



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

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**A TRADITION OF
INDEPENDENT
THINKING**



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Pain in Dementia

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 in Persons with Dementia

- Pain is what the person says it is occurring when he/she says it does.

- ❖ Lower back pain
- ❖ Musculoskeletal conditions such as rheumatoid arthritis
- ❖ Cancer

Dementia

- ❖ Wounds
- ❖ Complications
- ❖ 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.



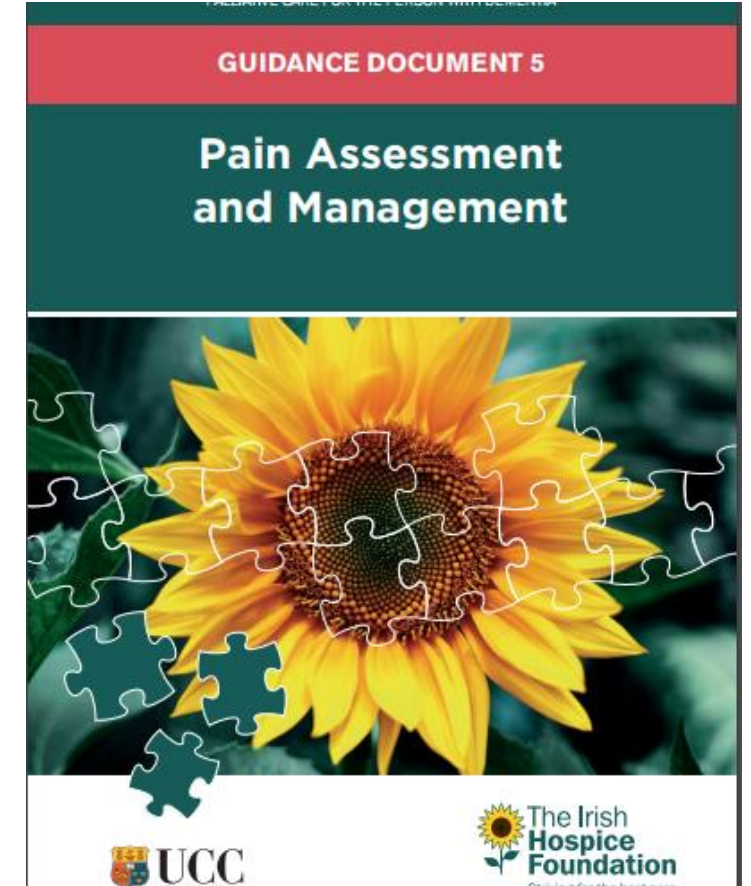
Suite of Guidance Documents

- 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.



Guidance Document 5

- 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* OR demented

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 (care OR clinical OR treatment) OR care N3 model OR framework OR 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/lab based studies

