Managing Pain for People with Dementia

Improving quality of care

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Managing Pain for People with Dementia

1. Introduction

People with dementia who are ill or have sustained an injury are as likely as anyone else, in the same circumstances, to experience pain. However studies have shown that people with dementia have higher rates of undiagnosed pain, are prescribed less pain relieving medication\(^1\), and are less likely to receive other treatments such as physiotherapy\(^2\).

Unrecognised and unmanaged pain can be misdiagnosed as behaviour that challenges, which means that pain is not addressed and can lead to worsening of behaviour.

This lack of recognition of pain can cause a great deal of unnecessary suffering.

Many organisations caring for people with dementia recognise this problem. This short guide is for all people working with or caring for a person with dementia. The guide lists the important areas to think about when assessing a person with dementia for pain, how pain can be treated, and how to monitor pain levels to ensure an improvement.

This guide is intended for use in all care settings for people with dementia.

2. Why can it be difficult to detect pain in someone with dementia?

The person with dementia may be unable to tell you about the pain they are experiencing e.g. they might not be able to find the right words to tell you about their pain. Instead, they may do the following:

- Express their pain indirectly e.g. shouting out, curling up in a ball, pushing you away
- Deny that they are experiencing pain
- Display behaviour that challenges

3. What should you do?

See Change, Think Pain

Has the person changed their habits recently or become resistant to interventions which they used to allow? For example, have they started to hit out when being assisted with personal care? Or perhaps their appetite has lessened, or they have stopped answering the door when the carer comes to visit?

Where possible, staff should talk to family members and carers, who know the person well. Family and carers will be able to give important information, which can help identify pain.

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4. Causes of Pain

If the person with dementia is in pain then you need to try and find the cause. This can be more difficult when a person is not able to tell you where and how they are experiencing their pain.

- Check for common causes of pain e.g. teeth/dentures, a urinary tract infection, ill-fitting footwear, arthritis, constipation.
- Think about the person’s recent activities - might they have injured themselves?
- Think about their medical history - do they have a history of experiencing pain, have they been unwell recently?

5. How can I assess pain?

Ask the person – if possible ALWAYS ask the person with dementia. Keep the questions simple, do you have pain? Where does it hurt? You may also wish to use verbal assessment tools. The best thing about pain assessment tools is that they make carers and health professionals think about pain.

Study their behaviour - For people who have problems with verbal communication it is important that you think about the person’s behaviour as well as what they are saying to you.

- Pick up on mood
- Assess verbal cues
- Inspect facial expression
- Notice body language

There are a number of observational pain assessment tools designed to be used with people with dementia where there is little verbal communication. These can help staff to think about the different signs that might show a person is in pain, but should only be used as part of the overall pain assessment. For examples of pain assessment tools please see the resources at the end of the document.

Talk to the people who know them best - Families and carers will be able to give important information about the person’s life history. Knowing about a person’s past can be helpful in identifying their baseline (what they are normally like) so that changes are easier to spot.

6. Management of pain (refers to actions taken to help cope with and reduce the impact of pain)

If a person is showing signs of pain or possible pain, each organisation will need to decide what action should be taken.

Action that should be taken will depend on:

- The severity of the pain which is being experienced e.g. the person who is crying out and clutching their arm would need immediate medical attention while a person who appears uncomfortable and less able to move around might be monitored for a while before calling the doctor.

And

- The type of care setting e.g. in a hospital the nurses might ask the team to complete a pain assessment or call the pain nurse specialist, while in a nursing home the GP might be called.
Where it is not possible to be sure if a person is distressed because of pain, consider a trial of a pain killer and monitor the person to see whether this treatment helps. Consider what measurable/observable symptom you are treating and how you will assess a response.

