

# Pain and dementia



Pain can often be hard to recognise in a person with dementia, which may mean it is underestimated or missed entirely. The person may have communication difficulties which make them less able to tell you about their pain, or may have difficulty interpreting or understanding the pain they feel.

Some people believe that people with dementia cannot feel pain, but this is not true. People with dementia do experience pain, but they may not be able to recognise, express 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 cause further discomfort and distress and reduce their quality of life.

When people feel vulnerable or afraid, their perception of pain can become more intense. This is especially true for people living with dementia. Dementia often causes confusion, fear and disorientation which can heighten emotional distress, making pain feel more severe than it might otherwise.

If the person you care for seems more confused or distressed than usual, it is a good idea to consider whether they may be in pain. Pain sometimes gets overshadowed or overlooked in people with dementia, as changes in behaviour are often attributed to their dementia symptoms.

### **Signs that a person with dementia might be in pain**

There are signs that you can look out for that can help you recognise pain in a person with dementia. Once you have identified that they are in pain, you can address the causes and help them seek appropriate treatment if necessary.

Indications that a person with dementia may be in pain can include:

- fidgeting, agitation and restlessness



- reacting with fear or distress during personal care such as washing or dressing – this may lead to verbal or physical aggression
- calling out, groaning or shouting (particularly if this is new behaviour, or has increased)
- showing discomfort when moving, or being less willing to move
- 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

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- holding a particular part of their body
- facial expressions, such as grimacing, tensing or frowning
- appearing low in mood, withdrawn or uncharacteristically quiet
- physical symptoms, such as a change in temperature, increased pulse, sweating, flushing or appearing pale
- visible injury such as swollen joints, cuts or bruises, pressure sores or mouth ulcers
- changes in appetite, such as refusing food

If you are looking after a person with dementia, you are likely to know them best. If you can, think back to past times when you knew they were in pain. How did they react then? Does that help you interpret their behaviour now?

If possible, you can ask the person directly if they are in pain, but as their condition 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 if they are uncomfortable – even if they are. They might use the wrong words to explain how they are feeling, such as saying ‘injection’ instead of ‘indigestion’.

Using simple words that the person is familiar with when you ask if they are in pain, and being specific about what you say, can help them express what they are feeling – for example, “Does it hurt here? Is your arm aching? Does it sting?”

### **Causes of pain and ways to alleviate it**

Finding out why the person with dementia is in pain is doubly important – it will help you find ways to make them feel more comfortable; and it will also avoid them being prescribed



unnecessary medication for restlessness or agitation, when these symptoms could improve if their pain was treated.

People with dementia, especially those who are older, are more likely to 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.

To help you work out why the person may be in pain, try keeping a diary, including:

- what sort of pain they are/appear to be experiencing
- when it happens, eg particular times of the day
- how often it happens

- changes in behaviour that indicate pain
- whether it is brought on by particular movements or activities such as personal care

Take this diary with you when visiting the person's GP so that you can discuss a plan for pain avoidance and management.

If pain seems to be an ongoing or regular problem, it is a good idea to continue to keep a diary, with the person's input if possible. This can be shared with health professionals to help them identify any patterns and decide on an appropriate treatment plan.

### Possible causes of pain

**Gum disease or other mouth problems:** these can be extremely painful and upsetting. Good dental hygiene 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 on p14 for more information on oral health and mouth care.

**Arthritis:** this can cause pain in the hands and feet, limbs, neck, spine and sometimes torso, and 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.

**Urinary tract infections (UTIs):** UTIs are common in people with dementia and can cause significant discomfort. Symptoms may include pain or a burning sensation when urinating, stomach or lower back pain, and increased confusion or sudden changes in behaviour.

In people with dementia, a UTI can sometimes lead to delirium: a sudden and severe state of confusion that can be frightening and distressing.





