DEMENTIA

End of life care for dementia: a guide for families

How to recognise the later stages of dementia, plan ahead, help with eating, drinking and pain, and who supports you when someone is dying at home.

By the JNP Sidona team · 21 November 2026 · 11 min read

End of life care for dementia is care that puts comfort, dignity and the person's own wishes first as dementia reaches its later stages. It can happen at home, in a care home, in a hospice or in hospital. At home, the GP, district nurses and the palliative care or hospice team look after symptoms and medicines, while family and paid carers give personal care, comfort and company. It is hard to predict how long the later stages will last, so plan early, and ask about fast-track NHS continuing healthcare if your relative is deteriorating quickly.

KEY POINTS

- The later stages can last many months. The Alzheimer's Society says a person may live with late-stage symptoms "for many months", and Marie Curie says life expectancy is difficult to predict.
- A sudden change in confusion or distress may have a treatable cause, such as pain or delirium. Speak to the GP or district nurse before assuming it is the end.
- Eating less is common near the end of life. Offer food and drink for as long as it is safe and the person shows interest, and keep the mouth moist and comfortable.
- NICE advises against routine tube feeding in severe dementia, unless it is for a condition that could be reversed.
- If your relative's health is deteriorating quickly, ask the GP, district nurse or hospital team about the NHS continuing healthcare fast-track pathway. The NHS says care is usually in place within 48 hours.

- Hospice care is free and can be given at home. Hospices also support the family, including after the death.

What does end of life care for dementia involve?

Palliative care is care that aims to keep someone comfortable when their illness cannot be cured. For dementia, NICE's guideline NG97 (https://www.nice.org.uk/guidance/ng97/chapter/Recommendations) says it should be offered "from diagnosis", and that it should be "flexible, needs-based" and take into account "how unpredictable dementia progression can be." End of life care is the part of palliative care that applies as death comes closer.

The NHS says (https://www.nhs.uk/conditions/dementia/living-with-dementia/palliative-care/) end of life care for dementia can be given at home, in a care home, in a hospice or in hospital, and may involve palliative care nurses, the GP, community nurses, hospice staff, social care staff and others. It involves "making you comfortable by managing pain and other distressing symptoms."

For earlier stages, see our guides to dementia care at home (/blog/dementia-care-at-home-guide) and dementia care plans (/blog/dementia-care-plan).

How do you recognise the later stages of dementia?

There is no exact test. The Alzheimer's Society (https://www.alzheimers.org.uk/get-support/help-dementia-care/recognising-when-someone-reaching-end-their-life) lists these as signs that a person with dementia is probably nearing the end of their life when most or all of them are present:

- speech limited to single words or phrases that may not make sense;
- a limited understanding of what is being said to them;
- needing help with most everyday activities;
- eating less and having difficulty swallowing;
- bowel and bladder incontinence;
- being unable to walk or stand, problems sitting up, and becoming bed-bound.

Marie Curie (https://www.mariecurie.org.uk/professionals/palliative-care-knowledge-zone/dementia) adds that when signs like these "are combined with frailty, repeated infections and/or pressure ulcers", someone is likely to be nearing the end of their life. Both charities stress the uncertainty: a person may have symptoms that suggest they are close to death and still live with them for many months.

Signs that death may be days or hours away

The Alzheimer's Society says that in the last days or hours a person may deteriorate more quickly, lose consciousness, be unable to swallow, become agitated or restless, develop an irregular breathing pattern, have a chesty or rattly sound to their breathing, and have cold hands and feet.

Check for something treatable first. Dementia UK (https://www.dementiauk.org/information-and-support/looking-after-yourself-as-a-carer/end-of-life-care/) says that signs such as eating less or becoming withdrawn "may also be signs of another condition that could be treated", and suggests asking the GP if you are unsure. Marie Curie notes that a sudden increase in distress or confusion can be a sign of delirium. Tell the GP or district nurse about any sudden change.

Planning ahead

NICE says that for people with dementia approaching the end of life, professionals should use an anticipatory healthcare planning process, involving the person and their family as far as possible. Where the person cannot make a decision, it must be made in their best interests.