7. Treatment of pain (refers to drugs or therapies aimed at reducing or removing the pain)

- Non pharmacological (non-drug) management of pain should always be tried and can be used alongside treatment with medication. Examples of non-pharmacological treatments include applying heat, changing a person's position and using distraction.
- It is also necessary to ensure that where possible, the underlying cause of the pain is treated e.g. giving antibiotics for a UTI or laxatives for constipation.
- It is often the case that an individual may have more than one reason for their pain.
- When using medication to help treat a person's pain, consider how the pain relief will be given e.g. tablets, liquids, patches and the support which is available to make sure medication is taken.
- Start with low dose and build up the dose as necessary.
- If simple pain killers are not making a difference, check there are no other causes of distress e.g. an unmet need such as hunger or boredom.
- Regularly review effectiveness of treatment to make sure it is still necessary and appropriate.
- If pain is not controlled with simple analgesia e.g. paracetamol, then refer to the World Health Organisation Analgesia ladder for step 2 and step 3 pain killers.
- Avoid over sedation as this can increase risks such as falls or mean that future problems could be masked.
- If the pain could be muscular or relates to movement, the person may need to be seen by a physiotherapist.

8. Treatment side effects

Painkillers are associated with side effects; some of these are quite common such as constipation. It is important that the side effects of medication are controlled, so that pain treatment is not stopped unnecessarily.

Standardised assessment and treatment of pain should be an integral part of the clinical pathway for people with dementia. It may be useful to develop a flow chart to guide staff through the different steps to identify and manage pain within your organisation. See the resources section for examples.
9. How to embed pain recognition into practice?

- Make pain assessment part of all staff training
- Have a pain scale easily available
- Ensure staff understand how to use the available pain assessments (include this in their training)
- Ensure pain assessment is part of all required assessments e.g.
  - At first assessment/formal reviews
  - Prior to GP medication review so it is built into normal practice
  - Have system for reviewing outcomes when pain identified
- Ensure staff understand how pain can be treated and how it can be managed

10. Resources

The following is a directory of pain assessment tools, including:

- The Abbey Pain Scale (Abbey, J., et al.)
- Assessment of Discomfort in Dementia (ADD) Protocol (Kovach, C.R., et al.)
- Certified Nurse Assistant Pain Assessment Tool (CPAT) (Cervo, F., et al.)
- Checklist of Nonverbal Pain Indicators (CNPI), (Feldt, K.)
- Disability Distress Assessment Tool (Dis DAT) (Regnard, D., et al.)
- Discomfort Behavior Scale (DBS) (Stevenson, K.)
- Discomfort Scale-Dementia of the Alzheimer’s Type (DS-DAT), (Hurley, A., et al.)
- Doloplus 2, (Wary, B.)
- Elderly Pain Caring Assessment 2 (EPCA-2) (Morello, R., et al.)
- Face, Legs, Activity, Cry and Consolability Pain Assessment Tool (the FLACC), (Merkel, S. I., et al.)
- Mobilization-Observation-Behavior-Intensity-Dementia Pain Scale (MOBID) (Husebo, B. S., et al.)
- Nursing Assistant-Administered Instrument to Assess Pain in Demented Individuals (NOPPAIN), (Snow, A. L., et al.)
- Pain Assessment in Advanced Dementia (PAINAD) Scale, (Warden, V., et al.)
- Pain Assessment for the Dementing Elderly (PADE), (Villaneuva, M.R., et al.)
- Pain Assessment in Noncommunicative Elderly Persons (PANE) (Cohen-Mansfield, J., et al.)
- Pain Assessment Scale for Seniors with Severe Dementia (PACSLAC), (Fuchs-Lacelle, S. K., et al.)
- Pain Behaviour for Osteoarthritis Instrument for Cognitively Impaired Elders (PBOICIE) (Tsai, P., et al.)

Staff will need to be trained before using these tools

11. Other useful links

- Guidelines in Practice for the management of pain in people with dementia
- Social Care Institute for Excellence guidance
- Health Education England guidance
- World Health Organisation’s Pain Relief Ladder