

End of life care

When a person with dementia is approaching the end of their life, it can be a very difficult time for them and the people around them. This factsheet looks at what happens when someone in the later stages of 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 having these difficult conversations with the person, and planning ahead, can ensure the person's needs are met at the end of their life. It will also help if health and social care professionals communicate well now, with you and with each other.

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End of life care

Planning for the end of life

Planning for the end of life is important for anyone who has a life-limiting condition. For a person with dementia it is important to try and have these conversations as early as possible, while they can make decisions for themselves. If they don't feel ready to think about the future at this time, getting to know their values, wishes and beliefs more generally can help in the future when decisions need to be made on their behalf (see 'Making decisions' below). There is more on making choices about future care (known as 'advance care planning') in factsheet 472, **Lasting power of attorney**, and factsheet 463, **Advance decisions and advance statements**.

Palliative and end of life care

Palliative care is for anyone diagnosed with a life-limiting illness, including dementia. It focuses on maintaining a person's quality of life by relieving discomfort or distress (whatever the cause). Someone can receive palliative care for several years and it may be offered alongside other treatments, especially in the earlier stages of dementia. Any palliative care in place will continue alongside end of life care.

End of life care aims to support someone in the later stages of a life-limiting condition 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 occasionally years – it is often difficult to know exactly when a person with dementia is approaching the end of their life.

End of life care should support the person to live as well as possible until they die. It supports all aspects of their wellbeing, especially:

- their physical needs (including pain relief and management of other symptoms)
- how they are feeling
- their relationships with others
- their spiritual beliefs and needs.

For many people a 'good death' means:

- being treated with compassion and respect
- being kept clean, comfortable and free from distressing symptoms
- being in a familiar place surrounded by those close to them.

End of life care for a person with dementia can involve a number of different professionals working together, including the GP, community nurses, social workers or care home staff. Palliative care professionals at a local hospice or hospital may give specialist input if this is needed. This team of professionals 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. Some areas have special staff who co-ordinate 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 life-limiting illness

Dementia is a life-limiting illness, but it is very difficult to know how long someone with dementia will live for. If a person also has another life-limiting illness (such as cancer), it is often easier to know how quickly their condition will get worse. A person may die from another condition at any stage of having dementia. Someone in the later stages of dementia who does not have another life-limiting illness gets worse slowly over many months. They gradually:

- become more frail
- have more frequent falls or infections
- become less mobile
- sleep more
- eat and talk less.

A person in the later stages of dementia may have symptoms that suggest that they are close to death, but actually live with these symptoms for many months. This uncertainty makes it very difficult to plan and put things in place for the end of someone's life.

For someone in the later stages of dementia, the most common immediate cause of their death is an infection such as pneumonia. At this point, the person is likely to be much frailer and have a weaker immune system, so is at greater risk of developing infections, which can last for a long time. There are changes that are likely to happen when the person is within a few days or hours of dying (see 'Recognising when someone is reaching the end of their life' below). Some of these changes may be distressing, but health and social care professionals can reassure you that the person is not suffering.

Recognising when someone is reaching the end of their life

It is important to know when a person with dementia is nearing the end of their life because it can help in giving them the right care. However it can be difficult to know when this time is. This uncertainty can have a big impact on how the person's family feel, and may also affect how they feel themselves. There are symptoms in the later stages of dementia that can suggest 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
- eating less and having difficulties swallowing
- bowel and bladder incontinence
- being unable to walk or stand, problems sitting up and controlling the head, and becoming bed-bound.

It is likely that a person with dementia is nearing the end of their life if they have these symptoms, along with other problems such as frailty, infections that keep coming back, and pressure ulcers (bedsores). For more information about pressure ulcers see factsheet 5 12, **Pressure ulcers (bedsores)**.

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 an irregular breathing pattern
- have cold hands and feet.

These changes are part of the dying process. Healthcare professionals can explain these changes so you understand what is happening. The person is often unaware of what is happening, and they should not be in pain or distress. Medication can be used to treat the person's symptoms. If the person can't swallow, there are other ways of providing this, such as medication patches on the skin, small injections or syringe drivers (devices that provide a continuous flow of medication under the person's skin). Speak to a GP or another health professional about this.

