



Pain in dementia

Introduction

This information sheet is aimed at people with dementia, their families & 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 with dementia gradually lose their memory and their understanding. They become confused and often frustrated as they cannot do things they used to do. Bit by bit, they become less able to look after themselves and have to rely on others to 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. Very 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 differently to people who don't have dementia.

Even if it is impossible for the people you care for to respond to questions about their pain, 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, looking frightened?

Verbal expressions

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

Body movements

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

Behavioural changes

Are there changes in their behaviour e.g. sleeping, eating or not wanting to get out of bed?

Emotional changes

Have you noticed any emotional changes e.g. irritability or distress?

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

If you see any of these signs, seek help from the doctor who will have information about their medical history and be able to make an assessment 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 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 such as constipation. 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 pain is managed appropriately.

Simple painkillers can give great relief and dramatically improve quality of life for people with dementia.

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