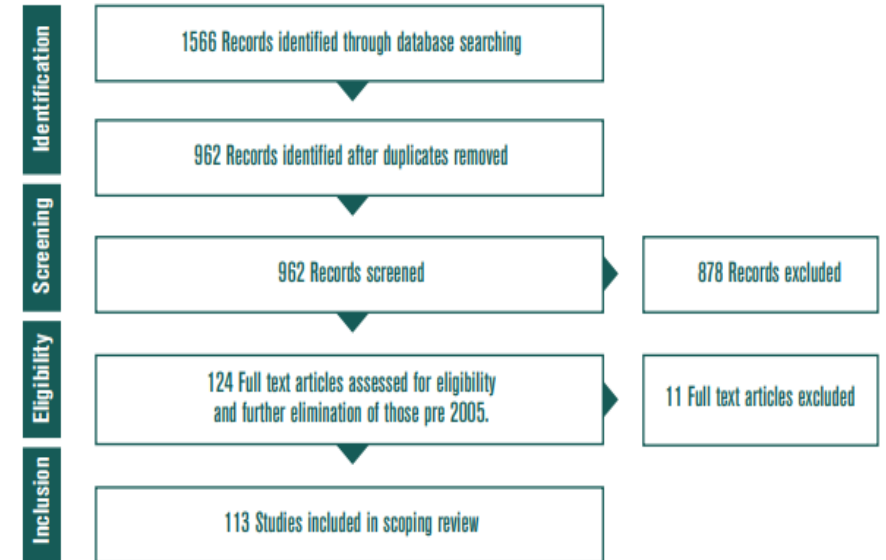
Papers generic to older people

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



Expert advisors

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

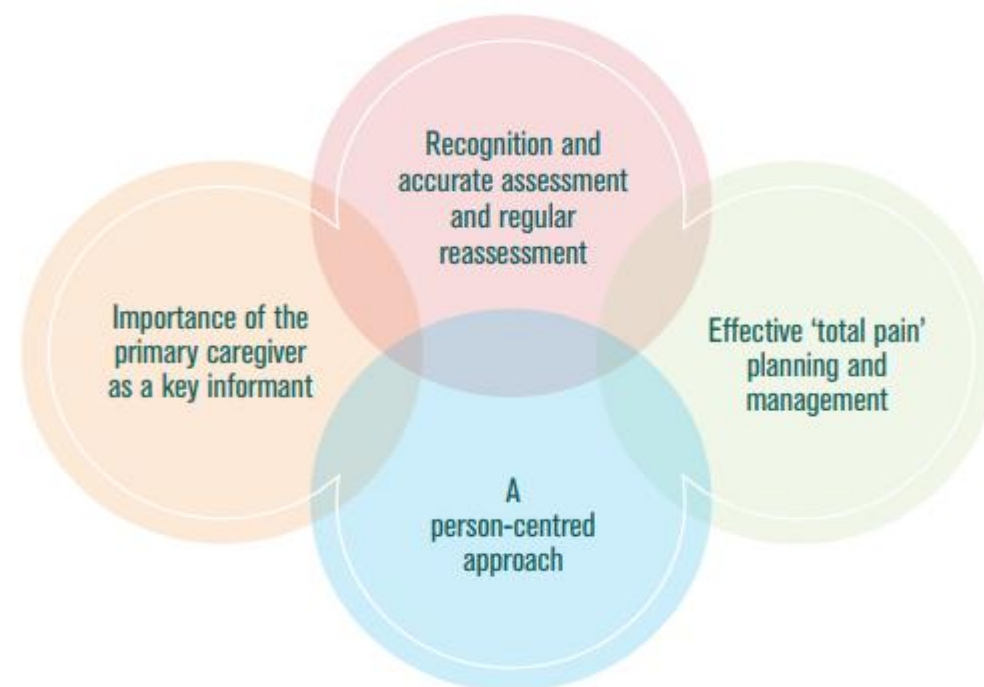


Figure 1: Four overarching principles to assessment and management of pain in dementia palliative care.

Scope of Guidance

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.

<http://hospicefoundation.ie/wp-content/uploads/2016/11/Final-Guidance-Document-5-Pain.pdf>



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. His 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 periodically. The family suspect Timmy is in pain.

The **OLD CARTS** 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 creating a management plan for Timmy.

