

End-of-life care

The period when someone with dementia is approaching the end of their life is inevitably difficult and emotional. People with dementia have the right to dignity and a 'good death'. This factsheet for carers looks at what happens when someone with advanced dementia is nearing the end of life, and when they die. It covers what carers can do to support the person, themselves and other close family or friends, and some of the issues they need to consider.

You might not want to think or talk about many of these things. You might find reading this factsheet upsetting. But if you have had these difficult conversations with the person, and they have planned ahead, this can help to ensure the person has a good death when the time comes. It will also help if care professionals communicate well now, with you and with each other.

Planning for the end of life should start as early as possible after a diagnosis. There is more on making choices about future care (advance care planning) in factsheet 467, Financial and legal affairs, factsheet 472, Lasting Power of Attorney and factsheet 463, Advance decisions and advance statements.

End-of-life and palliative care

End-of-life care aims to support someone with advanced incurable disease to live as well as possible until they die. It also aims to support family and carers during this time and after the person dies. End-of-life care may last for weeks, months or years.

Good end-of-life care focuses on the quality of the person's life and death, not on the length of life. It supports the person to die naturally and with dignity when the time comes. It covers all aspects of wellbeing: physical, psychological, social and spiritual.

For many people a 'good death' means being treated with compassion and respect; being kept clean, comfortable and free from distressing symptoms; and being in a familiar place surrounded by those close to them.

Palliative care shares the same aims as end-of-life care. But there is a particular emphasis on actively doing things to relieve (palliate) discomfort or distress (whatever the cause), rather than on curing the underlying illness. This means addressing symptoms as they arise for that individual.

End-of-life care for a person with dementia requires a team approach, including the GP, community nurses, social worker or care home staff – among others. Palliative care staff at a local hospice or hospital may give specialist input as required. The team should keep you updated as the person's condition changes and involve you in any decisions.

The person should always have an up-to-date care plan that includes end-of-life plans and is shared with those involved in the person's care as appropriate. Some areas have special staff who coordinate end-of-life care for people with dementia. Ask the GP, community nurse or local hospice (if you have one) about what is available in your area.

Dementia as a terminal illness

Dementia shortens life expectancy, but it is very difficult to know how long someone with dementia will live for. If the person also has another life-limiting illness, their condition is likely to worsen in a more predictable way over a period of weeks or days. This may mean that the person dies from another condition (eg cancer) when their dementia is at a relatively early stage.

But someone with later-stage dementia without another life-limiting illness often deteriorates slowly over many months. They gradually become more frail, have more frequent falls or infections, become less mobile, sleep more, and eat and talk less.

A person with later-stage dementia may have symptoms that suggest that they are close to death, but actually live with these symptoms for many months. This uncertainty makes planning for the end of someone's life difficult.

For someone with later-stage dementia, the most common immediate cause of death is an infection such as pneumonia. There are changes when the person is within a few days or hours of dying (see 'Recognising when someone is reaching the end of life' below). Families often find these changes distressing. Healthcare staff can help to reassure relatives that the person is not suffering.

Recognising when someone is reaching the end of life

Telling when a person with dementia is nearing the end of their life is difficult but very important, because it can help in giving the person the right care. This uncertainty can have a huge emotional impact on the family and possibly the person with dementia.

There are symptoms of later-stage dementia that can signal that the person is reaching the final stage of their illness. These include:

- speech limited to single words or phrases that may not make sense
- needing help with most everyday activities
- reduced eating and difficulties swallowing
- bowel and bladder incontinence
- inability to walk or stand, problems sitting up and controlling the head, and becoming bed-bound.

When these symptoms are combined with complications such as frailty, recurrent infections or pressure ulcers (bed sores), it is likely the person is nearing the end of life. Intrusive medical procedures such as resuscitation are now unlikely to be in the person's interests.

As someone's condition worsens and they get to within a few days or hours of dying, further changes are common. The person will often:

- deteriorate more quickly than before
- lose consciousness
- be unable to swallow
- become agitated or restless
- develop a characteristic irregular breathing pattern
- have cold hands and feet.

Healthcare professionals can explain these changes so you understand what is happening. By this stage the person is 'actively dying', but they are often unaware and should not be suffering. Medication can be used to treat any symptoms that may arise.

Communication

Problems with communication are a feature of the later stages of dementia. The person will generally have limited or no speech. They will also have reduced ability to understand what is being said to them. Relying only on verbal communication can lead to difficulties understanding what the person is trying to communicate, possibly missing basic needs such as pain, hunger and thirst.

