

Advanced dementia

A white ECG line graphic on a blue background, positioned to the right of the title.

Information for relatives and carers

This leaflet aims to help you understand dementia as it advances to its later stages. It explains common issues and what you can do to support someone with advanced dementia to make them more comfortable. It also gives you advice on decision making, planning for the future and dealing with stress.

Confirming your identity

Before you have a treatment or procedure, our staff will ask you your **name** and **date of birth** and check your **ID band**. If you don't have an ID band we will also ask you to confirm your address.

If we don't ask these questions, then please ask us to check.
Ensuring your safety is our primary concern.

What is advanced dementia?

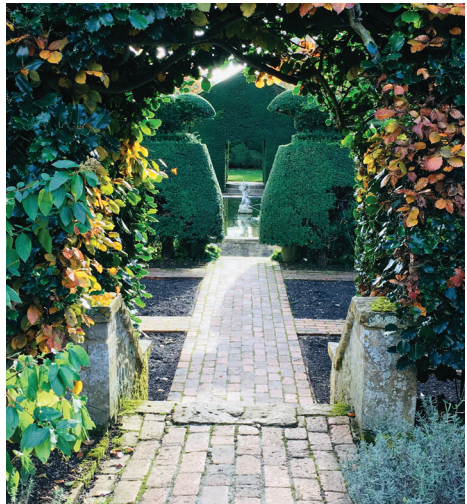
As dementia progresses, it increasingly affects other body functions as well as the brain. This includes moving and talking as well as eating, drinking and swallowing safely.

Someone with advanced dementia may also have troubling thoughts and behave in ways that can be difficult to manage. They are vulnerable to illness and their physical and mental states may suddenly become worse.

Once someone has advanced dementia, they are unlikely to survive for a long time. Advanced dementia should be regarded as a terminal condition.

What are the signs of advanced dementia?

The commonest features of advanced dementia include severe forgetfulness, frailty, an increasing need for help with personal care including continence and reducing mobility. Many people with advanced dementia can live well with the appropriate support but some people will also experience distressing symptoms too. There are a number of signs and symptoms that show that someone is entering the final stage of dementia. Here we look at common symptoms and explain some of the ways in which a person with advanced dementia can be helped.



Vulnerability to illness and delirium

Dementia progresses slowly but sometimes it can suddenly get worse. Someone with advanced dementia is especially prone to illnesses and infections, as well as other problems such as constipation, falls or skin damage.

Very often, these problems cause a sudden worsening of their mental state as well as their existing dementia symptoms. This is called delirium. While delirium can sometimes improve by treating the illness that caused it, someone with advanced dementia does not always go back to their previous level of memory and function afterwards.

How can I help?

These risks can be reduced by:

- Using a mattress that eases pressure. If concerned about possible skin damage please discuss with the ward staff/GP for further advice
- Turning them regularly or making sure they change their position often
- Ensuring they have enough fluids
- Ensuring they do not get constipated by encouraging them to eat the right food or giving them medication such as laxatives.

Problems communicating

Dementia affects the way that a person's brain functions. This can cause problems with communication and speech. They become less able to understand what is going on around them and less able to work out how to say things or express what they want.

But people can (and often do) live well even with advanced dementia and they can continue to play a part in family life. This is greatly helped by a gentle and understanding approach and changing the way we communicate and offer care and help.



How can I help?

Someone with advanced dementia may need extra help to tell others their needs.

They need to:

- Be given time
- Spoken to simply and in short sentences
- Offered limited choices with yes/no answers
- Offered visual cues such as pictures.

Difficulty eating and drinking

Someone with advanced dementia often wants to eat and drink less and may not feel hungry or thirsty. This is caused by changes in the way their brain controls eating. This generally makes them lose weight, including muscle mass. These changes are a central part of advanced dementia.

When someone stops (or nearly stops) eating and drinking altogether, it may be a sign that their dementia has entered its terminal stages. Build-up drinks and supplements can slow down the weight loss but they do not generally help someone to gain very much weight. We would not recommend artificial feeding through a tube because it is often uncomfortable, makes the person more likely to get a chest infection and does not help them to live longer.