To prevent UTIs, is important to:

- Encourage the person with dementia to take fluids regularly throughout the day to help prevent infections
- Watch for changes in behaviour, mood or physical symptoms that might indicate a UTI
- Contact the GP promptly if you suspect a UTI, as early treatment can prevent complications

**Constipation:** this can cause pain and discomfort, such as bloating and cramps. 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 on p13 for our information on eating and drinking). If constipation is occurring frequently, speak to your pharmacist or GP.

**Immobility:** limited movement can lead to discomfort and health issues for people with dementia. Many people spend long periods in bed or sitting in a chair, which can contribute to joint stiffness, constipation, pressure sores and increased pain or discomfort. You can help the person by:

- Encouraging gentle movement throughout the day: even short walks around the room or to the kitchen for a drink can make a big difference
- Incorporating movement into daily routines, such as standing up during TV commercials or stretching during their morning personal care routine
- Offering support and reassurance, especially if the person feels unsure or unsteady on their feet

**Poor positioning in a chair or bed:** 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 Social Services needs assessment to see if adaptations to their chair, bed or house could improve their mobility and reduce pain – see Sources of support on p14.

**Falls:** people with dementia are often prone to falls, and as they become more frail, even minor falls can cause serious and painful injuries. This is especially true if they have osteoporosis – a weakness in the bones that can make them break more easily, which becomes more likely as people age and is more common in women than men.

You can reduce the risk of falls at home by taking some simple safety measures: please see Sources of support on p13 and p14 for our information on falls, and on making the home safe and comfortable for a person with dementia. A Social Services needs





assessment will also help you identify if adaptations could be made to the home to help prevent falls.

### **Young onset dementia and pain**

People with young onset dementia (where symptoms develop before the age of 65) may have different causes of pain. They may injure themselves at work, during sports, lifting heavy objects or doing DIY. If they still menstruate, they may experience period pain, or if they are going through menopause, they may have uncomfortable symptoms like headaches and migraines, joint and muscle aches, or vaginal dryness and pain.

### **Ways of managing pain**

If you believe the source of the person's pain could be serious, please speak to their GP urgently, call NHS 111 for 24-hour advice, or go to A&E if necessary.



Physiotherapy or massage can be good for soreness or stiffness caused by sitting still for too long, for muscle strains and sprains, and for general aches and pains. You may be able to give the person with dementia a gentle massage yourself, but do not be too vigorous. Explain what is going to happen and stop if they appear to be in any distress or discomfort. If they see a professional massage therapist or physiotherapist, ensure they know that the person has dementia.

Applying heat or cold may soothe localised pain. Heat is useful for treating aches and stiffness, whereas cold is better for inflammation and injuries like a sprained ankle. Never use a direct source of heat or cold – for example, if you use a hot water bottle, it should be in a cover; or if you use ice, it should be wrapped in a tea towel. You can also buy ice and heat packs from pharmacies.

When using heat or cold, always ask the person how it feels, and watch their face and body language to see how they react. For information on using heat and cold safely, please see Sources of support on p14.

Relaxation techniques such as breathing exercises or mindfulness can help with pain by distracting the person and helping to relax tense muscles and joints (please see Sources of support on p14).

Gentle exercise can also be beneficial but please seek advice from the person's GP before trying anything new. If the person already exercises and wants to continue, ensure they do this safely – for example, they may not realise the need to warm up and down to prevent injury, or the importance of resting a muscle or joint strain rather than continuing to exercise and putting extra stress on the injured area.

If the person with dementia works, they should ensure any workplace health and safety assessments are up to date, such as a workstation assessment to make sure they are sitting correctly while using a computer, and that they understand any specific safety advice, for example around lifting heavy objects.

If you think the person would benefit from pain medication, speak to their GP. If medication is recommended, make sure the person takes it regularly, as prescribed or according to the instructions on the label/packet, 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. Pharmacists can also offer advice on the best treatments for pain.



