

THE  
NATIONAL  
COUNCIL FOR  
PALLIATIVE  
CARE

HOW WOULD I KNOW?  
WHAT CAN I DO?

How to help someone with dementia  
who is in pain or distress



## Unusual behaviour may be a sign of pain or distress

If you are giving care or support to somebody with dementia, particularly as it advances and their ability to communicate reduces, you may find that they sometimes behave out of character. This can be displayed in different ways, including being agitated, frustrated, confused, wandering, anxious, pacing, calling out, aggressive or fearful.

Behaviour like this can be alarming and challenging to cope with. However it is not something that's "just part and parcel" of having dementia or that nothing can be done about. It's likely that something is causing this behaviour. The behaviour may well be a symptom or a sign of distress, or an attempt to communicate an unmet need, and not an untreatable part of the disease.

And if you can find out what the cause is, you might be able to do something about it.


It could be that they are in pain or discomfort. People with dementia can still experience pain, although they might find it hard to tell you what's troubling them.

Or it might be something else that's causing them distress.

## Tip:

“Life story” information is vital to help you understand the person and who they are. What have they done in the past? Which people, relationships, activities or things are important to them? What are their pleasures or dislikes? How have they coped in difficult situations or found sources of peace and comfort in the past? What might reassure or frighten them? How might that be affecting them in the here and now? Is there anything they can normally do for themselves that they can't do at the moment?

Consider how you can work with the person and other people involved in their care to record their life story and use it to help support their quality of life and care.



She started to  
behave really oddly...  
...She got angry. It was really  
unlike her. I didn't know what  
was happening to her...  
...I felt so helpless.

# Knowing whether someone is in pain or distress

There are simple things you can do:

- **Ask the person what the matter is**
- **Listen to them**
- **Observe their behaviour and what's going on**
- **Act on what you've seen and heard**

It can be hard to know exactly what's going on, particularly when somebody has advanced dementia and finds it very hard to communicate clearly. But there may be clues in how they are behaving.

- What does their face look like? Are they grimacing or grinding or clenching their teeth?



- Are they rubbing, pointing or pulling at a particular part of their body?
- Are they irritable? Crying or tearful? Or groaning? Are they shouting or screaming?
- What is their body language like? Are they stiff, or rocking or perhaps guarding part of their body?
- What happens when they move? Are they less mobile, or moving differently? Are they pacing, unable to settle for long, restless or fidgeting?
- Are they looking fearful? Do they seem to be seeing things or to be frightened?
- Has their appetite changed?
- Has their breathing pattern changed?

*She seems really withdrawn, and she's hugging herself. I wonder how she's feeling?*

Check to see if the person has a temperature. There may be other physical clues: for example have they recently fallen, do they have an infection or are they constipated?

### Tip:

Remember what their body and behaviour has told you in the past. Are there any signs that you have come to associate with them being in pain. Is the same happening now?

*I knew he was hurting because he was moaning and trying to scratch his tummy.*

## Some examples of things that might be causing pain or distress

- Sore mouth, toothache or ill-fitting dentures
- Earache
- Being lifted or moved in an uncomfortable or painful way
- Difficulty in going to the toilet or a urinary tract infection
- Painful joints
- Painful sores
- Uncut finger or toenails
- Being in an uncomfortable position or the same position for a long time



# What can you do if someone is in pain?

## **People with dementia can feel pain, and there are things you can do to treat it.**

It depends on the severity of the pain, but things that might help include the following.

- **Changing their position**
- **Touch, massage, presence and reassurance**
- **Cool compress, or warmth**
- **Using easily available painkillers such as paracetamol**

However sometimes this may not be enough, and it may be necessary to speak to a doctor or a dentist, or to ask for prescription painkillers, and use them if you already have been given them.

This progression from weaker to stronger types of pain relief is sometime called the “analgesic ladder”.

You may need to act as an advocate or supporter for the person with dementia to make sure other pain medications are considered or tried.

## Tips:

- Give the person pain relief medicine regularly – don't wait until they are already showing signs of pain. Seek advice about this if needs be.
- Reassess them to see if the medicine is working. Has their troubling behaviour changed or reduced?
- If the person is obviously already in significant discomfort you don't need to start on the first rung of the "ladder"! Don't get stuck there either if the problem is continuing.