It can sometimes be very difficult to watch someone you are caring for turn down food and drink. Feeding someone with advanced dementia usually focuses on helping them to eat for pleasure and comfort rather than nutrition.

How can I help?

- Offer them little snacks often if they do not want full meals and give them whatever food they like even if it is not 'healthy'



- Sometimes food they can eat with their fingers rather than cutlery can be easier for them to enjoy
- Extra flavouring or spices can also encourage them to eat.

Problems swallowing

As a person's dementia gets worse, it is common for them to have problems swallowing. This is due to changes in their brain that cause muscle weakness and make it hard to control the movements needed to swallow. As a result, there is a risk food and drink can go towards their lungs and cause chest infections. This is called aspiration pneumonia.

They often hold food in their mouth and appear to forget to chew, or they may cough and splutter when swallowing.



How can I help?

- Changing the consistency, temperature or taste of their food, or using ways of supporting eating and drinking, can help to reduce their discomfort and their risk of a chest infection
- Offer them thickened fluids and softer, chopped up and eventually mashed up food
- If they have severe swallowing problems you may not be able to prevent the risks altogether, but we can help you to make their eating and drinking as safe and pleasurable as possible. This is known as Risk Feeding
- Try to support them to eat and drink while they are awake, alert and sitting upright
- Stop if they cough or splutter and try again later
- Consider having them assessed by a speech and language therapist (SLT) so you can get personalised information and advice.

Difficulty moving and walking

Because dementia affects the brain, it starts to affect balance and walking as it gets worse.

At first, someone might be unsteady and find it hard to coordinate their feet to walk or simply slow down. However as the condition progresses, they become more likely to have falls and injuries. Some people can no longer remember how to stand up or walk.

Once someone is unable to get about, their risk of pressure damage to their skin, constipation, infection and contractures (tightening of the joints) is greater.

How can I help?

These risks can be reduced by:

- Using a hoist to help them sit out in a chair





- Using a mattress that eases pressure
- Turning them regularly or making sure they change their position often.

Problems with pain

Pain can make any mobility problems worse and people living with dementia are not always able to tell us that they are in pain and how bad it is.

How can I help?

- Check for pain by looking for signs such as grimacing or changes in their behaviour
- Ask a doctor to review why the pain is occurring
- Give painkillers and assess effectiveness
- Regular pain relief is often better than 'as required'.





Problems with incontinence

People with advanced dementia may find it more difficult to control their bladder and bowels. This might be caused by them being less able to sense the feeling of needing to use the toilet or being unable to remember how to go to toilet. This can be made worse if they are having increasing problems with moving about.

Incontinence can be very distressing for a person with advanced dementia and their caregiver.

We do not usually recommend managing incontinence using a urethral catheter (where a tube is put into a person's bladder to drain urine) because it can be painful and cause bleeding, infection and delirium.



How can I help?

It is important to make sure the healthcare professionals caring for a person with advanced dementia know that they are incontinent so a suitable management plan can be made.

The management plan:

- Might include using incontinence pads or devising a toileting programme to establish a set routine. This might include taking a person with advanced dementia to the toilet every two to three hours
- Should include how to prevent urine infections, skin damage and constipation, as dementia makes people more likely to develop these problems.

Distress and behaviour that shows distress

Many people with dementia do well and some are happier than they ever were before they developed dementia. But dementia can make some people feel distressed.

This distress can make some people in the later stages of dementia behave in ways that are out of character. Behaviour can also be a way of someone communicating an unmet need. It might show that they feel scared, anxious or distressed, or be a sign of another need that is not being met.

Behaviours and signs of distress in people with advanced dementia

Agitation or wandering: The person might be confused about where they are, whom they are with or what they are meant to be doing.

Sun-downing: They might become more agitated or confused in the late afternoon or early evening due to disturbances in their body clock or changes in their sleep pattern.