## Sources of support

If you are living with dementia or caring for someone with the condition, register for our free online sessions, ‘Dementia: what next?’ at [▶ dementiauk.org/dementia-what-next](https://dementiauk.org/dementia-what-next)

To speak to a dementia specialist Admiral Nurse, call our free Helpline on **0800 888 6678** (Monday-Friday 9am-9pm, Saturday and Sunday 9am-5pm, every day except 25<sup>th</sup> December) or email [▶ helpline@dementiauk.org](mailto:helpline@dementiauk.org)

If you prefer, you can book a phone or video call with an Admiral Nurse at a time to suit you: please visit [▶ dementiauk.org/book](https://dementiauk.org/book)

## Dementia UK resources

### Delirium

[▶ dementiauk.org/delirium](https://dementiauk.org/delirium)

### Eating and drinking

[▶ dementiauk.org/eating-and-drinking](https://dementiauk.org/eating-and-drinking)

### Falls

[▶ dementiauk.org/dementia-and-falls](https://dementiauk.org/dementia-and-falls)

### Good hydration for a person with dementia

[▶ dementiauk.org/hydration](https://dementiauk.org/hydration)

### Making the home safe and comfortable

[▶ dementiauk.org/making-the-home-safe-and-comfortable](https://dementiauk.org/making-the-home-safe-and-comfortable)

### Medication for people with dementia

[▶ dementiauk.org/medication](https://dementiauk.org/medication)

### **Menopause and perimenopause**

➤ [dementiauk.org/perimenopause-and-menopause](https://dementiauk.org/perimenopause-and-menopause)

### **Oral health and mouth care**

➤ [dementiauk.org/mouth-care](https://dementiauk.org/mouth-care)

### **Restlessness and agitation**

➤ [dementiauk.org/dealing-with-restlessness](https://dementiauk.org/dealing-with-restlessness)

### **Staying healthy with dementia**

➤ [dementiauk.org/staying-healthy](https://dementiauk.org/staying-healthy)

## **Other resources**

### **Apply for a needs assessment**

➤ [gov.uk/apply-needs-assessment-social-services](https://gov.uk/apply-needs-assessment-social-services)

### **Ice and heat treatment**

➤ [gloshospitals.nhs.uk/your-visit/patient-information-leaflets/ice-and-heat-treatment](https://gloshospitals.nhs.uk/your-visit/patient-information-leaflets/ice-and-heat-treatment)

### **NHS 111 – for urgent medical advice**

Call 111

➤ [111.nhs.uk](https://111.nhs.uk)

### **NHS: arthritis**

➤ [nhs.uk/conditions/arthritis](https://nhs.uk/conditions/arthritis)

### **NHS: constipation**

➤ [nhs.uk/conditions/constipation](https://nhs.uk/conditions/constipation)

### **NHS: mindfulness**

➤ [nhs.uk/mental-health/self-help/tips-and-support/mindfulness](https://nhs.uk/mental-health/self-help/tips-and-support/mindfulness)



**NHS: osteoporosis**

➤ [nhs.uk/conditions/osteoporosis](https://nhs.uk/conditions/osteoporosis)

**NHS: physiotherapy**

➤ [nhs.uk/conditions/physiotherapy](https://nhs.uk/conditions/physiotherapy)

**NHS: urinary tract infections (UTIs)**

➤ [nhs.uk/conditions/urinary-tract-infections-utis](https://nhs.uk/conditions/urinary-tract-infections-utis)



**To speak to a dementia specialist Admiral Nurse  
about any aspect of dementia:**

Contact our Helpline:

**0800 888 6678** or ➔ **helpline@dementiauk.org**

Book a virtual appointment:

➔ **dementiauk.org/book**

**Our charity relies entirely on donations to fund our  
life-changing work. If you would like to donate to help us  
support more families:**

- Call **0300 365 5500**
- Visit ➔ **dementiauk.org/donate**
- Scan the QR code



**Thank you.**



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