

Pain and dementia



Introduction

Pain can often be missed or not recognised in people with dementia. They may have communication difficulties which makes them less able to tell you about their pain, or have difficulty interpreting or understanding the pain they feel.

Some people mistakenly believe that people with dementia can't feel pain. This is not true. People with dementia 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, then they are more likely to experience a more significant reaction to pain. Dementia can cause people to feel confused and frightened, which can mean

that they experience pain in a heightened way. 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 and content.

Signs that a person with dementia might be in pain

Changes in the way the person is reacting might be possible signs of pain, for instance:

- behaviour, such as fidgeting, restlessness, or reacting with fear or distress during personal care such as washing or dressing
- speech, such as calling out, groaning or shouting (particularly if this is new behaviour, or has increased)
- sleep, such as sleeping more or less than usual
- body language, such as appearing panicked, bracing or guarding, or repetitive movements, such as rubbing or twitching
- facial expressions, such as grimacing, tensing or frowning
- mood, such as withdrawal or uncharacteristic quietness, low mood
- physical state, such as change in temperature, increased pulse, sweating, flushing or appearing pale
- appetite, such as refusing food



If you are looking after a person with dementia, then you might know the person 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 consider 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 likely to tell you they are in pain. 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 to you 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

People with dementia, and 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 medication prescribed to them, to try and keep them as well as possible, alongside their dementia.

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

Gum disease or poor dental hygiene can be extremely painful and upsetting. Good dental health can be difficult for people with dementia to achieve (please see Sources of support at the end of this leaflet for details of our separate leaflet on Mouth care), but with support, they can brush



daily, use a mouthwash and visit the dentist regularly.

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 your 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 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.

Depression and social isolation can have an impact on pain. Does the person spend long periods of time alone? Are they low in mood? Encouraging them to remain socially connected and doing activities they enjoy may help.

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. They may need an occupational health

assessment to see if adaptations for their chair or house are necessary to aid with mobility and reduce pain. You can request this from your GP.

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; 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 treatment inflammation and is therefore more appropriate if the person has an injury, such as a sprained ankle. You can wrap both 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 (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 the person appears to be in pain; what times of

day; whether this is brought on by particular movements or activities etc. Take this diary with you when visiting the GP so that you can better 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 is given the medication regularly, as prescribed, and that it is reviewed by a nurse or the GP for its effectiveness and any side effects. If the person struggles to swallow or has difficulty taking tablets, speak to the GP about other options for medication, such as patches.

If you have any questions or concerns about pain in dementia, or anything else, please call the specialist dementia nurses on the Admiral Nurse Dementia Helpline, on **0800 888 6678** or helpline@dementiauk.org. The Helpline is open Monday to Friday from 9am-9pm and 9am-5pm at weekends.

Sources of support

- Dementia UK leaflet on Mouth care
www.dementiauk.org/get-support/maintaining-health-in-dementia/mouth-care-dementia/
- Dementia UK leaflet on Eating and drinking
www.dementiauk.org/get-support/maintaining-health-in-dementia/eating-and-drinking/
- Dementia UK video on Calming techniques
www.dementiauk.org/get-support/maintaining-health-in-dementia-videos/
- Dementia UK leaflet on Dealing with restlessness
www.dementiauk.org/get-support/understanding-changes-in-behaviour/dealing-with-restlessness/
- Dementia UK leaflet on Managing anxiety and depression in a person with dementia
www.dementiauk.org/get-support/maintaining-health-in-dementia/managing-anxiety-and-depression-in-a-person-living-with-dementia/

Our Admiral Nurses can help

If you have any questions or concerns please contact our Admiral Nurse Dementia Helpline to speak to a specialist dementia nurse.

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

Opening hours:

Monday – Friday, 9am – 9pm, Saturday – Sunday, 9am – 5pm

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 www.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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