Aggression: Among the many reasons for aggression are pain, feeling threatened and not understanding what is going on. For example, if a carer tries to change their clothes without explaining why.

Restlessness: They may become restless, fidget or pace up and down. This could be caused by pain or discomfort, needing the toilet, lack of stimulation, or because the person used to move around a lot in their job.

Repetitive behaviour: Because of their memory loss, the person no longer understands where they are and why. Repetitive behaviour is their way of trying to make sense of what is going on or comfort themselves.



Hallucinations and delusions: Dementia can cause hallucinations in which people hear or see things that are not really there, or they might misinterpret something they have seen as being something else. They may develop beliefs that are not based on reality but feel real to them, known as delusions. Sometimes these can be due to the person trying to make sense of what is happening. For example, if their memory loss leads to them misplacing items, they may accuse others of having stolen them.

What can I do to help?

- Try to understand what is causing the distress or behaviour and whether the person needs something. Are they comfortable, in pain, too hot, cold, hungry or thirsty? Do they need the toilet?
- Check that they are not being disturbed or overstimulated by their environment. For example, are there too many people around them or too much activity, loud or sudden noises or movements?
- Are they bored? Try to engage the person in meaningful activities
- Make sure their glasses and hearing aids are clean and working properly
- If you are helping with personal care, explain in simple terms what you are doing and why. Try to remain calm and patient if the person is distressed
- If the person is restless it may help to encourage them to do an activity that is related to their past roles and interests or to go for a walk
- Check with the doctors whether the person is on the right medication if you think they might be in pain or unwell
- If the person is distressed by hallucinations or delusions, speak to the GP/ ward doctors or liaison psychiatry team about medications that can help with these symptoms.



What else can be done to help someone with advanced dementia?

There are a number of things that can be done to help a person with advanced dementia feel more comfortable.

Medication

There are no specific drug treatments for advanced dementia. It is helpful for someone with advanced dementia to have their medication reviewed by a doctor and/or a pharmacist. This ensures that their medication is appropriate and needed to treat any current symptoms or to prevent any that might affect their wellbeing.

Medication to treat acute illnesses such as infections can be helpful for some people. However, it can sometimes be better for a person

with advanced dementia to stop taking medicines for long-term conditions (such as statins for raised cholesterol) after discussion with their doctor.

Someone with dementia cannot always clearly say or show that they are in pain, so it is important that the healthcare team considers whether pain is causing any of their agitation or restlessness and has a plan for managing this.

If the person finds it hard to take medication, it is important to find out why. The medicine might be difficult to swallow, taste unpleasant or be causing side effects. It can sometimes be easier for them to take medication as a liquid or a patch rather than tablets, or to take it with food or drink.

If the person refuses to take medication and lacks the mental capacity to understand the importance of taking it, the medical team will discuss how to manage this with you.

Very rarely, the medical team will advise that medication is hidden in food (such as yoghurt) or drink. This is called covert medication. This is only done with a properly agreed and written plan.

Meaningful activities

Keeping someone with advanced dementia occupied can feel like a challenge. Activities that might have worked before such as watching TV, reading, going out and about and reminiscing become increasingly difficult. The person may be bored but not find it easy to tell anyone how they feel.

For someone who is still able to get involved, try activities that stimulate their senses with objects that they like touching, smelling and looking at. 'Fiddle mitts' and 'rummage boxes' are good examples.



For someone who is no longer able to actively engage, try providing sensory stimulation such as using massage, scent or interesting visual scenes such as ceiling mobiles.

Other activities you can try include:

- Bird feeders at the window
- Fish tanks
- Interactive art works and pictures
- Wall clocks
- Pet therapy, for example, dogs, cats and rabbits they can touch
- Dolls and stuffed animals, fiddle mitts
- Hand massage with scented lotions
- Touch, if this is something the person previously found comfortable
- Reading
- Smell, aromatherapy.