Even though spoken language is severely affected, the person with dementia may still use non-verbal communication and behaviour to show their needs and feelings. This may include body language, facial expressions or agitation. Importantly, the person will still be able to respond at an emotional level, even when they can no longer communicate verbally and their dementia is very advanced.

Communicating with the person with dementia at the end of life: tips for carers

- Non-verbal communication from you, through gestures, body language, facial expression and touch, can help.
- Use appropriate physical contact such as holding hands or a hug to reassure the person that you are there for them.
- Take your time and look for non-verbal signals from the person with dementia.
- Continue talking to the person, even if you don't think they can follow what you are saying. They will understand at some level and may respond to the tone of your voice even if the factual content is lost.

Making decisions

As someone nears the end of life there will be important decisions to make about their care. These may include whether they should be resuscitated if they have a heart attack, where they wish to die and whether any religious practices are to be observed at or after their death.

Understandably, many people struggle with discussing these issues in advance, and both you and professionals may find them difficult. If the person with dementia has previously had open discussions about their future wishes and preferences (advance care planning), it will be much easier to act on their wishes when they are no longer able to decide.

Relatives closest to the person often assume that, as next of kin, they automatically have the final say on matters if the person loses the capacity to decide. However, who makes decisions for the person will vary according to the decision and what advance planning is in place. Decisions will always need to be made in the person's best interests.

Professionals should always involve you in decisions about the person and discuss things with you in a sensitive and straightforward way. While certain medical treatments can be refused, nobody can refuse (or be refused) basic comfort and care (eg pain relief, washing) or demand that a particular treatment is given.

If the person has previously made an advance statement of their wishes (for example in a 'Preferred priorities for care' document), this should be taken into account. However, it will not be legally binding. In contrast, an advance decision (or an advance directive in Northern Ireland) to refuse treatment is legally binding.

The person may have made a health and welfare Lasting Power of Attorney (LPA), in which case their attorney will act as their 'voice' in decisions about care. The attorney will need to discuss decisions with care staff and act in the person's best interests. The attorney may be able to refuse or consent to life-sustaining treatments on the person's behalf.

The senior doctor in charge of the person's care may decide that trying to resuscitate them if their heart or breathing stops would not be in their best interests, often because it is unlikely to be successful. The doctor will then make out a DNACPR (do not attempt cardiopulmonary resuscitation) order – sometimes just called a DNR (do not resuscitate) or DNAR (do not attempt resuscitation). The doctor should discuss this decision and the reasons for it with those close to the person (such as carers, relatives or close friends), and must consult with any health and welfare attorney(s).

For more information see factsheet 460, Mental Capacity Act 2005, factsheet 463, Advance decisions and advance statements and factsheet 472, Lasting Power of Attorney. In Northern Ireland the situation is different; for more information see factsheet NI472, Enduring Power of Attorney and Controllership.

Pain

People with dementia are at risk of pain from conditions such as arthritis, pressure ulcers (bed sores), urinary tract infections and constipation. It is sometimes assumed that people with dementia don't feel pain, but this is not true. Failure to recognise and adequately treat pain in people with advanced dementia is a significant cause of unnecessary distress.

As dementia progresses the person becomes less able to tell others that they are in pain. Staff and family carers need to understand this and look for other signs of pain (eg body language), so that it can be treated. Staff might sometimes also assume that challenging behaviours, such as shouting or agitation, are a symptom of the dementia, and not investigate them further. These behaviours may actually be a sign that the person is in pain and staff should give attention to understanding and acting on them.

Recognising when someone is in pain

Healthcare professionals should still ask the person if they are in pain. They can use pain assessment tools that may help to identify and rate pain in people with dementia. There are other things that may help when assessing whether the person is in pain:

- **Knowledge of the person** – There may be certain things that they typically do when they are in pain such as cry out or become very withdrawn.
- **Observation** – Signs that someone is in pain include their behaviour (eg being agitated, irritable, tearful, or unable to sleep), facial expressions (eg grimacing), body language (if they are tense or rocking, or pulling at a particular part of their body) and vocalisations (eg shouting out, screaming and moaning).
- **Bodily changes** – A high temperature, sweating or looking very pale can also indicate pain.

Doctors treating pain may start with paracetamol, which is a relatively weak pain-killer but often works well. If paracetamol fails then they will try stronger drugs, although these may have side effects (eg increased confusion) and should be carefully monitored. Doctors will also treat any underlying medical conditions that may be causing pain, such as constipation.

Comfort-based approaches may also help relieve pain. These can include gentle exercise, massage and aromatherapy.