Communication

In the later stages of dementia, the person is likely to have problems with communication such as limited or no speech. They will be less able to understand what people are saying to them. Relying only on verbal communication can make it difficult to understand what the person is trying to communicate, which may mean not noticing if they are in pain, hungry or thirsty, for example.

The person with dementia may communicate their needs and feelings without using speech (non-verbal communication). They may use body language, facial expressions or show agitation. Importantly, the person will still have feelings about what is going on even though they are in the later stages of dementia and can no longer communicate verbally. For example, they may feel happy hearing you talk to them.

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.
- Maintain eye contact as much as possible.
- 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 may respond to the tone of your voice and feel a level of connection with you even if they don't understand what you're saying.
- Talk about things of interest to the person or reminisce about things from the past.

Physical needs

Pain

People with dementia are at risk of pain from conditions such as arthritis, pressure ulcers (bedsores), urinary tract infections (UTIs) and constipation, or other diseases that cause pain such as cancer or heart failure. Some people assume that people with dementia don't feel pain, but this is not true. If a person with dementia is in pain, and this is not recognised and treated properly, they may become very distressed.

As dementia progresses, the person becomes less able to tell others that they are in pain or discomfort. Health and social care professionals and family carers need to understand this and look for other signs, such as the person's body language that might indicate they are in pain. Staff might sometimes also assume that behaviours that challenge, such as shouting or agitation, are a symptom of dementia. These behaviours may actually be a sign that the person is in pain or discomfort. It is important for staff to understand this so that any pain can be treated.

Some people assume that people with dementia don't feel pain, but this is not true. If a person with dementia is in pain, and this is not recognised and treated properly, they may become very distressed.

Recognising when someone is in pain

A person with dementia might not always be able to let someone know they are experiencing pain, so it is important for carers and health and social care professionals to ask the person if they are in pain. Healthcare professionals may use a pain assessment tool for people with dementia. This usually involves recording information about the person and using a scale, chart or checklist to help identify and rate pain. The following things 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 (such as being agitated, irritable, tearful, or unable to sleep), facial expressions (such as grimacing), body language (if they are tense or rocking, or pulling at a particular part of their body) and vocalisations (for example, 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 often works well (though it is not as strong as other painkillers). If paracetamol fails then they will try stronger drugs, although these may have side effects (such as increased confusion) and should be carefully monitored. Some people may be on regular pain relief for conditions such as cancer. If pain is suspected the dose may need reviewing. Doctors will also treat any underlying medical conditions that may be causing pain, such as constipation.

There are ways to make the person comfortable that may also help relieve pain. These can include gentle exercise, massage, aromatherapy and warm packs placed over the suspected area of pain.

If a person with dementia is unable to say they are in pain but shows some of the behaviours indicated above, it is useful to look for other possible causes. For example are they hungry or thirsty? Are they too hot or too cold? Is the environment calm and supportive? Could they be anxious or upset?

Eating and drinking

As dementia progresses, people often develop problems with eating and drinking. The person's appetite decreases and in the later stages of dementia they often have difficulties with swallowing safely. People with swallowing problems are at risk 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 in the later stages of 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. Soft food is often easier for them to eat and liquids that are thickened may cause fewer problems with choking. It is better if the person is able to sit upright when eating and drinking.

It is often distressing to see that the person is no longer able to take food and fluid normally by mouth. Try to remember it is normal for a person approaching the end of their life. The person with dementia will generally be unable to communicate thirst or hunger for themselves, which can also be distressing.

When a person is close to death, they will usually stop eating and drinking. You might worry that the person is starving or getting dehydrated and not being cared for properly. It can be very hard to see, but you should be reassured to know that the person is not suffering. Talk to professionals about food and fluids for the person, including what the person has said or recorded as their wishes. It is important that what is in the person's best interests comes first.

Artificial nutrition and hydration

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

- **a 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 problems with eating, drinking or swallowing are because their dementia is in the later stages. 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 going into hospital which might be distressing
- tubes can cause discomfort or sores
- tubes can also become infected or dislodged, or pulled out.

When a person has no appetite, care professionals will still make sure 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 in the later stages of dementia are at greater risk of infections such as urinary tract infections (UTIs) or chest infections (such as pneumonia). These can be caused by lower fluid intake, swallowing problems and reduced mobility.