## Remember

- There are different ways of delivering pain relief. For example patches can be used if it's difficult for the person to take them orally.
- Some different painkillers can be taken at the same time (ask your doctor or pharmacist about this)
- Pain relief for moderate and severe pain will require medical advice and prescription
- Some pain relief can carry side effects, for example constipation. Take medical advice about this.





## If you are a health or care worker...

Remember that pain assessment tools are available which can help you assess the person's pain and manage their symptoms. It is important to assess pain both when the person is at rest and during activity, such as doing everyday tasks.

Examples of these pain assessment tools include: PAINAD, Abbey and Doloplus. Links to more information are provided at [www.ncpc.org.uk/dementia](http://www.ncpc.org.uk/dementia)



# What else might be causing the problem?

There are several possible causes of troubled behaviour, in addition to pain and physical symptoms, and a number of different approaches that might help.

- Depression sadness or anxiety
- Boredom
- Unfamiliar surroundings or people
- Frustration
- Fear
- Cold, hunger or neglect



# Possible solutions & tips

## ASK

- Use simple language to ask the person how they are feeling and what's troubling them. If they say something is wrong, ask them what it is. If they say something hurts, ask where and how bad it feels.
- Try different phrases or expressions, for example: Are you feeling sad? Are you cold? Do you feel sick?
- Try non-verbal ways to communicate, for example gestures or facial expression

## LISTEN

- Spend time with the person to see whether they can identify reasons for why they might be feeling sad, anxious or depressed
- Might they be missing somebody or something important? Perhaps a loved one or a pet?
- People with dementia can become confused if they are in unfamiliar surroundings or with new people. How can you reassure them and make them feel safe?
- Allow enough time for the person to do whatever it is they are trying to do
- Ask if they need help, without crowding them
- Avoid showing impatience

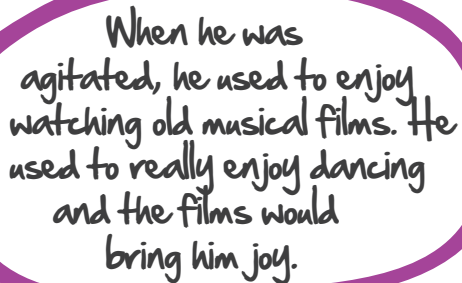
## OBSERVE

- Write down the behaviour, describing it as precisely as you can and its frequency. What has happened before the behaviour occurs? What has relieved it in the past?
- Check for pulse rate, breathing pattern and temperature
- Check the person's full body for new swellings or inflammation, e.g. their gums or ears, which may not have been identified
- Be aware of how the person reacts to external sights and sounds e.g. TV or radio, different types of music, mirrors, or bright sunlight
- Ensure the person has appropriate clothing for the temperature and environment
- Make sure they have time to eat, with assistance where necessary



## ACT

- Is there something that they like doing that will lift their mood or reassure them? Music or touch may help, for example, or some activity that they enjoy
- Are there familiar people, places, or objects that can help reassure them?
- If their symptoms persist, think about who the best person is to ask for help and advice, and ask them. Depending on the problem, this could be the person's GP, or a nurse or a dentist. Don't be afraid to speak to people about your concerns, nor to ask for more specialist advice if the person's pain or distress is continuing.



When he was agitated, he used to enjoy watching old musical films. He used to really enjoy dancing and the films would bring him joy.

## Further information

A list of helpful sources of further information can be found at [www.ncpc.org.uk/dementia](http://www.ncpc.org.uk/dementia)

Grateful thanks to the members of NCPC's Dementia Working Group, with whose help and support this leaflet was produced.



Remember..

**Ask**

**Listen**

**Observe**

**Act**

# About NCPC

## THE NATIONAL COUNCIL FOR PALLIATIVE CARE

**Dying  
Matters**

*Let's talk  
about it*

The National Council for Palliative Care (NCPC) is the umbrella charity for all those involved in palliative, end of life and hospice care in England, Wales and Northern Ireland. We believe that everyone approaching the end of life has the right to the highest quality care and support, wherever they live, and whatever their condition. We work with government, health and social care staff and people with personal experience to improve end of life care for all.

NCPC leads the Dying Matters coalition which aims to change public attitudes and behaviours around dying, death and bereavement.

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