The earlier these conversations happen, the more the person can take part. Cover:

- **Lasting Power of Attorney.** A health and welfare LPA lets someone the person trusts make care decisions when they cannot. GOV.UK says (https://www.gov.uk/power-of-attorney) the person must have mental capacity when they make it.
- **An advance statement** of wishes, beliefs and values. The NHS says it is not legally binding, but anyone making decisions about the person's care must take it into account.
- **An advance decision to refuse treatment**, if the person wants one. It is legally binding if it meets the conditions, and a refusal of life-sustaining treatment must be written, signed and witnessed.
- **Preferred place of care and death.** The Alzheimer's Society says (https://www.alzheimers.org.uk/get-support/help-dementia-care/end-life-care-place-death) a person with dementia "should be supported to die in the place of their choice whenever possible", and that the care plan should record their preference.
- **Resuscitation.** The Alzheimer's Society explains (https://www.alzheimers.org.uk/get-support/help-dementia-care/end-life-care-making-decisions) that a doctor may decide resuscitation would not be in the person's interests, often because it is unlikely to succeed, and record a DNACPR (do not

attempt cardiopulmonary resuscitation) decision. The doctor should discuss this with those close to the person.

In London, a doctor or nurse can record the person's wishes on the Universal Care Plan (https://onelondon.online/?p=5590), which can be seen by the London Ambulance Service, NHS 111 and out-of-hours GPs. Ask the GP or district nurse whether one has been set up.

Fast-track NHS continuing healthcare

The NHS says (https://www.nhs.uk/social-care-and-support/money-work-and-benefits/nhs-continuing-healthcare/) that if someone's health "is deteriorating quickly" and they are nearing the end of their life, they should be considered for the NHS continuing healthcare fast-track pathway, with a care package "usually within 48 hours." The NHS dementia guidance adds that the NHS then covers the cost of care at home or in a care home. Ask the GP, district nurse or hospital palliative care team to start it. Our guide to NHS continuing healthcare (/blog/nhs-continuing-healthcare-guide) explains the wider process.

For people over State Pension age who claim (with form SR1), Attendance Allowance is also paid at the higher rate, £114.60 a week (https://www.gov.uk/attendance-allowance/what-youll-get) (see our rates guide (/blog/attendance-allowance-rates) for the April 2027 rise), when a medical professional has said someone is nearing the end of life.

Eating and drinking at the end of life

Families often find this the hardest part. The guidance says:

- **Offer, do not push.** Marie Curie says to offer food and drink "for as long as it is safe, and they show an interest." Dementia UK suggests just a few mouthfuls at a time, offered carefully from a teaspoon, with the focus on comfort and enjoyment.
- **Eating less is expected.** The Alzheimer's Society (https://www.alzheimers.org.uk/get-support/help-dementia-care/end-life-care-communication-physical-needs) says a person "may not feel hungry if they are very unwell." Marie Curie says that someone with dementia may stop eating or drinking in the last days of life, and that while this is distressing for those around them, "it's normal for people who are approaching the end of life."
- **Get swallowing advice.** Food may need blending and drinks thickening to reduce the risk of choking. The Alzheimer's Society says a speech and language therapist or dietitian should be able to advise, and NICE says to consider involving a speech and language therapist when there are concerns about safety when eating and drinking.
- **Tube feeding.** NICE says not to use enteral (tube) feeding routinely in severe dementia, "unless indicated for a potentially reversible comorbidity", and has a decision aid for families.

The Alzheimer's Society says most professionals agree it is generally not appropriate when swallowing problems are caused by very advanced dementia, because "tube feeding does not help to make the person more comfortable."

- **Keep the mouth comfortable.** If the person can still swallow, the Alzheimer's Society suggests sips of iced water or juice, or gently rubbing an ice cube on the lips, and a balm to stop lips cracking. Marie Curie says to keep the lips moist and clean.

Pain and distress

Someone in the later stages of dementia may not be able to say that they are in pain. The Alzheimer's Society lists signs to look for:

- **behaviour:** upset, restless, irritable, weepy or unable to sleep;
- **face:** looking sad or frightened, or grimacing;
- **body:** tensing, rocking, fidgeting, clenched fists, or pulling at a painful area;
- **sounds:** shouting, screaming, swearing or moaning;
- **physical changes:** altered breathing, fever, sweating or unusual paleness.

It also lists pressure ulcers (bedsores) as a possible source of pain. NICE recommends that professionals consider a structured observational pain assessment tool for people with moderate to severe dementia, and repeat pain assessments when someone seems to be in pain, when behaviour changes in a way that could be caused by pain, and after any treatment. Before treating distress, NICE says to look for causes such as "pain, delirium or inappropriate care."

Write down what you see and when, and tell the district nurse or GP. The Alzheimer's Society also suggests keeping on talking, because the person "may respond to the tone of your voice", and using gentle touch and familiar music.

Staying at home: who does what

The Alzheimer's Society says palliative care at home is increasingly available, and suggests raising it early so plans can be made. The NHS says (https://www.nhs.uk/tests-and-treatments/end-of-life-care/what-it-involves-and-when-it-starts/) the GP has "overall responsibility" for care at home, and can arrange for community nurses to visit.