People disagree about whether antibiotics should be used to treat infections for a person in the later stages of dementia. It may be appropriate to use antibiotics to ease distress and discomfort at the end of life even if the infection cannot be cured or is likely to happen again. Doctors should think about whether to give antibiotics on an individual basis. They will consider:

- the likely benefits
- the risk of side effects
- the burden of giving the drugs
- the person's wishes (if known).

If the person has infections that keep coming back, professionals caring for the person will talk to you about whether it is in the person's best interests to try and treat any serious infections in the future. In particular, they may point out that treating further infections is likely to involve the person going back into hospital for further antibiotics (which are often injected into a vein). It is important to consider whether that is in the person's best interests.

Making decisions

As someone nears the end of their 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.

Many people – including health and social care professionals – find it difficult to talk about these issues in advance. 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.

Those closest to the person often assume that, as next of kin, they automatically have the final say on decisions if the person has lost the capacity to make them. However, the person who can make 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. In cases where there is doubt or disagreement over what is in the person's best interests, it may sometimes be necessary to make an application to the Court of Protection (or the High Court in Northern Ireland) for it to decide.

Health and social care 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 (for example, pain relief, washing) or demand that a particular treatment is given.

The person may have expressed their wishes using the one of the following:

- Advance decision (or advance directive in Northern Ireland) to refuse treatment. This is a legally binding document.
- Advance statement of wishes (for example, in a 'Preferred priorities for care' document). This is not legally binding, but it should be taken into account.

If the person is in England or Wales they may have made a health and welfare Lasting power of attorney (LPA) or a health and welfare deputy may have been appointed by the Court of Protection (though this is much less common). The person appointed as their attorney or deputy will need to discuss decisions with health and social care professionals and act in the person's best interests. They may be able to refuse or consent to life-sustaining treatments on the person's behalf. Health and welfare LPAs and deputyships are not currently available in Northern Ireland.

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), or an advocate if one has been appointed. They must also consult with any health and welfare attorney(s) or deputy.

For more information see factsheet 460, **Mental Capacity Act 2005**, factsheet 463, **Advance decisions and advance statements**, factsheet 472, **Lasting power of attorney**, and factsheet 530, **Becoming a deputy for a person with dementia**. If the person is in Northern Ireland see factsheet NI472, **Enduring power of attorney and controllership**.

A person in the later stages of dementia will still have needs based on how they are feeling, and any cultural, spiritual or religious beliefs and practices. Through advance care planning or their knowledge of the person, all those supporting the person (including care professionals) should try to meet their needs as best they can.

Psychological, cultural, religious and spiritual needs

A person in the later stages of dementia will still have needs based on how they are feeling, and any cultural, spiritual or religious beliefs and practices. Through advance care planning or their knowledge of the person, all those supporting the person (including care professionals) should try to meet their needs as best they can. For example, if the person becomes distressed or depressed, doing small things can help a lot – for example, talking to the person, brushing their hair or holding their hand. Meaningful connections like this can help you to meet emotional needs and be close to the person.

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 (such as lavender) and hand massages.

The person's cultural needs should be acknowledged and respected. Cultural needs can be influenced by a range of factors such as where the person lives, their gender and their language. They can include how soon the person would like their funeral, whether they would like to be buried or cremated, and any rituals or ceremonies that are important to them. Talk to care staff about these needs.

The person's spiritual needs will be individual to them, and may include questions about meaning, faith and belief. These needs should be addressed and respected as much as the medical aspects of care. Personal or religious objects, symbols or rituals (including prayer or readings) may be used. People with dementia usually keep older memories for longer, so they may respond to things they recall from earlier in their life such as religious readings or hymns.

As a carer you may have your own spiritual and cultural 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.

However, many people with dementia are admitted to hospital towards the end of their lives and end up dying there. Moving to a busy and unfamiliar environment such as a hospital ward is often difficult or distressing and not what most people would have wanted.

If the person has previously expressed a preference to be cared for where they usually live, this should be included in their care plan. This will help avoid an unnecessary admission to hospital at the end of life. Achieving this will require that all those involved in the person's care know about this preference.

