

Pain in dementia

Introduction

This information sheet is for people who are living with dementia, their families and friends. It was originally published as an information leaflet by NHS Dumfries and Galloway and developed in conjunction with Alzheimer Scotland's development team.

People can live well with dementia for many years but over time, memory and understanding can decline. People who are affected can become frustrated as they become less able to do the things they used to do. Gradually, they have to rely on others for help.

Older people in general tend to experience more pain due to medical conditions. While each person feels pain differently, sometimes people with dementia are unable to describe their pain in words.

As dementia progresses, people's ability to express and communicate their thoughts, feelings and needs may decline. Often, they will express these feelings as changes in behaviour. They may not understand questions, may not recall that they have been in pain or may be unable to interpret the feelings they are having.

Sometimes it is accepted that older people will suffer pain but this does not mean that it cannot be treated. People who have chronic pain (e.g. back pain or arthritis) need to take regular painkillers to achieve pain control.

Unfortunately, painkillers may not be taken correctly due to lack of understanding of how they work and a mistaken belief that all painkillers are addictive.

What are the signs?

People with dementia may express their pain in a different way to those who don't have dementia.

Even if it is impossible for the people you care for to respond to questions about any pain they may be experiencing, by observing them carefully you can pick up important clues to alert you to their discomfort.

Facial expressions

When you look at the person's face, are they telling you they are in pain e.g. frowning, grimacing or looking frightened?

Verbal expressions

Is the person making unexplained or different noises e.g. groaning or crying?

Body movements

Is the person's body language telling you they are in pain e.g. are they pacing or rocking?

Behavioural changes

Have you noticed changes in their behaviour? Have their eating habits changed or do they want to stay in bed?

Emotional changes

Has the person shown any emotional or mood changes, such as irritability or distress? Do they seem more anxious than normal?

As a family member/carer, you are more attuned to knowing when the person with dementia is in pain.

If you notice any of these signs, seek help from the doctor who will have information about the person's medical history, make an assessment of the source of the pain and treat accordingly.

Common causes of pain

It is important to rule out causes of pain that can be easily treated. Constipation or urinary tract infections occur frequently and can cause great distress. Sitting or lying in one position and wearing uncomfortable or tight clothes can lead to muscle spasms or pressure sores. Other causes of pain include arthritis, headaches, foot problems, dental pain and osteoporosis.

What can you do to help?

If it appears that the person has minor conditions such as constipation or headaches, make sure these are treated. Your local pharmacist or GP can give you advice.

If you know that the person has previously suffered from joint pains, then it is likely that the aches will still be present. Non drug treatments such as massage, rubbing, heat pads or gentle exercise can help a number of aches and pains.

Paracetamol* given regularly is very effective for mild to moderate pain and has almost no side effects. It is important to add in the right painkillers to ensure adequate relief from pain. Speak to the doctor if you feel that pain is still persistent despite the person taking regular paracetamol.

*no more than 8 tablets in 24 hours. Other medicines such as some cold & flu remedies and co-codamol contain paracetamol.

In summary

Thinking about pain as a possible cause of changes in behaviour can make a real difference in making sure that it is managed appropriately. Simple painkillers can give great relief and dramatically improve quality of life for people with dementia.