



**DementiaUK**

Helping families face dementia

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





## What is end of life care?

Dementia is a progressive neurological condition which is life-limiting – although many people with dementia may 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's important that plans are made to ensure they receive good end of life care. This can include a shift away from treatments that may cause distress with limited benefit, and more towards a focus on comfort care.

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's usually understood that a person will move towards end of life care when it's 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's better to focus on their needs rather than on how long they may have left to live.

This leaflet aims to help you identify when someone has reached the end of life stage, how to recognise their needs, and what you can do to help. You might want to use it as a guide for steering your conversations with professionals, so you and the person you care for both get the support you need at this time.

## Recognising the signs of the end of life

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

- significantly reduced appetite, loss of interest in food and drink, or refusing it completely
- weight loss
- swallowing difficulties (for example, coughing/throat-clearing during or after eating or drinking, taking a long time to chew 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- becoming more withdrawn, or agitated and/or restless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 to discuss this – there may be an underlying cause that could be treated or managed better, such as pain or delirium. See Sources of support for you on page 12 for our leaflets on these.

### Decision-making towards the end of life

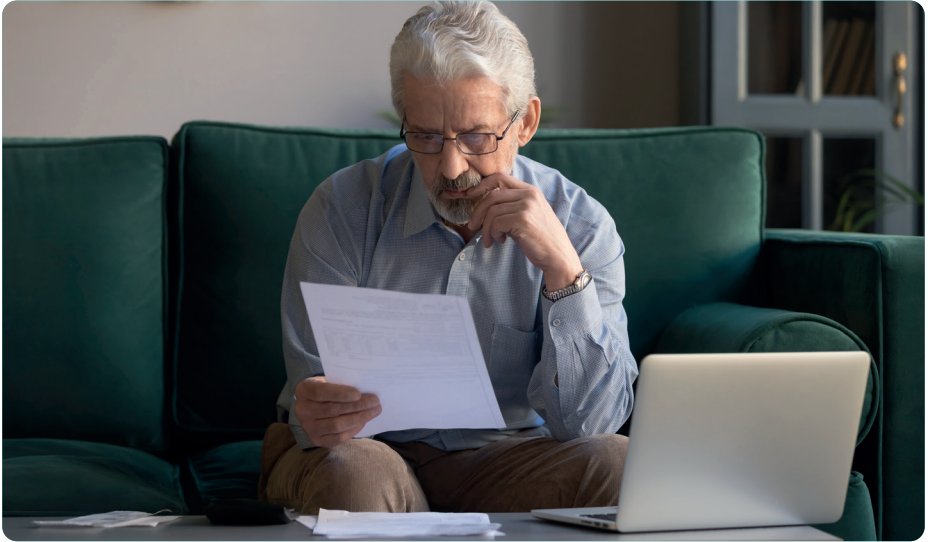
If the person you care for is entering the later stages of dementia or another condition, it's important to think about how their end of life care should be provided.

Making a clear, documented plan for end of life care 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 prevent having to make decisions in a crisis, which may be distressing.

If possible, a 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:

- **Advance Care Planning:** 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](https://dementiauk.org/care-plan-template)





- **Advance Decision to Refuse Treatment:** also known just as an Advance Decision or ‘living Will’, this states which treatments they do not wish to receive, such as antibiotics, ventilation and/or resuscitation. You can find more information on this in our booklet on Planning for your future (see Sources of support for you on page 12) or on the NHS website at [nhs.uk/conditions/end-of-life-care/advance-decision-to-refuse-treatment/](https://www.nhs.uk/conditions/end-of-life-care/advance-decision-to-refuse-treatment/)

You might want to ask their GP for help and advice with putting together an Advance Care Plan

or Advance Decision to Refuse Treatment. They may be able to advise on local resources that could support you. You could also call the Admiral Nurse Dementia Helpline for advice – see page 12 for more information.

If a person with dementia has not previously made their wishes and preferences known, it should not be assumed that they are now unable to do so. However, some people in the later stages of dementia may lack the mental capacity to make some decisions, so other people may need to make these decisions on their behalf, in their best interests.



You can find out more in the Dementia UK leaflet on Capacity and decision-making: see Sources of support for you on page 12 for details.