If the person is living in their own home and has expressed a wish to die there, talk to professionals caring for the person early on about this. This allows time for plans to be made so that the person is able to die at home.

The person's environment

When a person with dementia is near the end of life it is important that they are in an environment where they feel comfortable and their needs are supported. It can help to make the environment familiar – for example, by including familiar objects and pictures. The space should be peaceful and not too overstimulating (without too much background noise or visual clutter).

The environment should support the person to engage in different ways – engaging with other people, any spiritual needs, and with their senses. This may take many forms and should be based on the person and their unique interests. However, it may include:

- being near a window
- access to nature
- familiar smells
- music
- enough space for those important to the person to be with them.

It is important that the environment supports the person's privacy and dignity. A good environment should also support staff and those close to the person. It should provide space for them to process what is happening and can help them know the person is comfortable and in a place that is supporting their needs.

Technology may be helpful for supporting the person at the end of life but should be based on the individual and what works for them. Some electronic aids include:

- **pressure sensors** – these are sensors that can be placed under a bed or chair and can raise an alert when the person moves or gets up
- **fall sensor** – a device that registers if the person wearing it falls over
- **sensory lights** – lights designed to give a stimulating, engaging or calming effect, which can help the person to engage with the world around them
- **tablets or computers** – images or videos on these can also help the person to engage with the world around them.

Support for carers, family and close friends

Most people find it difficult to come to terms with the person with dementia approaching the end of life. Many carers say they are grieving over time while the person is alive and as the dementia progresses. This may be because of the dementia progressing over a long period of time, and the changes that they are seeing in the person.

You should tell health and social care professionals about your own wishes, including the need to say goodbye to the person and whether you want to be with them at the end of their life, 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 supported the person through dying and death often value this as an important memory.

After the person has died

As a carer, you will experience and approach bereavement in your own way and it is important that you are supported to grieve as you need and want to. You may experience a range of emotions, including:

- numbness
- finding it difficult to accept the situation
- anger
- regret
- sadness
- relief
- feeling isolated
- loss of purpose.

You may feel very strong emotions, or you may feel that you have no strong emotions left.

Sometimes, other people may assume that you have already grieved for the person with dementia as their condition has worsened. Whether or not this is something you've felt, many people will still feel grief when the person dies.

The period around the funeral is often a time when others offer most support. Afterwards you may need time to adjust to no longer caring for the person (this is sometimes called a 'delayed bereavement'). You may need to rebuild friendships that your caring role put on hold. You may continue to need emotional support during this time, but you may find that fewer people offer it.

Talking through feelings with family and close friends can often provide comfort, so try to tell people when you feel you need this support. 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, loss and bereavement**.

What to do after the person has died

There are practical issues to think about after a person dies. Though you may find it difficult, it is important to think about the following:

- registering the death
- funeral plans
- changes to financial and legal documents and benefits.

You can find out more from your local Citizens Advice (see 'Other useful organisations').

Other useful organisations

Carers Trust

32–36 Loman Street
London SE1 0EH

0300 772 9600
info@carers.org
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

0808 808 7777 (free carers' line, 10am–4pm weekdays)
info@carersuk.org
www.carersuk.org
www.carersuk.org/forum (online discussion forum)

Carers UK provides information, advice and support for carers.

Citizens Advice

Various locations
www.citizensadvice.org.uk

Your local Citizens Advice can provide information and advice in confidence or point you to further sources of support. Trained advisers can offer information on benefits in a way that is easy to understand. To find your nearest Citizens Advice, 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

0808 808 1677 (national helpline)
helpline@cruse.org.uk
www.cruse.org.uk

A 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

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

National coalition that 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.

The National Council for Palliative Care (NCPC)

Hospice House
34–44 Britannia Street
London
WC1X 9JG

020 7697 1520
enquiries@ncpc.org.uk
www.ncpc.org.uk

An 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.

Factsheet 531

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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–8pm Monday–Wednesday

9am–5pm Thursday–Friday

10am–4pm Saturday–Sunday

alzheimers.org.uk

Alzheimer's Society is the UK's leading dementia charity. We provide information and support, improve care, fund research, and create lasting change for people affected by dementia.

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