WaMH in PC
Wales Mental Health in Primary Care
Information Sheet 18

A Briefing Note for GPs and Primary Care Practitioners
Pain Assessment and Management in Patients with Dementia

A collaborative piece of work between:

- Royal College of General Practitioners Wales
- NAPP Pharmaceuticals Limited
- Welsh Pain Society

Please note: Content has been written independently; Napp Pharmaceuticals Limited has had no involvement in the writing of this Information Sheet. Napp Pharmaceuticals Limited has provided factual accuracy and financial support in the printing of this Information Sheet.

Aims of this information sheet:

- Raise the awareness of primary care practitioners concerning the prevalence, common causes and reasons for poor recognition of pain in patients with dementia.
- Improve the knowledge of practitioners regarding the consequences of undertreating pain in patients with dementia.
- Provide sources of information that can be useful for facilitating effective pain assessment in patients with dementia.
- Outline the principles of pain management in this group of patients.

Background information - dementia

Dementia is a topical public health issue affecting up to 20% of people over 85 years old, this equates to 700,000 people in the UK at present (Alzheimer Society 2007) and is set to rise to a predicted 1,400,000 people by 2050.

Patients with dementia experience pain the same as any other patient, even though they may not be able to communicate it adequately. The British Pain Society (2007) suggest the prevalence of pain is somewhere between 49 and 83% in patients with dementia.

Common causes of pain to consider in patients suffering from dementia:

- Soft tissue or bony injuries relating to falls
- Constipation
- Urinary tract infections
- Chest infections
- Pressure area related pain e.g. from sitting or lying without regular change in position, tight clothing or shoes.
- Oral pain related to ill fitting dentures or tooth decay
- Cellulitis
- DVT
- Arthritis
- Contractures
- Known painful co-diagnoses

Raise awareness of reasons for poor recognition of pain in patients with dementia

Patients with dementia often do not have their pain adequately recognised, assessed or treated. The reasons for this include:

- A gross misconception that patients with dementia do not experience pain to the same degree as other patients.
- A tendency to normalise pain because dementia is an age related condition; aching, pain and soreness in the elderly is seen as 'normal' and expected with increasing age.
- Patients either don't or are unable to complain of pain, often due to communication difficulties such as speech problems, memory impairment, decline in ability to interpret and process thoughts and feelings verbally, or simply a lack of understanding when asked questions about pain.
- People may think that some behaviour, for example calling out for help repeatedly, are due to 'the dementia' rather than poorly managed pain.
- Poor compliance with analgesic medication, due to a lack of understanding why the medication is prescribed and required and due to a lack of prompting to remember to take medication.
- Poly-pharmacy and altered pharmacokinetics and pharmacodynamics
- Concern on the part of health care professionals that analgesics may increase confusion in the patient. The more disorientated patients receive even less analgesia (McAuliffe et al. 2012).
- People with dementia are prescribed and given less analgesia than other older people (Kimberly S. et al 2008).
- Even when analgesia is prescribed to a person with dementia, the majority do not receive their medication. There may be many reasons for this, some of which are listed above.

Consequences of undertreating pain

Good pain management is a fundamental human right for all patients, poor treatment of pain can lead to the patient suffering unnecessary distress.

In the case of a patient with dementia, this distress can lead to:

- problematic behaviours
- decreased physical functioning
- increased depression and social withdrawal
- poor sleep patterns and a slower than expected recovery time from illness or injury

This can have a significant detrimental effect not only on the patient themselves but also their carers, and can lead to an unnecessary over-reliance on the use of sedatives and tranquilizers.

'Pain is positively associated with screaming, aggression and verbal agitation in dementia.'

(Cohen-Mansfield et al. 1999).

Assessing pain in dementia patients

Relatives and carers know the patient better than anyone else. They will not only notice marked changes in their loved one, but also subtle differences that provide invaluable clues. Their knowledge and expertise should ALWAYS be taken into account.

A thorough assessment is imperative; this should take a systematic approach looking at the numerous changes that can occur in a patient who is experiencing pain.