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 that resuscitation should not be attempted 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-dnacpr-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's 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. You can read more about this by scrolling down to the plain English summary at [cochranelibrary.com/cdsr/doi/10.1002/14651858.CDo13503.pub2/full](https://cochranelibrary.com/cdsr/doi/10.1002/14651858.CDo13503.pub2/full)

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 page 12 for details of our leaflets on eating and drinking 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's important to consult the person's GP if they are showing signs of infection to discuss the best course of action.

If a person with dementia can still swallow, they may be prescribed liquid antibiotics to be taken by mouth. Antibiotics may not be successful in curing the infection, but they could help to relieve symptoms and reduce discomfort and distress. However, the GP may feel that antibiotics are not appropriate, and prescribe other types of medication to help keep

the person as comfortable and peaceful as possible.

### **Mobility and falls**

In the later stages of dementia, many people may 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's a good idea to see 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's 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.

Our leaflet on pain in dementia explains more about identifying

and treating pain: see Sources of support for you on page 12.

Becoming 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. You might like to ask your GP if they could make a referral to a District Nurse or other healthcare professional for advice.

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

It's 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's also important to take your own feelings into account – for example, whether you think you can continue to care for them at home.

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's important for them to remain at home, you may want to consider support in the home 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, or paid home carers.

You can apply directly for a Needs Assessment at [gov.uk/apply-needs-assessment-social-services](https://www.gov.uk/apply-needs-assessment-social-services). If you would like to request a Carer's Assessment, you will need to contact your local Social Services: you can find their details at [nhs.uk/service-search/other-services/Local-Authority-Adult-Social-Care/LocationSearch/1918](https://nhs.uk/service-search/other-services/Local-Authority-Adult-Social-Care/LocationSearch/1918)

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're letting the person down, but often, 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 help you at this stage – you'll find details in Sources of support on page 12.

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 remain as comfortable as possible in a familiar and reassuring environment.

Hospices may also provide a place to die with comfort and dignity, although it's uncommon for people with dementia to be admitted to a hospice to die, and only usually happens if the person has acute and intense symptoms that cannot be managed at home.

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 – 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's thought that feelings may remain intact. They may not be able to tell you how they are feeling – although

their behaviour may be a good indicator – but it's important that they continue to feel loved, safe and secure.

Using the senses is a powerful way to maintain connections and give them 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

Everyone has their own unique values that are important to them. If a person with dementia has not already created a Life Story, you may want to do this before or as they enter the end of life stage. This is a record of things that are important to them, such as their family, friends, work history, important occasions in their past, likes, dislikes, hobbies, and religious beliefs.

A Life Story can be recorded in a book, a computer document, an app, a memory box, a collage 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.

Read our leaflet on creating a Life Story for more information – see Sources of support for you on page 12 for details.

## Sources of support for you

It's important that as a carer or family member of a person at the end of life, 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 (local or online)
- a local hospice
- health or social care professionals, eg your GP or a counsellor

You can also contact our free Dementia 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 25<sup>th</sup> December), or email [helpline@dementiauk.org](mailto:helpline@dementiauk.org).

If you prefer, you can book an appointment by phone or video call with an Admiral Nurse clinic at a time to suit you: visit [dementiauk.org/get-support/closer-to-home/](https://dementiauk.org/get-support/closer-to-home/) for details.

You may find the following leaflets and organisations helpful:

**Dementia UK leaflet on Understanding dying**

[dementiauk.org/get-support/understanding-changes-in-behaviour/understanding-dying/](https://dementiauk.org/get-support/understanding-changes-in-behaviour/understanding-dying/)

**Dementia UK leaflet on Advance Care Planning**

[dementiauk.org/get-support/legal-and-financial-information/advance-care-planning/](https://dementiauk.org/get-support/legal-and-financial-information/advance-care-planning/)

**Dementia UK leaflet on Pain in dementia**

[dementiauk.org/get-support/maintaining-health-in-dementia/pain-in-dementia/](https://dementiauk.org/get-support/maintaining-health-in-dementia/pain-in-dementia/)

**Dementia UK leaflet on Delirium**

[dementiauk.org/get-support/understanding-changes-in-behaviour/delirium/](https://dementiauk.org/get-support/understanding-changes-in-behaviour/delirium/)