Eating and drinking

This is one of the most difficult areas for families and professionals. As dementia progresses, people often develop problems eating and drinking. The person's appetite decreases and in later-stage dementia they often have difficulties with swallowing safely. People with swallowing problems are at risk both of choking and of food or saliva going down the windpipe, causing an infection. In their final days a person with dementia may stop eating or drinking altogether.

Someone with advanced dementia should be offered food and fluids – even if these are just mouthfuls or sips – for as long as they show an interest and can take them safely. You might wish to help with this as part of the person's care. When this is no longer possible, it is often distressing for carers to see that the person is not taking food and fluid normally by mouth. The situation is made worse because the person with dementia will generally be unable to communicate thirst or hunger for themselves.

Families are often concerned that the person is starving or dehydrating and not being cared for properly. It can be very hard to watch, but you should be reassured to know that the person is not suffering and that this 'shutting down' is a natural part of the dying process. You should discuss the person's feeding with professionals, taking into account the person's expressed wishes and preferences. What is in the person's best interests needs to come first.

Artificial nutrition and hydration

If a person is struggling to eat and drink enough, and their swallowing is unsafe, a natural response might be to consider artificial nutrition and hydration or 'tube feeding'. The most widely used treatments are:

- nasogastric tube – this passes down the nose and into the stomach
- a PEG tube – this passes directly into the stomach through a hole in the skin.

Each person's situation should be considered individually. Most healthcare professionals now agree that giving food and fluids artificially is not appropriate if the person's swallowing difficulties and reduced intake are a result of advancing dementia. This is because there are no clear benefits from tube feeding, such as better quality of life or better nutrition. However, there are clear disadvantages. For example, PEG means the distress of going into hospital. Tubes cause discomfort, and can also become infected or dislodged, cause sores or be pulled out.

When a person has no appetite, care staff will still ensure that their mouth feels comfortable. They should keep the person's lips moist and clean, and provide sips of iced water or juice, or an ice cube, if the person can still swallow. They may also moisten the mouth and apply lip balm to keep the person comfortable. Again, you might want to help give some of this care.

Infections

People with later-stage dementia are at greater risk of infections such as urinary tract infections or chest infections (eg pneumonia). These can be caused by lower fluid intake, swallowing problems and reduced mobility.

There is some controversy about using antibiotics to treat infections if someone has advanced dementia. However, it may be appropriate to

use antibiotics to ease distress and discomfort at the end of life even if the infection cannot be cured.

The use of antibiotics should be considered on an individual basis. Doctors will weigh up the likely benefits, risk of side effects, the burden of giving the drugs, and the person's wishes (if known). If the person has recurrent infections, the care team will talk to you about what they think is in the person's interests if they have another serious infection. In particular, they may discuss with you whether admitting the person to hospital for further antibiotics – often injected into a vein – is really best for them.

Psychological, social and spiritual needs

A person with later-stage dementia can still become distressed or depressed, and they will still have emotional, spiritual or religious needs. Through advance care planning or their knowledge of the person, staff and family should seek to minimise distress and meet these needs as best they can.

Little things such as talking to the person, brushing their hair or holding their hand can help considerably. Meaningful connections like this can help you to meet emotional needs and be close to the person.

Spirituality can be hard to define and it is not just about religious beliefs, although these may be a part of it. Everybody has their own unique spiritual life. Spiritual needs should be addressed and honoured just as much as the medical aspects of care.

Whenever possible, it's best to ensure the person is in a calm, familiar environment with people they are close to. The person might enjoy things that stimulate their senses, such as familiar music or aromas (eg lavender) and hand massages. Personal or religious objects, symbols or rituals (including prayer or readings) may be used. Early memories are generally retained longest in dementia so the person may respond to older recollections.

As a carer you will have your own spiritual needs and it is important that you are supported to express these and have them met. Talk to care staff about your feelings and what spiritual and faith-based support is available.

Place of death

A person with dementia should be supported to die in a place of their choice whenever possible. For many people this will be somewhere familiar such as their own home or the sheltered housing or care home in which they live.

In spite of this wish, many people with dementia are admitted to hospital towards the end of their lives and end up dying there. In most cases, moving to a busy and unfamiliar environment such as a hospital ward is difficult or distressing and not what the person would have wanted.

If the person has previously expressed a preference to be cared for where they usually live, this should be included in the care plan. This will help avoid an unnecessary admission to hospital at the end of life. Achieving this will require coordination so that all those involved in the person's care – whether it be relatives, the GP, staff at a care home or sheltered housing, or other professionals – know about this preference.

