Palliative Care for the Person With Dementia: Evidence-Based Guidance on Pain Assessment and Management

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People with dementia experience pain just as much as anyone else. Uncontrolled pain can seriously affect a person’s quality of life.

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 (Richmond, 2005).
Pain is what the person says it is, occurring when he/she says it does.

- Lower back pain
- Musculoskeletal pain
- Osteoarthritis
- Rheumatoid arthritis
- Cancer
- Leg cramps
- Gout
- Peripheral Vascular Disease
- Herpes Zoster
- Trigeminal Neuralgia
- Postherpetic Neuralgia
- Headache
- Temporal arthritis
- Diabetes Neuropathies
- Angina
- Wounds
- Constipation
- Procedures
Background to Guidance Development

• In 2013, the Irish Hospice Foundation (IHF) embarked on a three-year programme entitled *Changing Minds: Promoting Excellence in end-of-life Care for People with Dementia*. The aim of this programme was to enable more people, particularly those living with dementia, to live and die with dignity at home or in residential care settings.

• There has been growing recognition of the complexities involved in providing end-of-life care for people with dementia, however, there remains a notable void of practice guidelines to support healthcare staff.
Suite of Guidance Documents

- Facilitating discussion on future end-of-life care with a person with dementia.
- Advance care planning and advance health care directives with a person with dementia.
- Loss and grief in dementia.
- Management of hydration and nutrition.
- Pain assessment and management.
- Ethical decision making in end-of-life care and the person with dementia.
- Medication and dementia: Palliative assessment and management.
The guidance document was developed over an 18 month period by a project team and overseen by a national steering committee, using the systematic and rigorous process of clinical guideline development (National Clinical Effectiveness Committee, 2013) as outlined in the following six stages;

✓ Completion of scoping review.
✓ Collation of key review themes to inform the guidance and principles of pain assessment and management.
✓ Preparation of Draft 1 of guidance document for comment by the project steering committee and national/international experts in the field.
✓ Preparation of Draft 2 for external consultation.
✓ Assimilation of feedback from external consultation to final draft.
✓ Final version published.
Scoping Review

SEARCH STRATEGY
The following key word strategy was agreed by the project team and used in EBSCO, adapted variations were developed for the other databases:
S1: palliative OR dying OR “end of life” OR “end of life” OR hospice OR terminal OR “end stage” OR “end stage” OR chronic OR “advanced illness” OR “advanced life limiting illness” OR “advanced life limiting illness” OR “advanced life limited illness” OR “advanced life limited illness” OR “late stage”
S2: Dementia OR Alzheimer’s OR dementia
S3: guideline OR guidance OR algorithm OR “decision aid” OR pathway OR policy OR policies OR protocol OR standard OR checklist OR Decision N3 (aid OR aids OR support OR tool OR tools OR system OR systems OR making) OR Standard N3 (case OR clinical CR treatment) OR case N3 model OR framework CR flowchart
S4: pain OR discomfort OR pharmacological
S5: S1 AND S2 AND S3 AND S4
References from relevant papers were scanned to identify additional papers as necessary.

INCLUSION CRITERIA
English language
Peer reviewed publication
Focus on adult populations (patients/family caregivers) with dementia
Studies published between 2005-2015

EXCLUSION CRITERIA
Written in a language other than English
Conference abstracts, thought pieces, reflective articles, dissertations, book chapters and book reviews
Focus on populations under 18 years of age
Studies with a purely biochemical focus
Animal-based studies
Papers generic to older people
Mixed populations e.g. Parkinson’s and Dementia where data themes relating to dementia could not be separated from other diseases
Not in English.

OUTCOME OF LITERATURE SEARCH
1566 Records identified through database searching
982 Records identified after duplicates removed
982 Records screened
124 Full text articles assessed for eligibility and further elimination of those per 2015.
113 Studies included in scoping review
868 Records excluded
11 Full text articles excluded
1. In your expert opinion does this guidance capture key/current issues related to pain in dementia?

2. Do you agree with the guidance provided across the 4 areas? Are there other areas for guidance that should have been addressed?

3. Are there any glaring errors / omissions/resources that should be included?

4. Do you think it will meet the needs of the intended audience?
External Consultation/Stakeholder Involvement

• A draft guidance document and accompanying factsheets were published on the Irish Hospice Foundation website on Wednesday 4th November 2015 for consultation. The consultation period ran until Monday 23rd November 2015.

• A consultation form was developed to facilitate submissions.

• Stakeholders were invited to give feedback using this form by return email or post.

• A targeted consultation campaign was undertaken to promote and raise awareness of the guidance document.

• Emails were sent out to over 640 stakeholders including relevant professional bodies and organizations, service and family representatives and to the dementia contact database held in the Irish Hospice Foundation,

• An ‘advance notice of consultation’ email was also sent two weeks in advance of the consultation launch, to flag that it was pending, to enable stakeholders to set some time aside to review the documents.
Feedback

• A total of 10 submissions were received focusing specifically on the pain guidance document.
• 80% of the submissions received were made on behalf of an organization.
• The remaining 20% were made in a personal capacity and included a senior nurse working in specialist palliative care services and a senior nurse from an acute hospital service.
• Submissions were reviewed by collating data from the specific questions within each of the 10 feedback forms.
• Data was collated into an Excel sheet and frequency of responses noted. Thematic analysis of qualitative comments received was also conducted.

"An excellent resource particularly if used online. Links are excellent very useful info available”.

“This guidance document has comprehensively covered all areas of relevance”.

