to emotional situations, and avoid having to make decisions in a crisis, which may be distressing.

If possible, the person with dementia should be involved in making decisions about their future care before they reach a stage

where they are unable to do so. This may include making:

- an advance care plan: this covers how they would like to be cared for and where they would like to die, as well as matters such as decisions about their Will and funeral. You can download a template at dementiauk.org/care-plan-template
- advance decision to refuse treatment (ADRT): also known as an advance decision or ‘living Will’, this states which treatments they do not wish to receive, such as antibiotics, ventilation and/or resuscitation (CPR). You can find out more at nhs.uk/conditions/end-of-life-care/advance-decision-to-refuse-treatment/

You might want to ask the GP for help with putting together an advance care plan or ADRT. They may be able to advise on local services that could support you. You can also contact our dementia specialist Admiral Nurses for advice – see p14 for more information.

If the person with dementia is reaching the end of life and has

not previously made their wishes and preferences known, it should not be assumed that they are now unable to do so. However, in the later stages of dementia, they may lack the mental capacity to make some decisions. In this case, other people may need to make these decisions on their behalf, in their best interests. For our information on capacity and decision-making, please see Sources of support on p15.

Some of the decisions you may want to think about include:

Resuscitation

Making the decision that someone should not be resuscitated if their heart stops can be extremely difficult. But resuscitation is often unsuccessful for a person in the advanced stages of dementia and could cause distress and trauma. If it is unsuccessful, it may also lead to them dying in an unfamiliar place, such as an ambulance or A&E department, rather than in their own home or care home.

For this reason, the person with dementia (if they still have mental capacity), their health and/or social care professionals and you



as their next of kin and/or carer may decide in advance that it is in their best interests not to attempt resuscitation at this stage.

The NHS has more information to help you decide whether resuscitation is appropriate for the person you care for as they near the end of life: [nhs.uk/conditions/do-not-attempt-cardiopulmonary-resuscitation-dnacpr-decisions](https://www.nhs.uk/conditions/do-not-attempt-cardiopulmonary-resuscitation-dnacr-pr-decisions)

Eating and drinking

At the end of life, people may have a reduced appetite or not want to eat or drink at all. This can be hard to accept, but it is a natural part of the dying process.

Invasive interventions like feeding through a tube or drip are unlikely to extend the person's life or improve their quality of life and may cause them distress. Instead, you and the person's care team might decide to focus on careful hand-feeding and giving food and drink for comfort and enjoyment, rather than nutrition. For example, you could:

- offer food and fluids from a teaspoon – carefully and in small amounts
- give foods with an appealing taste and texture

- give just a few mouthfuls at a time
- use ice chips or artificial saliva spray to keep their mouth comfortable
- ask the person's GP for a referral to a speech and language therapist for advice, especially if they have difficulty swallowing

Please see Sources of support on p14-15 for details of our leaflets on eating and drinking; hydration for a person with dementia; and understanding dying, which may be helpful at this stage.

Infections

Frequent infections are common in the end stages of life, especially chest infections, pneumonia and urinary tract infections (UTIs). It is important to consult the person's GP if they are showing signs of infection to discuss the best course of action.

If the person with dementia can still swallow, they may be prescribed liquid antibiotics to be taken by mouth. Even if they do not cure the infection, they could help to relieve symptoms and reduce discomfort and distress. However,

the GP may feel that antibiotics are not appropriate – for example, if the person has swallowing difficulties and antibiotics would have to be administered by drip – and prescribe other types of medication to help keep them as comfortable and peaceful as possible.

Frailty, mobility and falls

In the later stages of dementia, many people become increasingly frail and experience mobility problems and falls. This is often part of the progression of the condition (or of other conditions that they have alongside dementia).

If the person you care for is having falls, it is a good idea to speak to their GP in case there is another cause that could be treated or managed, such as low blood pressure, problems with their balance, or poor eyesight.

You and the person's GP and/or other health and social care professionals may want to discuss whether it is right for them to be admitted to hospital if they fall. For example, if the GP believes the person may have a fracture or other



serious injury, they may require hospital assessment and/or treatment. Otherwise, they may feel they can be supported to stay at home or in their care home.

Becoming frail and less mobile may lead to other health problems – for instance, if the person is spending long periods of time in a bed or chair, they may be more likely to develop constipation and pressure sores. The person’s GP may be able to refer them to a district nurse for advice and support on keeping them comfortable.

