



DementiaUK
Helping families face dementia

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 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 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 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 help them seek appropriate treatment so they feel more comfortable.

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
- 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- appearing low in mood, withdrawn or uncharacteristically quiet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 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?

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 this is not true. 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 getting 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 treatment.

Some possible causes of pain include:

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 p10 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): these are common in people with dementia and can cause pain or a burning sensation when they pass urine, as well as stomach and lower back pain. It is important to encourage the person to drink plenty of fluids throughout the day and seek medical advice if you believe they have a UTI, as it can lead to delirium – a sudden, intense state of confusion that is common in people with dementia.

Constipation: this can cause pain and discomfort, such as a bloated feeling 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 p10 for our information on eating and drinking). If constipation is occurring frequently, speak to your pharmacist or GP.

Immobility: a lack of movement can contribute to pain. If the person spends long periods of time in bed or 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 and prevent problems like joint stiffness, constipation and pressure sores.

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 free social services needs assessment to see if adaptations to their chair, bed or house could improve their 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)

Falls: people with dementia are often prone to falls, and as they become more frail, even minor falls can cause serious and painful injury. 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 p10 for our information on falls, and on making the home safe and comfortable for a person with dementia.

People with young onset dementia (where symptoms develop before the age of 65) may have different causes of pain. For example, if they are physically fit and active, they may have a sport-related injury. They may injure themselves at work, or while 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 p11.

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 p11).

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 painkillers, 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

To speak to a specialist dementia nurse about pain or any other aspect of dementia, please call our Helpline on **0800 888 6678** (Monday to Friday 9am-9pm, Saturday and Sunday 9am-5pm) or email helpline@dementiauk.org

To book a phone or video call appointment with an Admiral Nurse, please visit dementiauk.org/book

Dementia UK resources

Dealing with restlessness
dementiauk.org/dealing-with-restlessness

Delirium
dementiauk.org/delirium

Eating and drinking
dementiauk.org/eating-and-drinking

Falls
dementiauk.org/dementia-and-falls

Good hydration for a person with dementia
dementiauk.org/hydration

Making the home safe and comfortable
dementiauk.org/making-the-home-safe-and-comfortable

Medication for people with dementia
dementiauk.org/medication-for-people-living-with-dementia

Menopause and perimenopause
dementiauk.org/perimenopause-and-menopause

Oral health and mouth care
dementiauk.org/mouth-care

Staying healthy with dementia
dementiauk.org/staying-healthy



Other resources

Accessing physiotherapy

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

Apply for a needs assessment

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

Ice and heat treatment

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

NHS 111 – for urgent medical advice

Call 111

111.nhs.uk

NHS: arthritis

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

NHS: constipation

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

NHS: mindfulness

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

NHS: osteoporosis

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

NHS: urinary tract

infections (UTIs)

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

The information in this leaflet is written and reviewed by dementia specialist Admiral Nurses. We hope you find it useful. If you have feedback, please email feedback@dementiauk.org

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We want to ensure no one has to face dementia alone – and we can only do this because of our generous supporters. If you would like to help, please consider making a kind gift.



To donate: call **0300 365 5500**,
visit dementiauk.org/donate-to-support
or scan the QR code.

Thank you.



If you have questions or concerns about any aspect of dementia, please contact our Admiral Nurses.
Helpline: **0800 888 6678** or helpline@dementiauk.org
Virtual clinics: dementiauk.org/book-an-appointment



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