Spirituality

Person-centred care is at the heart of dementia care. This means that staff use an all-round (holistic) approach to looking after their patients which includes their religious and spiritual needs, too.

You can tell staff what is important to your loved one when considering their spirituality by putting this in their 'This is me' document.

Spirituality is about the things that give people with dementia a sense of peace and wellbeing and it is unique to each person. In some cases, these things will be religious.

Someone with advanced dementia may become agitated or distressed by religious activities that need a lot of concentration, memory and understanding.

But things that need less understanding – for example, holding a religious object (such as rosary beads, a holding cross, or a book), singing familiar hymns or saying favourite prayers, listening to audio recordings, or lighting incense (in safe conditions) might trigger memories for your loved one.

For some people spirituality is less about religious themes and more about their senses. This can include hand massage, listening to music, being close to a person who has been central in their life, recalling memories or just holding somebody's hand. For others spirituality is powerfully about what happens to them after death, and doing all they can to prepare for life after death. It is helpful at this point to seek spiritual care. Such care should not only be offered at the point of death. Early access to the Chaplaincy Service can be very helpful for support on site with the possibility of contact and



liaison with local faith and belief leaders where appropriate.

As a caregiver you will also have your own unique spiritual and religious needs. This is a difficult time for you and you might like to take comfort by visiting our chapel or talking to a member of our Chaplaincy Service. This service will do all they can to support you. Just ask a member of staff (in hospital) and they will make a referral to the service.

Planning future care

It is helpful to make an advance care plan to prepare for a situation in which a person becomes very unwell and decisions need to be made quickly. Advance care planning is simply making plans about future care. A good way to start thinking about what should be in the advance care plan is what you can do to increase the person's comfort and reduce any distress such as whether an admission to hospital is in a person's best interest.



Someone with advanced dementia is more likely to develop acute illnesses or conditions such as chest infections, urinary infections and loss of appetite. They may also have other unrelated medical conditions such as heart, lung or kidney disease, or cancer. There will be a point when invasive treatments for such illnesses are unlikely to help and may even cause more suffering and distress.

Advance care planning involves thinking about the illnesses that are likely to affect your loved one and deciding how to manage them after looking at the advantages and disadvantages of various treatments.

Decisions about cardio-pulmonary resuscitation

All patients admitted to hospital should have a decision made about whether to attempt cardiopulmonary resuscitation (CPR). This is the treatment given when someone stops breathing and/or their heart stops beating (cardiac arrest).

By law, we have to discuss the decision not to do CPR (DNACPR) with patients and/or their next of kin. It is unlikely that someone with advanced dementia will be able to take part in these discussions, so we will discuss it with their next of kin.

We realise you may find this very difficult to discuss. Ultimately, the decision to attempt CPR is a medical one. We do not attempt CPR if it would leave a patient worse off than before their heart stopped. In conditions such as advanced dementia, CPR is highly unlikely to work and could be harmful.





Mental capacity and decision-making

People with advanced dementia lose their ability to make decisions for themselves so they need to be made for them. The Mental Capacity Act 2005 (MCA), which protects the rights of people who cannot make decisions for themselves, states that decisions have to be made in a person's best interest.

Some people with dementia may have given Lasting Power of Attorney (LPA) to a family member or close friend while they still had capacity to do so. This gives the named person the legal authority to make decisions on behalf of the person with dementia. An LPA for Property and Financial Affairs covers decisions about money and LPA for Health and Welfare covers decisions about health and personal welfare.



Some decisions about treatment will need to be made by the medical team, depending on what is best for the person and the chances of the treatment helping them. Family cannot demand a treatment that the healthcare professionals do not think will help the person.

Care decisions for those with advanced dementia are often not clear-cut and should also depend on what the person would have wanted when they were able to make decisions for themselves.

A 'best interest' discussion or meeting will be held when major decisions need to be made. This should involve relevant family members, healthcare professionals and sometimes a social worker or Independent Mental Capacity Advocate (IMCA).