- O** Onset: Timmy 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?

Source of OLD CARTS mnemonic: Seidel HA, Ball JK, Davis JC, Deneckere GRL. Mosby's Guide to Physical Examination (9th Ed). Mosby: St Louis, 2005.

CASE STUDY 2 | DEIRDRE

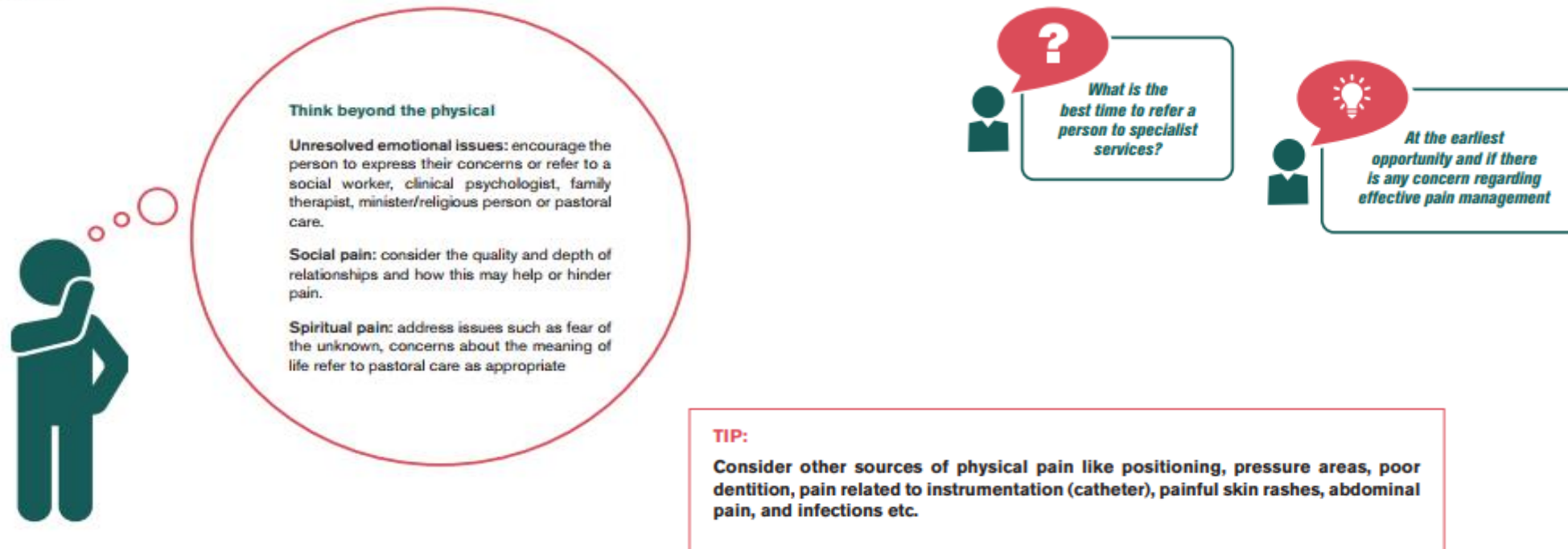
Deirdre is a resident of Woodlands nursing home. She was diagnosed with dementia a number of years ago. Her husband of 40 years visits regularly. She needs assistance with all aspects of daily living. Care staff have reported that when they are repositioning Deirdre or assisting her to mobilise she becomes aggressive 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 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 in fact represents pain behaviours.