Where the person will be cared for at the end of life

It is important to think about where the person with dementia will be cared for at the end of life and any wishes they have expressed about where they would like to die. It is also important to take your own feelings into account – for example, whether you think you can continue to care for them at home or would find the memory of them dying at home traumatic.

People at the end of life often need 24-hour care. It may be extremely difficult to provide this care yourself, so if you and the person with dementia feel it is important

for them to remain at home, you may want to consider support from professional carers.

Social services can arrange a needs assessment for the person with dementia and a carer's assessment for the family carer to explore the support options available, such as respite care, adaptations to make the home safer and more comfortable, paid home carers, or home-based palliative care. For information on applying for these assessments, please see Sources of support on p14-15.

As the person's care needs increase, you may want to consider a move to a care home or nursing home. This can be a very big and emotional decision, and you may feel you are letting the person down, but care homes can provide the extra support they need so you can focus on spending time together. Our leaflet on moving into a care home may be helpful – please see Sources of support on p15.

If there is a hospice in your area, they may be able to support you in caring for the person with dementia at the end of their

life. This might include advice on symptom management and supportive care that involves family members and helps the person stay as comfortable as possible in a familiar and reassuring environment.

While some people are admitted to a hospice at the end of life, it is more likely that the hospice nurses will support the person to remain at home, unless they have acute and intense symptoms that cannot be managed at home – which may be the result of another condition like cancer. Your GP can advise on any local hospices and palliative care provision that may be able to support you.

Keep in mind that decisions about the person's care may need to be revisited and adapted as circumstances change – for example, it may be necessary for them to be admitted to hospital – but even if the person is being cared for elsewhere, you can still play a vital part in helping to meet their needs.



Emotional care

Although a person's physical abilities, memory and ability to communicate often deteriorate as their dementia advances, it is thought that feelings remain intact. The person may not be able to tell you how they are feeling – although their behaviour may be a good indicator – but it is important that they continue to feel loved, safe and secure.

The senses can be a powerful way to maintain connections and give comfort and pleasure. This could include:

- using scents that they find appealing or that have been favourites in the past, such as a perfume, aftershave or soap that they like to use
- looking at photos together
- playing music that they enjoy listening to
- giving them a gentle hand massage
- compiling a memory box to look through and handle together
- brushing their hair

- giving them small amounts of their favourite food and drink
- giving them something comforting to hold, such as a fluffy blanket or soft toy
- talking about happy occasions in their past

Compiling a life story

If a person with dementia has not already created a life story, you may want to do this before or as they enter the later stages of dementia. This is a record of things that are important to them, such as their family and friends; work history; important occasions in their past; likes and dislikes; religious, cultural and spiritual beliefs; and future wishes.

A life story can be recorded in a book, a computer document, an app, a memory box, a collage and/or a video recording. You can make it together with the person with dementia or, if their condition is too advanced, on their behalf. It can then be shared with professionals and carers to help them connect with the person in an individual and meaningful way.

For more information and our life story template, please see Sources of support on p15.

Faith, spirituality and culture

For many people, faith, spirituality and culture play a big part in their life. It is important that these values and needs are considered at the end of life, such as through religious practices or ceremonies, traditional rituals, songs/music, meditation, or clothing.

For example:

- If the person with dementia follows a religion, a visit, blessing or prayer from a religious leader may provide comfort and reassurance
- If their religious or cultural community has rituals around the end of life, such as what should happen immediately before or after they die (eg receiving the last rites) they may need assurance that these will be followed
- There may be particular people that the person wants to see before they die to ensure they feel at peace



The best way to find out what is important to the person with dementia is to ask them, if possible; if not, their family, other people who are close to them, or a religious or cultural leader may be able to help. You could include this information in their care plan or life story (see p14-15).

Young onset dementia and the end of life

Good end of life care and support for people affected by young onset dementia (where symptoms develop before the age of 65) and

their families is vital. Depending on their level of understanding, the person with dementia may have worries that are specific to their age and life stage – for example, they may be distressed about leaving a young family, or anxious about their partner having to manage financial commitments like a mortgage alone.

The emotional impact of the person dying at a younger age, the loss of the future they had imagined, and having to manage without them can be very difficult for families. Losing the

person's salary or benefits can also cause financial stress for family members.