If the person is living in their own home and has expressed a wish to die there, talk to the care team early on about this, as plans will need to be made.

Support for carers, family and close friends

Most people find it difficult to come to terms with the approaching death of the person with dementia. Many carers talk of a progressive grieving while the person is alive and the dementia advances. This grieving may reflect the often long duration of the disease and the changes to the person which inevitably occur.

You should tell staff about your own wishes, including the need to say goodbye to the person and whether you want to be with them at the end if this is possible. Caring for someone at the end of life can be a rewarding experience and a time of great closeness. Carers who have helped the person to have a good death often hold this memory (that they were able to support the person right up to the end) particularly close.

After death

Each carer will experience and approach bereavement in their own way and it is important that you are supported to grieve as you want to. You may experience a range of emotions, including numbness, inability to accept the situation, anger, regret, sadness, relief, isolation and a loss of purpose. You may feel very strong emotions, or you may feel that you have no strong emotions left.

It may be assumed that you have already grieved for the person with dementia as their condition has worsened, but many people will still feel grief at their death.

There are practical but emotionally difficult issues to think about after a person dies: registering the death, funeral plans, and changes to financial and legal documents and benefits. You can find out more from your local Citizens Advice Bureau (see 'Other useful organisations').

The period around the funeral is often a time when others offer most support. Afterwards there may be a 'delayed bereavement' when you adjust to no longer having to care for the person with dementia. You may need to rebuild friendships that your caring role put on hold. Emotional support may help, and talking feelings through with family and close friends is often a source of comfort.

If you need more support or are becoming depressed (which is different from grieving), ask your GP about local bereavement services or contact Cruse Bereavement Care (see 'Other useful organisations'). Your local carers' centre may also be able to help. For more information see factsheet 507, Grief and bereavement.

Other useful organisations

Carers Trust

32–36 Loman Street
London SE1 0EH

T 0844 800 4361

E info@carers.org

W www.carers.org

Works to improve support, services and recognition for anyone living with the challenges of caring, unpaid, for a family member or friend who is ill, frail, disabled or has mental health or addiction problems.

Carers UK

20 Great Dover Street
London SE1 4LX

T 0808 808 7777 (free carers' line, 10am–4pm weekdays)

E info@carersuk.org

W www.carersuk.org

www.carersuk.org/forum (online discussion forum)

Carers UK provides information, advice and support for carers.

Citizens Advice Bureau

Various locations

W www.citizensadvice.org.uk

www.adviceguide.org.uk (online information resource)

Your local CAB can provide information and advice in confidence or point you to further sources of support. Trained CAB advisers can offer information on benefits in a way that is easy to understand. To find your nearest CAB, look in the phone book, ask at your local library or look on the website (above). Opening times vary.

Cruse Bereavement Care

PO Box 800
Richmond
Surrey TW9 1RG

T 0844 477 9400 (national helpline)
E helpline@cruse.org.uk
W www.cruse.org.uk

Cruse is the leading national charity for bereaved people in England, Wales and Northern Ireland. It offers support, advice and information to children, young people and adults when someone dies and works to enhance society's care of bereaved people.

Dying Matters

T 0800 021 4466
W www.dyingmatters.org
www.dyingmatters.org/contact (web form)

Dying Matters is a broad-based and inclusive national coalition led by the National Council for Palliative Care. It aims to change public knowledge, attitudes and behaviours towards dying, death and bereavement. They produce information to help people talk about death, dying and bereavement, including a 'Preferred priorities for care' form to complete. You can search for local services via the website.

National Council for Palliative Care (NCPC)

The Fitzpatrick Building
188–194 York Way
London N7 9AS

T 020 7697 1520
E enquiries@ncpc.org.uk
W www.ncpc.org.uk

The National Council for Palliative Care (NCPC) is the umbrella charity for all those involved in palliative, end-of-life and hospice care in England, Wales and Northern Ireland. They work with government, health and social care staff and people with personal experience to improve end-of-life care for all. They also produce information to help people talk about death and dying.

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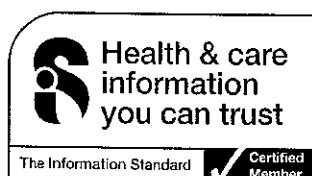
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This factsheet has also been reviewed
by people affected by dementia.
A list of sources is available on
request.



Alzheimer's Society National
Dementia Helpline

England, Wales and Northern Ireland:
0300 222 1122

9am–5pm Monday–Friday
10am–4pm Saturday–Sunday

alzheimers.org.uk

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leading support and research charity
for people with dementia, their
families and carers.

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