1. A **self-report** is requested from Deirdre using plain, simple language. Example: Do you have pain? Other descriptors might be used such as *discomfort* or *soreness*. This question may need to be repeated up to 3 times.
2. It is important to search for a **cause**. Does Deirdre have a history of falls, fracture, or arthritis. Is she constipated? Is there any history of shingles, diabetes, cancer?
3. **Observe** the person's behaviours. It is clear that Deirdre is displaying pain behaviours – calling out, aggression, moaning on movement, loss of appetite. The use of a **behavioural pain assessment tool** is recommended. This will enable accurate recording over time and assist in determining if pain treatments are effective.
4. Elicit **surrogate reporting**. Ask Deirdre's husband if he thinks she is in pain. If he thinks she is, try to develop an understanding of the cues 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 (at a minimum) daily pain assessments to determine if there is a change in behaviours and/or pain report. Consider complementing this trial with non-pharmacological methods, for example, massage.

Presentation of Information


Ongoing reassessment of pain is a central feature of a palliative approach to caring for a person with dementia.




Factsheets


FACT SHEET 5A 5B 5C 5D

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.
- 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



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

 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

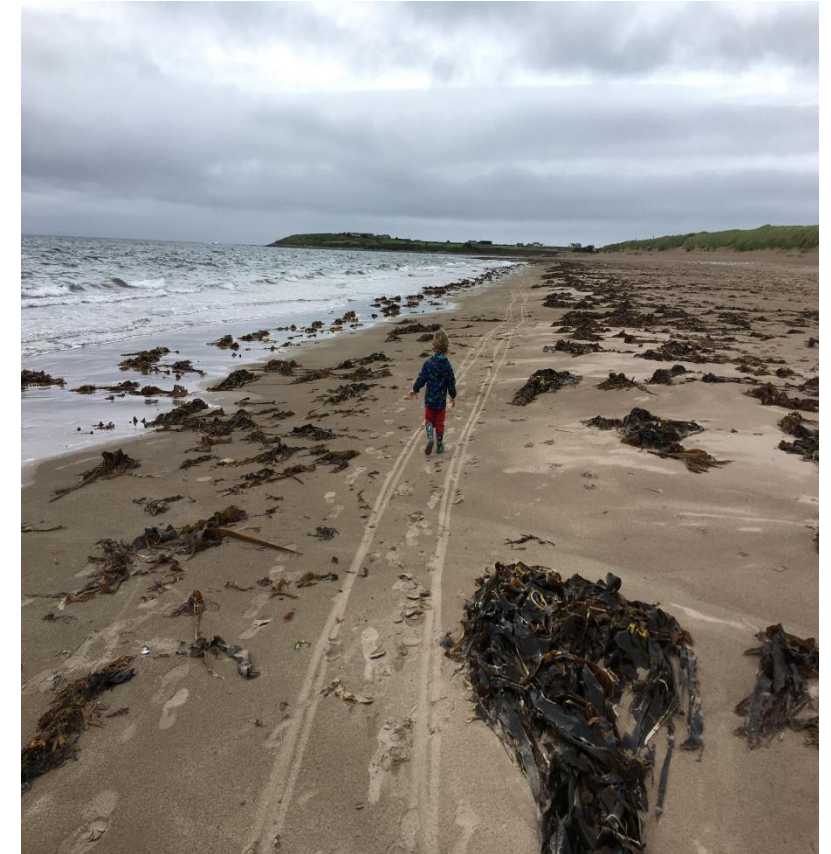
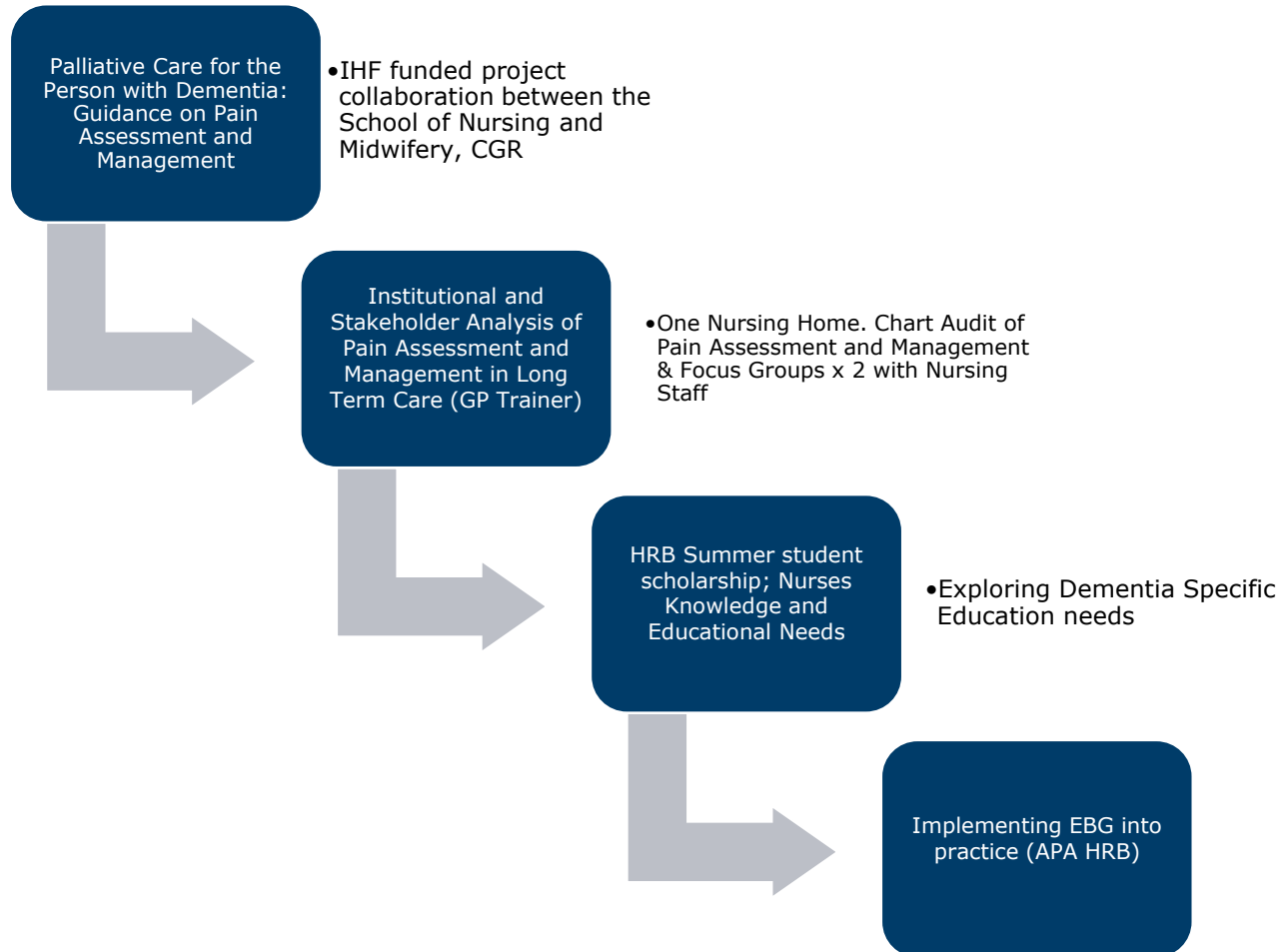
FACT SHEET 5A 5B 5C 5D

Pain Assessment and Management in Dementia Palliative Care



Regularly assess for the possibility of presence of pain.

Future Research



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.

Acknowledgments

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