**Dementia UK leaflet on Capacity and decision-making**

[dementiauk.org/get-support/diagnosis-and-next-steps/changes-in-care/capacity-decision-making/](https://dementiauk.org/get-support/diagnosis-and-next-steps/changes-in-care/capacity-decision-making/)

**Dementia UK leaflet on Looking after yourself**

[dementiauk.org/get-support/looking-after-yourself-as-a-carer/looking-after-yourself-when-you-care-for-someone-with-dementia](https://dementiauk.org/get-support/looking-after-yourself-as-a-carer/looking-after-yourself-when-you-care-for-someone-with-dementia)

**Dementia UK leaflet on Creating a Life Story**

[dementiauk.org/get-support/maintaining-health-in-dementia/creating-a-life-story/](https://dementiauk.org/get-support/maintaining-health-in-dementia/creating-a-life-story/)

**Dementia UK Advice on Moving into a care home**

[dementiauk.org/advice-on-moving-into-a-care-home/](https://dementiauk.org/advice-on-moving-into-a-care-home/)

**Dementia UK leaflet on The Carer's Assessment**

[dementiauk.org/get-support/legal-and-financial-information/the-carers-assessment/](https://dementiauk.org/get-support/legal-and-financial-information/the-carers-assessment/)

**Dementia UK leaflet on Changes in care: capacity and decision-making**

[dementiauk.org/get-support/diagnosis-and-next-steps/changes-in-care/capacity-decision-making/](https://dementiauk.org/get-support/diagnosis-and-next-steps/changes-in-care/capacity-decision-making/)

**Dementia UK leaflet on Changes in care: a stay in hospital**

[dementiauk.org/get-support/diagnosis-and-next-steps/changes-in-care/changes-in-care-a-stay-in-hospital](https://dementiauk.org/get-support/diagnosis-and-next-steps/changes-in-care/changes-in-care-a-stay-in-hospital)

**Dementia UK leaflet on Changes in care: choosing a care home**

[dementiauk.org/get-support/diagnosis-and-next-steps/changes-in-care/choosing-a-care-home/](https://dementiauk.org/get-support/diagnosis-and-next-steps/changes-in-care/choosing-a-care-home/)



**Dementia UK leaflet on Eating and drinking**

[dementiauk.org/get-support/maintaining-health-in-dementia/eating-and-drinking/](https://dementiauk.org/get-support/maintaining-health-in-dementia/eating-and-drinking/)

**Dementia UK leaflet on Grief, bereavement and loss**

[dementiauk.org/get-support/looking-after-yourself-as-a-carer/bereavement/](https://dementiauk.org/get-support/looking-after-yourself-as-a-carer/bereavement/)

**Dementia UK leaflet on Lasting power of attorney**

[dementiauk.org/get-support/legal-and-financial-information/lasting-power-of-attorney/](https://dementiauk.org/get-support/legal-and-financial-information/lasting-power-of-attorney/)

**Dementia UK booklet on Planning for your future**

[dementiauk.org/wp-content/uploads/2020/02/ACP-Booklet-A4-2018-online.pdf](https://dementiauk.org/wp-content/uploads/2020/02/ACP-Booklet-A4-2018-online.pdf)

**Dying Matters**

[dyingmatters.org](https://dyingmatters.org)

**Hospice UK**

[hospiceuk.org/contact-us](https://hospiceuk.org/contact-us)

**Marie Curie: care and support through terminal illness**

[mariecurie.org.uk](https://mariecurie.org.uk)

Helpline: **0800 090 2309**

(Monday-Friday 8am-6pm, Saturday 11am-5pm)

**My Decisions**

[mydecisions.org.uk](https://mydecisions.org.uk)

Information line: **0800 999 2434**

(Monday-Friday 11am-3pm)

**Resuscitation Council UK**

[resus.org.uk](https://resus.org.uk)



## Our Admiral Nurses can help

If you have any questions or concerns about dementia, you can call the dementia specialist Admiral Nurses on our Helpline for free.

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

Opening hours:

Monday-Friday, 9am-9pm

Saturday-Sunday, 9am-5pm

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 [dementiauk.org/donate](https://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



**[dementiauk.org](https://dementiauk.org)** • **[info@dementiauk.org](mailto:info@dementiauk.org)**

Dementia UK, 7<sup>th</sup> Floor, One Aldgate, London EC3N 1RE  
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