“A very welcome document, as you highlight pain in older people is undiagnosed and undertreated, and particularly for people with dementia. The research on pain assessment tools is an excellent resource to nurses in determining the correct tool for each stage of dementia. This will increase knowledge and confidence to assess pain and therefore help ensure effective care plans are implemented, using non-pharmacological and pharmacological interventions”.

“Excellent document, very concise and excellent resources and online links.”
The guidance provided in the 57 page document focuses on four key areas.
1. List the principles that govern good pain assessment and management.

2. Provide specific guidance on:
   (a) recognising pain in dementia;
   (b) pain assessment in mild through to severe dementia;
   (c) developing a pain management care plan and
   (d) when and who to refer for specialist assessment and management.

Case Studies

**CASE STUDY 1 | TIMMY**

Timmy was diagnosed with mild dementia 12 months ago. He lives with his son and daughter-in-law. He needs assistance with some activities of daily living.

Lately, his son has noticed that his father does not appear rested in the morning and suspects that his sleep is disturbed. The daughter-in-law has also noticed that he is not walking around the garden as much and when he does she can see him rubbing his knee communally. The family noticed Timmy is in pain.

The COLD CART mnemonic can be applied to assess pain further. Documenting the answers to the following questions, together with observation over a period of time will help to build a very good picture and assist when assessing a management plan for Timmy.

**O** Onset: When did your pain start?

**L** Location: Where is your pain, is it in your knee?

**D** Duration: Is it there all the time or only when you walk?

**C** Characteristics: When the pain is there, can you describe what it feels like? Is it sharp, dull, aching...

**A** Aggravating factors: What makes the pain worse?

**R** Relieving factors: What makes the pain better?

**T** Treatment: What medications or non-medication treatments (hot/cold packs etc) ease the pain?

**S** Severity: How severe is the pain?

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**CASE STUDY 2 | DEIRDRE**

Deirdre is a resident of Woodlands Nursing Home. She was diagnosed with dementia a number of years ago. Her husband of 40 years died recently. She needs assistance with all aspects of daily living. Care staff have reported that when they are reassessing Deirdre or assisting her to mobilise she becomes agitated and can sometimes moan. Sometimes she calls out and it is often difficult to reassure her.

There has also been a recent change in her appetite. Deirdre can respond consistently to certain questions.

Applying the Hierarchy of Pain Assessment Techniques systematically can help staff to re-establish if Deirdre has physical pain, what may be causing it and determine if her recent behaviour is resulting from a worsening in her illness, or if it represents pain behaviour.

1. **A self-report** is requested from Deirdre using plain, simple language. Example: Do you have pain? Other descriptors might be used such as discontent or discomfort.

2. **It is important to seek for a cause.** Does Deirdre have a history of falls, fractures, arthritis? Is she constipated? Is there any history of diabetes, endocrine, cancer?

3. **Observe the person’s behaviours.** It is clear that Deirdre is displaying pain behaviours – crying out, agitated, screaming, increased movement, loss of appetite. The use of a behavioural pain assessment tool is recommended. This will enable accurate recording over time and enable in determining if pain treatments are effective.

4. **Engage in prompt reporting.** Ask Deirdre’s husband if he thinks she is in pain. If he thinks she is, try to develop an understanding of all the issues he has noticed, document these and incorporate into future assessment.

5. **Attempt an analgesic trial.** Develop a pain-care plan for Deirdre that includes the introduction of analgesics. Start low and go slow. Conduct a retinal daily pain assessment to determine if there is a change in behaviour and/or pain report. Consider implementing this tool with non-pharmacological methods, for example, massage.
Ongoing reassessment of pain is a central feature of a palliative approach to caring for a person with dementia.

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.

TIP:
Consider other sources of physical pain like positioning, pressure areas, poor dentition, pain related to instrumentation (catheter), painful skin rashes, abdominal pain, and infections etc.
Factsheets

Pain Assessment and Management in Dementia Palliative Care

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.

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.
- Person-centred approach.
- Effective management of total pain.

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Recognise, Assess and Reassess for 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.

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

Feeling Hunted
Feeling Hungry
Feeling Unhappy
Feeling Lonely
Isolating
YES
YES
YES
YES
YES
YES

Could this mean pain?

NOT SURE


FACT SHEET 5A 5B GC 5D

Pain Assessment and Management in Dementia Palliative Care

Regularly assess for the possibility of presence of pain.
Future Research

- IHF funded project collaboration between the School of Nursing and Midwifery, CGR
- Institutional and Stakeholder Analysis of Pain Assessment and Management in Long Term Care (GP Trainer)
- One Nursing Home. Chart Audit of Pain Assessment and Management & Focus Groups x 2 with Nursing Staff
- Exploring Dementia Specific Education needs
- HRB Summer student scholarship; Nurses Knowledge and Educational Needs
- Implementing EBG into practice (APA HRB)
Implementing Evidence Based Guidance for Dementia Palliative Care through Participatory Action Research

• **Aim** To support the implementation of evidence based practice (EBP) guidance for pain, hydration and nutrition and medication management in dementia palliative care practice.

• **Design** A multi-site Participatory Action Research (PAR) approach will be used. Three Long Term Care (LTC) facilities will be recruited as study sites and one evidence based guidance area will be implemented per site.

• **Data Collection** Data will be collected using mixed methods and guided by the hybrid of frameworks. Pre intervention baseline situational (institutional and stakeholder) analysis will be conducted to determine implementation feasibility, policy/procedure and education requirements. Qualitative data will be collected throughout via interviews, observations, focus groups and Work Based Learning Groups (WBLG) to reflect and evaluate guidance and site specific requirements. Post implementation a situational analysis will be repeated to evaluate uptake, outcomes and process of implementation.
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