Who usually helps when someone with dementia is cared for at home at the end of life

Who	What they do	How to reach them
GP	Overall responsibility for care at home; can arrange community nurses	The person's GP surgery
District (community) nurses	Nursing care at home, including palliative care	Usually through the GP
Community palliative care team	Coordinate care for people with an incurable illness, and advise other professionals	Referral by the GP, district nurse or hospital
Hospice, including care at home	Medical and nursing care, including managing pain and other symptoms; support for the family, including after the death. Free	Referral by a doctor or nurse
Council adult social care	Assessments, and services and equipment to help the person stay at home	The person's borough council
Home care agency	Personal care, comfort, company and practical help between nursing visits	Directly, or through the council

The NHS says (https://www.nhs.uk/tests-and-treatments/end-of-life-care/where-you-can-have-care/hospice-care/) hospice care can be provided at home, in a care home or as a day patient, and that it is "free, paid for through a combination of NHS funding and public donation." It usually needs a referral. If nights become hard, ask the district nurse or hospice what overnight support is available locally. Our guide to overnight care options (/blog/overnight-care-options) explains the choices.

What a non-nursing carer can do

Home care workers are not nurses. They do not manage syringe drivers, give injections or decide on symptom control; that is the job of the district nurse and the palliative team. What a carer can give is time and steady hands:

- gentle personal care: washing, mouth care, changing and continence care;
- help with comfort and changing position, in line with the nursing plan;
- offering sips and small mouthfuls, without pressure;
- company, music, reading aloud and a familiar voice;
- noticing changes and passing them to the family and the district nurse;
- giving the family time to rest, eat, sleep or simply sit with the person.

Our page on palliative and end of life care at home (/palliative-care-london) explains how our carers fit around the NHS team.

Support for the family

Caring for someone with dementia at the end of life is exhausting, and grief often starts long before the death. The Alzheimer's Society says many carers have "already started grieving while the person is alive." After the death, it says, feelings may include relief, guilt and numbness.

- **Ask for a carer's assessment.** NICE says carers should be told about their right to a carer's assessment and to an assessment for respite. See our carer's assessment guide (/blog/carers-assessment-guide), and our page on respite care (/respite-care-london).
- **Use the hospice.** The NHS says hospice care extends to those close to the patient, and into the bereavement period.
- **Call a helpline.** Dementia UK's Admiral Nurse Dementia Helpline is on 0800 888 6678. The Marie Curie Support Line (https://www.mariecurie.org.uk/services/support-line) is free on 0800 090 2309, including for questions about symptoms and bereavement. The Alzheimer's Society Dementia Support Line is on 0333 150 3456. Numbers were checked on 21 November 2026; see each site for opening hours.

If your relative needs someone in the house most of the time, live-in care (/live-in-care-london) can mean a carer is there through the day. A live-in carer sleeps at night, so it is not the same as waking night care.

After the death

When the death is expected, ask the district nurse or GP in advance who to call, including at night. GOV.UK says (https://www.gov.uk/after-a-death) a doctor must confirm the death, and to register it within 5 days of getting the confirmation (8 days in Scotland). Its Tell Us Once (https://www.gov.uk/after-a-death) service lets you tell the relevant government departments at the same time.

The Alzheimer's Society notes that grief can sometimes be delayed until after the funeral. It suggests talking to the GP about bereavement services, or contacting Cruse. Cruse Bereavement Support's (https://www.cruse.org.uk/get-support/helpline/) free helpline is 0808 808 1677.

Questions families ask

How long does the end stage of dementia last?

Is it wrong to stop trying to get Mum to eat?

Can someone with dementia die at home?

Is end of life care for dementia free?

How we can help

JNP Sidona is a small CQC-registered home care provider on Lewisham High Street, and dementia is one of the specialisms on our registration. CQC has not yet inspected us, so we do not have a rating. Our carers are not nurses and we do not provide waking nights. What we offer is gentle personal care, comfort and company for your relative, and some relief for you, working around the district nurses and the hospice team. Visiting care covers Lewisham, nearby south-east London and parts of central and east London, and live-in care is available across London. It starts with a free home assessment with Jackie, our registered manager, and we write a care plan with you after the assessment. Read more about our dementia care at home (/dementia-care-london) and palliative care at home (/palliative-care-london).

Sources

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About this guide

Written by the JNP Sidona team using the official sources listed above, which we checked on 21 November 2026. Rules, rates and thresholds change, usually each April, so always confirm the current position with the source or your council. This guide is general information, not medical, legal or financial advice. If you spot something out of date, email info@jnpsidonasupportservices.co.uk (mailto:info@jnpsidonasupportservices.co.uk) and we will correct it.