Most of the advice around end of life care with dementia also applies to young onset dementia, and important issues like advance care planning and resuscitation should still be considered, even though the person may appear in better physical health and less frail than an older person.

However, there might be matters to consider that are specific to younger people, such as where they will be cared for in the later stages (some care homes are less able to cater for younger people with dementia); whether their young children should be able to visit them at the end of life; and whether it is appropriate for the person to stay at home to die if there are children living there.

Time together as a whole family, including the person who is dying if this is possible and reflects their needs and wishes, can be important in making lasting memories and ensuring everyone feels involved and valued. Working together on a life story (see

p15) can be beneficial in helping maintain connections between parent and child, as well as other family members.

If the person has school-age children, talk to their school about what is happening so they understand that they may need extra support or time off at short notice. If you work, you should also make your employer aware so you can access carer's leave and bereavement support to help ease any financial worries about taking time off work.

It is important that the person with young onset dementia and their family have professional support as they think about the later stages of dementia and move towards the end of life. Please see Sources of support on p14 for information on accessing support and advice.

Sources of support

As a carer or family member of a person at the end of life, it is vital that you feel well supported and able to look after your own needs. You may wish to seek support from:

- other family members or friends
- carers' support groups (in person or online)
- a local hospice
- health or social care professionals, eg your GP or a counsellor
- religious or community leaders

You can also contact our free Helpline to speak to a dementia specialist Admiral Nurse: please call **0800 888 6678** (Monday-Friday 9am-9pm, Saturday and Sunday 9am-5pm, every day except 25th December), or email helpline@dementiauk.org

If you prefer, you can book a phone or video call appointment with an Admiral Nurse at a time to suit you: visit dementiauk.org/book





Dementia UK resources

Advance care planning
dementiauk.org/advance-care-planning

Advance care plan template
dementiauk.org/care-plan-template

A stay in hospital
dementiauk.org/changes-in-care-a-stay-in-hospital

The carer's assessment
dementiauk.org/the-carers-assessment

Continence
dementiauk.org/continence

Delirium
dementiauk.org/delirium

Eating and drinking
dementiauk.org/eating-and-drinking

Falls
dementiauk.org/dementia-and-falls

Frailty and dementia
dementiauk.org/frailty

Good hydration for a person with dementia
dementiauk.org/hydration

Grief, bereavement and loss
dementiauk.org/bereavement

Lasting power of attorney
dementiauk.org/lasting-power-of-attorney

Life story template

dementiauk.org/wp-content/uploads/2023/05/My-life-story-template-9_FINAL.pdf

Life story work

dementiauk.org/life-story

Looking after yourself as a carer

dementiauk.org/looking-after-yourself

Mental capacity and decision-making

dementiauk.org/capacity-decision-making

Moving into a care home

dementiauk.org/changes-in-care/choosing-a-care-home

Pain and dementia

dementiauk.org/pain

Supporting children and adolescents when a parent has young onset dementia

dementiauk.org/supporting-children-and-adolescents

Understanding dying

dementiauk.org/understanding-dying

Young onset dementia: choosing a care home

dementiauk.org/young-onset-dementia-choosing-a-care-home

Other resources

Carer's assessment – find your local social services

nhs.uk/service-search/other-services/Local-Authority-Adult-Social-Care/LocationSearch/1918

Child Bereavement UK

childbereavementuk.org
Helpline: 0800 028 8840

Compassion in Dying:

living Will advice
compassionindying.org.uk

Dying Matters

dyingmatters.org

Hospice UK

hospiceuk.org

Marie Curie: care and support through terminal illness

mariecurie.org.uk
Helpline: 0800 090 2309

The needs assessment

gov.uk/apply-needs-assessment-social-services

Resuscitation Council UK:

ReSPECT plan for emergency care and CPR

resus.org.uk/respect/respect-patients-and-carers

The information in this leaflet is written and reviewed by dementia specialist Admiral Nurses. We hope you find it useful. If you have feedback, please email feedback@dementiauk.org

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We want to ensure no one has to face dementia alone – and we can only do this because of our generous supporters. If you would like to help, please consider making a kind gift.



To donate: call **0300 365 5500**,
visit dementiauk.org/donate-to-support
or scan the QR code.

Thank you.



If you have questions or concerns about any aspect of dementia, please contact our Admiral Nurses.
Helpline: **0800 888 6678** or helpline@dementiauk.org
Virtual clinics: dementiauk.org/book-an-appointment



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