These include:

- **Physical sign changes:** Blood pressure, pulse, sweating, pallor, breathing rate, constipation, retention of urine or a distended abdomen. Any physical examination that is required must include reassurance to the patient and an easy to understand explanation of what is going to happen.
- **Mobility / activity changes:** Reduced mobility, changes in gait or changes in activity levels.
- **Behavioural changes:** Fidgeting, restlessness, repetitive behaviours, pacing or wandering, unusually resistive to care, pushing away carers, aggressive or angry.
- **Mood changes:** Depression and withdrawal.
- **Facial expression:** Frowning, sad, grimacing, tense or frightened.
- **Body language:** Guarding, bracing, rubbing or holding the painful part of the body.
- **Speech:** Shouting out repeatedly, screaming, crying or groaning.
- **Signs to look for on physical examination:** Pressure sores, broken skin, arthritis or deformities in the joints.
- **Eating habits:** Refusal of food or reduced appetite.

Keep questioning direct and simple, used closed questions that require only a yes or no answer. Don't use medical jargon. Use non-verbal cues, such as when asking if their 'tummy' hurts, rub the abdomen, use pictures to communicate and talk to the relatives or carers if they are present. Allow plenty of time for the assessment.

Recognised multi-dimensional pain assessment tools or instruments can be used which are specifically designed for use in patients with cognitive impairment, focusing on a number of specific indicators such as breathing, facial and body expressions and vocalisation. Commonly used self-reporting verbal or numerical pain rating scales are neither valid nor reliable in this population. Tools that include observational behavioural cues as external markers of internal states include:

- PAINAD (Pain Assessment in Advanced Dementia Scale)
- Abbey Pain Scale
- PACSLAC (Pain Assessment Checklist for Seniors with Limited Ability to Communicate
- Doloplus 2 Scale
- Disability Distress Assessment Tool (DisDAT)

(Download these tools from our website: www.wamhinpc.org.uk/blog/information-sheet-18-pain-assessment-and-management-patients-dementia)

It should however be remembered that no behaviours are unique to pain. There could be other factors influencing the behaviours other than pain. Also, pain behaviours are unique to the individual, and therefore a generic tool may not adequately assess the patient.

Pain management in dementia patients

In line with the potential reasons for pain set out above, treatments may not necessarily be pharmacological in nature but need to directly address the cause. Where pressure area pain is noted, pressure-relieving devices such as cushions or specialist mattresses, and regular repositioning are essential. Joint splinting or support may reduce discomfort for soft tissue or bone injuries. Tight-fitting clothing or ill-fitting shoes need to be addressed. Where the issues relate to dental care a review by an appropriate dental practitioner is required.

Where medication is indicated simple pain-killers such as paracetamol (+/- NSAIDs where indicated) should be considered for mild to moderate pain, as per the World Health Organisation's Analgesic Ladder. Analgesia taken on a regular rather than as required (PRN) basis is most effective. For severe pain opioid medication should be considered, along with the simple analgesia.

- Always consider the best route for administration.
- Regular review of efficacy and adverse drug reactions should be undertaken.
- Medication compliance can be a problem due to swallowing difficulties or remembering to take the medication as prescribed etc.

Treating pain, not behaviours

Agitation and aggression is common in people with moderate to severe dementia. It is associated with increased distress for families and presents a significant challenge for healthcare professionals.

It is important to look for ways to reduce agitation without prescribing an anti-psychotic drug. This class of drug can make the symptoms of dementia worse, as well as increasing the chances of stroke, or even death. Despite this knowledge, these powerful drugs are overused, with the Department of Health (England) estimating that as many as two thirds of the prescriptions are inappropriate. Ensuring a robust approach to pain assessment and management is essential, as adequate pain management may contribute to the overall prevention and management of agitation (Husebo et al. 2011).

'Patients that probably have dementia were being prescribed anti-psychotics without a proper assessment with the inappropriate use of sedation for 'aggression' being observed'.

(Andrews report 2014)

Key messages:

- Pain in dementia is common.
- Patients with dementia experience the same levels of pain as anyone else.
- Pain in patients with dementia is often poorly reported, assessed and treated.
- Family members and carers should be involved in pain management as much as possible.
- Poorly controlled pain can significantly affect a patient with dementia and their family and carers' quality of life.

Useful information:

- **See change: think pain** campaign: www.paincentrenapp.co.uk/pain-in-dementia/
- A free set of **Pain in Dementia** CPD accredited eModules are hosted by Cardiff University on www.paincommunitycentre.org/article/pain-and-dementia alongside interactive podcasts featuring healthcare professionals across Wales.
- Alzheimer's Society and RCN **This is me** tool: www.alzheimers.org.uk/thisisme
- McAuliffe, L., Brown, D., Fetherstonehaugh, D. (2012) Pain and dementia; an overview of the literature. International Journal of Older People Nursing 7, 219 - 226

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