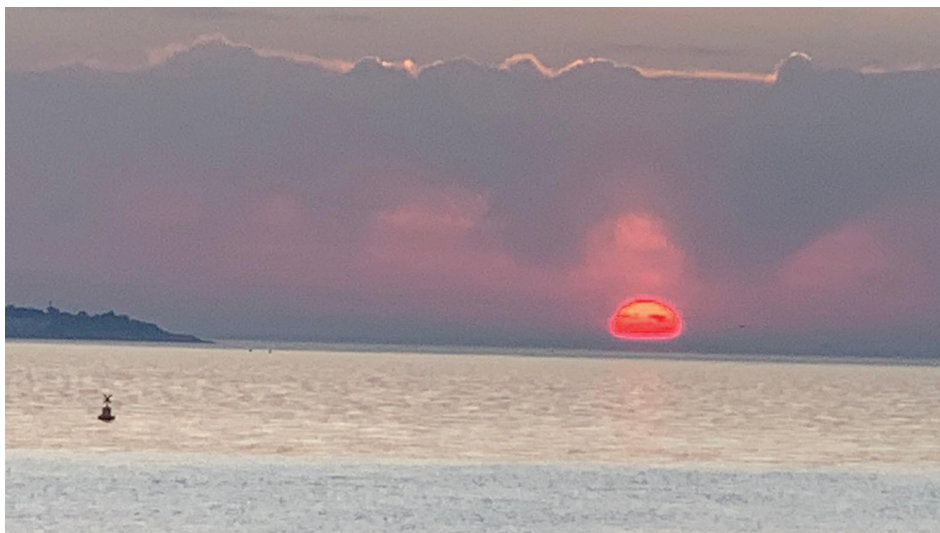
Best interest care planning usually happens when decisions need to be made about medical treatment, feeding problems and care after leaving hospital.

Support for carers

Caring for a person with advanced dementia can be very stressful. You may feel a range of emotions including guilt, fear and even anger. During a hospital stay, a patient with advanced dementia might be referred to the Dementia and Delirium (DAD) and/or the Old Age Liaison Psychiatry teams for more support. The Palliative Care team might also be involved.

As a carer, relative or friend, it is important that you have an opportunity to talk through any concerns you have during a hospital admission. Ward nursing and medical staff are available to help you. They might also refer you to other services at the hospital for support.





Leaving hospital

Before a person with dementia leaves hospital, carers and relatives should be closely involved in planning their discharge. This might involve family meetings and very often, a best interest meeting with members of the ward team, including nursing and medical staff, therapists and social workers, to work out the care needs for the person with dementia as well as the carer's needs, such as a sitting service.

An increasing number of people with advanced dementia are being supported to live well and die at home, usually with a mixture of support from health and social care services and family. But for some people care homes may offer the best option for care with better comfort and less distress.

When a loved one is discharged from hospital they might be referred to community Palliative Care services. These services provide advice on how to control symptoms and support for the carers and families of people with advanced dementia who are nearing the end of their life.



Other sources of support

The Alzheimer's Society

Helpline: 0300 222 11 22

www.alzheimers.org.uk

Carers UK

Helpline: 0808 808 7777

www.carersuk.org

PALS

The Patient Advice and Liaison Service (PALS) offers support, information and assistance to patients, relatives and visitors. They can also provide help and advice if you have a concern or complaint that staff have not been able to resolve for you. The PALS office is on the ground floor of the Hambleton Wing, near the main entrance on Bessemer Road – staff will be happy to direct you.

PALS at King's College Hospital, Denmark Hill, London SE5 9RS:

Tel: **020 3299 3601**

Email: **kch-tr.palsdh@nhs.net**

You can also contact us by using our online form at

www.kch.nhs.uk/contact/pals

PALS at Princess Royal University Hospital, Farnborough Common, Orpington, Kent BR6 8ND

Tel: **01689 863252**

Email: **kch-tr.palspruh@nhs.net**

If you would like the information in this leaflet in a different language or format, please contact PALS on 020 3299 1844.



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Notes



