The principles of pain assessment and management in Dementia Palliative Care include:

- Regular, accurate assessment and reassessment.
- Importance of the primary caregiver as a key informant.
- A person-centred approach.
- Effective management of total pain.

Pain can be:

- Physical – Acute (i.e. chest pain, fracture) or chronic (i.e. arthritis)
- Psychological – Grief, uncertainty around diagnosis or symptoms etc.
- Social – loss of independence, changing family and friend relationships
- Spiritual – fear of the unknown

Central to the philosophy of palliative care is effective pain management, working within the concept of ‘total pain’ as being physical, psychological, social and spiritual.

Recognise, Assess and Reassess for Pain

- Staff should gather a comprehensive pain history from the person with dementia, their family and other healthcare professionals who have treated the person with dementia in the past.
- Self-report from the person with dementia should be sought regardless of level of dementia.
- Observe for pain behaviours.
- Surrogate reporting should complement any attempts of self-report.
- Use pain assessment tools that are selected based on the person’s needs and communication level, not on what is easily accessible.

Why is this important?

The pain experience can be extremely challenging for people living with dementia and many variables such as depression, fatigue and agitation can influence response.
Recognise, Assess and Reassess for Pain

A simple PAIN mnemonic to assist caregivers to recognise and identify that pain might be present

**P**ick up on mood changes

**A**ssess verbal cues

**I**nspect facial expressions

**N**otice body language

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COULD THIS MEAN PAIN?
NON SPECIFIC SIGNS IN PEOPLE WITH DEMENTIA

### Facial Expression
- Is his/her expression distorted?
- Frowning?
- Looking frightened?
- Eyes tightly closed?

**YES**
Could this mean pain?

### Vocally
- Is he/she:
  - Groaning?
  - Calling out?
  - Asking for help?
  - Chanting? Crying?

**YES**
Could this mean pain?

### Body Movement
- Is his/her body movement
  - Tense?
  - Rigid?
  - Restricted?
  - Is he/she resisting care?

**YES**
Could this mean pain?

### Changes/worsening?
- Inter personal interaction?
- Mental status?
- Routines?
- Wandering?

**YES**
Could this mean pain?

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**NOT SURE**

**Rule out:** Fear; Thirst/Hunger; Too hot/cold; Delirium/hallucination; Urge to urinate, defecate or vomit; Infection

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This Factsheet is a visual aid to accompany the IHF dementia palliative care guidance document: ‘Pain assessment and management’. This is available to download from www.hospicefoundation.ie
Regularly assess for the possibility of presence of pain.

### Management of Pain

The first steps in the management of pain should always be to:

- Identify the cause of the pain where possible and remedy the cause.
- Explore the potential role and use of non-drug approaches of all kinds, before proceeding to even simple analgesia (Step One of the WHO ladder).
- Determine whether the use of opioids is necessary. The lowest effective dose should be used, increasing the dose slowly and only if necessary to get the desired effect. i.e. Start Low and Go Slow.
- Consider referral to the multidisciplinary team

### Pain

1. **Non-opioid ± adjuvant**
2. **Opioid for mild to moderate pain ± non-opioid ± adjuvant**
3. **Opioid for moderate to severe pain ± non-opioid ± adjuvant**

**Freedom from pain**

- Titrate until adequate pain control is achieved
- Proceed to next step if pain persists or increases
- Proceed to next step if pain increases

### Consider Non Pharmacological Therapies for Pain

Acupuncture, transcutaneous electrical nerve stimulation (TENS) and massage can reduce pain and anxiety.
People with dementia, experiencing pain require comprehensive, individualised care plans that incorporate personal goals, specify treatments, and address strategies to minimise the pain and its consequences on functioning, sleep, mood, and behaviour.

The goal for pain management and the best possible outcome is the relief and control of pain.

1. **Assess:** Assess the person with dementia for signs and symptoms of pain. If possible obtain a self-report of pain. If not, ask family and carers to describe their understanding of the person’s pain i.e. how it affects their interactions, mobilisation, and behaviour. Obtain a report of whether any activities cause increase in intensity or duration of pain. Ask the person or family/carer to identify what relieves or exacerbates the pain.

2. **Plan:** Develop a plan to provide methods of pain relief for the person with dementia. These methods should include both pharmacological and non-pharmacological methods of pain relief. The plan should address the person or family/carer’s identified goals for pain relief.

3. **Implement:** Implement a pain management plan that incorporates the identified goals. Minimise adverse side effects associated with pharmacological interventions. Educate the person with dementia and family/carer about the pain management strategies chosen. Address any misconceptions and concerns.

4. **Evaluate:** Reassess the person’s response to the prescribed analgesia or the non-pharmacological method of pain relief. Monitor presence and location of pain, intensity and severity of pain and effectiveness of chosen method of pain relief. Gather both self-reports from the person with dementia and observations of family.

**Think beyond the physical.**

**Unresolved emotional issues:** encourage the person to express their concerns or refer to a social worker, clinical psychologist, family therapist, minister/religious person or pastoral care.

**Social pain:** consider the quality and depth of relationships and how this may help or hinder pain.

**Spiritual pain:** address issues such as fear of the unknown, concerns about the meaning of life refer to pastoral care as appropriate.

**IF YOU ARE CONCERNED ABOUT EFFECTIVE PAIN CONTROL FOR A PERSON WITH DEMENTIA – REFER TO SPECIALIST PALLIATIVE CARE OR TO A PAIN SPECIALIST.**