

Pain and dementia



Introduction

Pain can often be missed or hard to recognise in people with dementia. They may have communication difficulties which make them less able to tell you about their pain, or have difficulty interpreting or understanding the pain they feel.

Some people believe that people with dementia can't feel pain, but this is not true. People with dementia do experience pain, but they may not be able to recognise or manage it the same way as someone who does not have dementia. This can mean that their pain is not treated properly, which can increase their discomfort and distress, and reduce their quality of life.

If people are feeling vulnerable or afraid, they may experience a more significant reaction to pain. As dementia can cause people to feel confused and frightened, they may experience pain in a heightened way.

Signs that a person with dementia might be in pain

There are things that you can look out for that can help you identify pain in a person with dementia. Once pain is identified, you can help the person seek appropriate treatment so they feel more comfortable.

Changes in the way the person is reacting might indicate that they're in pain. For instance:

- behaviours like fidgeting, restlessness, or reacting with fear or distress during personal care such as washing or dressing
- calling out, groaning or shouting (particularly if this is new behaviour, or has increased)
- sleeping more or less than usual
- changes in body language, such as appearing panicked, bracing or guarding themselves, or making repetitive movements, such as rubbing or twitching
- facial expressions, such as grimacing, tensing or frowning

- appearing low in mood, withdrawn or uncharacteristically quiet
- physical signs, such as a change in temperature, increased pulse, sweating, flushing or appearing pale
- changes in appetite, such as refusing food

If you are looking after a person with dementia, you may know them best. If you can, think back to a time before their diagnosis or in their earlier life when you knew they were in pain. How did they react then? Does that help you interpret their behaviour now?

Asking someone if they are in pain is the best way to find out, but as the person's dementia progresses, they may be less able to tell you. They may not be able to describe where the pain is coming from, and may say “no” if you ask – even if this is not true. They might use jumbled up words to explain how they are feeling, such as saying ‘injection’ instead of indigestion’.

Using words they are familiar with when you ask if they are in pain can help them identify what they are feeling: “Does it hurt here? Is your arm aching? Does it sting?”



Causes of pain and ways to alleviate it

Investigating why the person with dementia is in pain is doubly important: to help them feel more comfortable, and also to avoid the unnecessary prescription of treatments for their restlessness or agitation.

People with dementia, especially people who are getting older, are more likely to also have other significant health conditions. It is important to keep up with regular health checks and ensure the person is taking any prescribed medication to try to keep them as well as possible.

Gum disease or other mouth problems can be extremely painful and upsetting. Good dental health can be difficult for people with dementia, but with support, they can brush their teeth daily, use a mouthwash and visit the dentist regularly. Please see Sources of support at the end of this leaflet for details of our separate leaflet on mouth care.

Arthritis can cause pain in the hands and feet, limbs, neck, spine and sometimes torso. It becomes more likely as people get older. Look out for swelling, redness, or stiffness in the joints, and speak to the person's GP or a pharmacist about possible treatment.

Constipation can cause pain and discomfort. Try to make sure that the person eats a balanced diet with plenty of fresh fruit and vegetables, and that they are drinking enough fluid (please see Sources of support for our leaflet on eating and drinking). If constipation is occurring frequently, speak to your pharmacist or GP.

A lack of movement can contribute to pain. Does the person spend long periods of time sitting in a chair? Encouraging them to get up and take a little walk around the room, or into the kitchen for a drink, regularly throughout the day, will help them stay mobile.

Being poorly positioned can also cause pain. Check that the person has cushions to help position them, if appropriate, and that the chair they sit in supports their back. You may like to arrange a free Social Services Needs Assessment to see if adaptations for their chair or house are necessary to aid mobility and reduce pain. You can request this at [gov.uk/apply-needs-assessment-social-services](https://www.gov.uk/apply-needs-assessment-social-services)

Other ways of managing pain

Physiotherapy or massage can be good for soreness or stiffness caused by sitting still for too long, or for general aches and pains that might come about from aging. Explain to the person with dementia what is going to happen and stop if they appear to be in any distress or discomfort.

Applying heat, such as a hot water bottle in a cover, or cold, such as an ice pack, can be good for treating localised pain. Heat is useful for treating aches and stiffness. Cold is useful for treating inflammation

and is therefore more appropriate if the person has an injury, such as a sprained ankle. You can wrap ice in a tea towel to avoid burns. Ask the person with dementia if it feels nice. Watch their face to see how they react.

Relaxation techniques such as breathing exercises or mindfulness can help with pain (please see Sources of support at the end of this leaflet.) Gentle exercise can also be beneficial but please seek medical advice from your GP before trying anything new.

Try keeping a diary of changes in the person with dementia, recording things such as when they appear to be in pain, at what times of day, whether it is brought on by particular movements or activities etc. Take this diary with you when visiting the GP so that you can discuss a plan for pain avoidance and treatment.

Speak to the person's GP about the suitability of painkillers. If medication is recommended, make sure the person takes it regularly,

as prescribed, and and that they see their GP or nurse as required to check that it is working effectively and not causing undue side effects. If the person struggles to swallow or has difficulty taking tablets, speak to their GP about other options for medication, such as patches.

For advice and support from a dementia specialist Admiral Nurse on our Helpline, please call **0800 888 6678** or email helpline@dementia.org

OR

You can book a phone or video appointment with an Admiral Nurse in our virtual clinics by visiting dementiauk.org/book-an-appointment



Sources of support

Dementia UK leaflet on Mouth care

dementiauk.org/mouth-care

Dementia UK leaflet on Eating and drinking

dementiauk.org/eating-and-drinking

Dementia UK video on Calming techniques

dementiauk.org/maintaining-health-in-dementia-videos

Dementia UK leaflet on Dealing with restlessness

dementiauk.org/dealing-with-restlessness

Dementia UK leaflet on Managing anxiety and depression in a person with dementia

dementiauk.org/anxiety-and-depression

Our Admiral Nurses can help

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

Call **0800 888 6678** or email helpline@dementia.org

Opening hours:

Monday-Friday, 9am-9pm

Saturday-Sunday, 9am-5pm

Every day except 25th December

The information in this booklet is written and reviewed by dementia specialist Admiral Nurses.

We are always looking to improve our resources, to provide the most relevant support for families living with dementia. If you have feedback about any of our leaflets, please email feedback@dementiauk.org

We receive no government funding and rely on voluntary donations, including gifts in Wills.

For more information on how to support Dementia UK, please visit dementiauk.org/donate or call **0300 365 5500**.

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If you're caring for someone with dementia or if you have any other concerns or questions, call or email our Admiral Nurses for specialist support and advice.



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